University of Alberta

Understanding Attrition in Pediatric Weight Management

by

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Abstract

There is limited information on families' decisions regarding their (dis)continuation of weight management care. This thesis includes two complementary studies that examined this issue. First, an integrative review was performed to characterize predictors of and reasons for attrition in pediatric weight management. Analyses revealed that insurance type was a consistent predictor of attrition, whereas children's sex and baseline weight status were not. The most commonly reported reasons for attrition were physical barriers and programs failing to meet families' needs, wants, or expectations. Second, a qualitative study was conducted with families to explore factors that influenced their attrition from pediatric weight management. Three main categories relating to attrition were identified: family, logistical, and health services factors. Together, this research demonstrated that attrition is a highly prevalent issue that needs to be addressed at multiple levels to optimize health services delivery for managing pediatric obesity.

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List of Abbreviations

Body mass index; BMI

Socio-economic status; SES

Family Adaptability and Cohesion Evaluation Scale; FACES

Standard deviation scores; SDS

Centres for Medicare and Medicaid; CMS

Short Message Service; SMS

Motivational Interviewing; MI

High density lipoprotein; HDL

Low density lipoprotein; LDL

Pediatric Centre for Weight and Health; PCWH

Parents as Agents of Change; PAC

Skills and Knowledge for Improved Lifestylez; SKILZ

Chapter 1:Introduction

Overview

This paper-based thesis includes two research papers prepared for publication based on my graduate research (M.Sc in Medical Sciences - Pediatrics), which focused on understanding attrition in pediatric weight management care. This introductory chapter describes the significance of my graduate research by providing background literature on pediatric weight management, outlining the purpose of my graduate work, and explaining each chapter's contribution to my thesis.

Background

Obesity has become an epidemic in many developed and developing countries in the world, including Canada (1-2). Obesity in childhood and adolescence is of particular concern due to its associated health consequences and negative long-term effects on mortality and morbidity (3-4). Additionally, obesity tends to persist into adulthood; approximately one-third of obese pre-school children and one-half of obese school-aged children remain obese as adults (5-6). Therefore, while the prevention of obesity in children and adolescents is important to combat the obesity epidemic, targeted interventions are needed for those individuals who are already obese.

From a health services perspective, even when effective interventions are developed and available, approximately half of participants prematurely discontinue pediatric weight management care (7). Therefore, a large number of families are not receiving the benefits of treatment, which minimizes the

(potentially) positive impact of treatment. While previous research provides some insight into families' reasons for discontinuing care (7-12), these reports have also underscored the clear need for additional research to examine why a substantial number of obese children, youth, and their parents fail to continue with pediatric weight management care (10).

Little research has explored the phenomenon of attrition in pediatric weight management care. Further, the use of only one data source may be insufficient to understand the complexity of issues related to attrition. Undertaking a review *and* a qualitative study can provide a better a better understanding of health system problems than either approach alone. Furthermore, the use of two studies allows for data to build sequentially on one another, providing a deeper understanding. Therefore, the purpose of my graduate research was to explore attrition in pediatric weight management care to understand how it can be minimized in order to improve obesity-related health services delivery.

Outline of Thesis

My thesis consists of two complementary papers. Chapter 2 presents my integrative review with the goal of examining predictors of and reasons for attrition from pediatric weight management care. Chapter 3 presents my qualitative study, which was designed to explore factors that influence attrition following commencement of a pediatric weight management program at the Pediatric Centre for Weight and Health (Stollery Children's Hospital, Edmonton, AB). Results from both papers can be used to help improve obesity-related health

services delivery in pediatric weight management. My thesis concludes with recommendations for future research, which are based on the findings of my graduate work. Lastly, **Appendix A** includes ethics documents, **Appendix B** is a description of my study protocol, including all recruitment materials and data collection tools, and **Appendix C** includes an expanded results table from my qualitative study (Chapter 3).

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Chapter 2: Attrition from pediatric weight management care:

An integrative review

Dhaliwal J, Nosworthy NMI, Holt NL, Zwaigenbaum L, Ball GDC.

Introduction

Obesity has become a global epidemic, with countries in North America, Europe, and parts of the Western Pacific possessing the highest levels of obesity among children (1). Among preschool children worldwide, while 4.2% were overweight or obese in 1990, 6.7% were overweight or obese in 2010, and 9.1% are expected to be overweight or obese by 2020 (2). Obesity during childhood is especially concerning because of its associated medical health risks, including type 2 diabetes (3), early cardiovascular disease (4), and obstructive sleep apnea (5), not to mention its influence on children's psychosocial development (6). Furthermore, there is a high likelihood of childhood obesity and its associated co-morbidities persisting into adulthood (7-8). While multi-level strategies are needed to prevent unhealthy weight gain, effective programs are needed to improve the health of children who are already obese (1).

Most pediatric weight management research has examined the efficacy of targeted interventions (9). However, there is little research describing effective interventions in clinical settings that provide care to a diverse population of obese children and their families (10). In these "real world" settings, patient attrition is a common phenomenon, with attrition rates as high as 90% (11). Because intervention attendance and intervention completion are positively correlated with success (12-14), individuals who discontinue care are unlikely to receive the benefits of treatment, such as developing the skills necessary for weight loss and management (9). Furthermore, attrition often creates feelings of failure for both clinicians and families, ultimately reducing the likelihood of families attempting

treatment again (15-16). Lastly, attrition is usually preceded by missed appointments, which decreases the productivity of clinicians (15-16), contributes to delays in accessing care for those waiting for treatment (17), and increases overall clinical expenses (15-16).

A recent review explored attrition from pediatric weight management care, reporting attrition rates ranging from 27% to 73% (18). A variety of predictors of attrition were identified, including ethnicity, socio-economic status (SES), degree of obesity, and psychosocial and behavioural stressors, with inconsistent findings across studies. In this review, Skelton and Beech (18) reported scheduling issues and care not meeting needs or expectations as families' main reasons for discontinuing care. Similarly, another review of the determinants of attrition from adult weight management programs (19) reported inconsistent results. However, from these adult data, psychological and behavioural patient factors (*e.g.,* poorer mental health, lower levels of physical activity, *etc.*) were more commonly associated with drop out than patient background characteristics (e.g., age, sex, *etc.*). Because many factors predictive of attrition may be modifiable (and potentially preventable), there is an urgent need to determine predictors that may identify families at risk for attrition, and also develop a thorough understanding of the reasons for families' drop out. Therefore, the purpose of this study was to investigate predictors of attrition as well as reasons for attrition from children's, parents', and/or clinicians' perspectives in order to understand attrition from family-based pediatric weight management programs in its broadest context.

Methods

Design

This review used an integrative approach to summarize the published literature, including both quantitative and qualitative research, to create a comprehensive understanding of predictors of and reasons for attrition from pediatric weight management (20). An integrative review is quantitative in nature and qualitative in methodology such that the literature is searched systematically but the results of primary studies are combined in a *narrative* description to draw overall conclusions (rather than a meta-analysis) (21). This type of review yields results from the analysis of a broad range of research and study designs, which are more useful for the purpose of this type of study compared to other types of literature reviews (*e.g.,* systematic reviews) (22).

Search methods

An electronic literature search strategy was conducted using search terms to locate studies that were indexed in the following five bibliographical databases: CINHAL from January, 1982 to December, 2011; EMBASE from January, 1990 to December, 2011; MEDLINE from January, 1948 to December, 2011; PsycINFO from January, 1806 to December, 2011; and Scopus from January, 1966 to December, 2011. Assistance in defining search terms was provided by a local research librarian to ensure the search was inclusive and comprehensive. The search strategy employed various combinations of the following search terms (keywords and Medical Search Headings) using Boolean operators (with asterisk [*] as an open-ended term): (*weight*, *obesity*, *lifestyle**, *clinic*, *centre*), *AND*,

(*retention*, *attrition*, *Patient Dropouts*, *dropout**, *success*, *Patient Compliance*, *compliance**, *nonreturn**, *non adher**, *premature end**, *predict**, *motivate**, *enroll**, *discontin**, *stop*, *disengage**, *treatment refus**), *AND*, (*pediatric**, *Pediatrics/Child*, *child*, *Preschool*, *minor*, *Minors*, *Adolescent*, *adolescen**, *teen**, *youth*, *children*, and *puberty*). Sample search strategies used in CINAHL, EMBASE, and MEDLINE can be found in **Table 2-1**.

The ancestry approach was employed whereby reference lists of studies included in the review and from other review papers were examined for potentially useful studies that were not found in the electronic literature search (23). Because the titles in reference lists can misrepresent content, reviews of the text of each publication, particularly the literature review and discussion, were also reviewed for references to identify other studies of potential interest (23). Articles in which the full text versions were not available online were located by manually searching through specific journals.

Inclusion criteria

Articles were included if they: (a) Were published in English in a peer-reviewed journal; (b) Focused on the pediatric population (0-18 years of age); (c) Had a primary focus on pediatric weight management and not other pediatric illnesses (*e.g.,* type 2 diabetes, metabolic syndrome, etc.); (d) Incorporated lifestyle and behavioural changes without the use of pharmacotherapy (e) Reported predictors (*e.g.*, body mass index (BMI), income, ethnicity, age, etc.) and/or reasons (*e.g.*, dissatisfaction with services, location of services, *etc*.) for attrition from a family-based (involving both the child and at least one caregiver)

structured intervention (delivered in a research or clinical setting whose purpose was to manage or treat overweight/obese children) or clinical program (involved clinician(s) delivering care in a weight management clinic) in which the child or family was either referred by a clinician or self-referred; and (f) Provided data on families that discontinued an intervention prior to its completion or stopped attending appointments within a clinical program. Although children can discontinue care at various points in an intervention *(e.g.,* in an initial intensive or long-term follow up phase), attrition in its broadest context was explored.

Exclusion criteria

Studies were excluded if they: (a) Focused on the primary prevention of obesity; (b) Focused on school-based or community-based obesity interventions or programs; (c) Provided attrition data exclusively in the absence of predictors or reasons; (d) Included data from adolescents (*e.g.,* 19 year olds) that had a primary focus on adult weight management; (e) Provided attrition data not exclusive to the *drop out* group (*e.g.,* data were provided for families who sporadically attended appointments *and* for families who withdrew from care); and (f) Provided attrition data only at specific time points during an intervention, but not at intervention conclusion.

Search outcome

The search strategy identified 895 potentially relevant sources of evidence, of which 193 were duplicates. The remaining article titles and abstracts were reviewed by one author (JD) to determine whether or not they were relevant; most did not meet inclusion criteria. The full text, rather than just the abstract, was

reviewed because initial reviews revealed that relevant attrition data were not always reported in the abstract. Therefore, a full article review of 152 studies was conducted independently by two authors (JD and NN). Authors met to discuss articles that were included or excluded to achieve consensus on the final decision. The authors could not achieve consensus on four articles (n=4/152; 2.6%). In these instances, a third author (GDCB) reviewed the articles and the inclusion/exclusion criteria to make a final decision. For one study (24), the three authors could not reach consensus because of confusion over the definition of attrition. Therefore, the author of this manuscript was contacted in order to clarify the definition. Based on the information provided, this article did not meet inclusion criteria. In addition, four full-text studies (25-28) could not be located because they were published in journals the University of Alberta libraries did not have access to and were also excluded from our study. In total, 20 articles met the inclusion criteria and were included in this review (**Figure 2-1**).

Quality appraisal

Evaluating the quality of primary studies as part of an integrative review can be complex since diverse primary sources are included (29). However, to enhance our methodological rigour, a quality checklist, originally created by Bowling (30) and adapted by Desborough, Forrest, and Parker (31), was used to critically appraise the articles included in this review (see **Table 2-2**). This tool was appropriate for our review as it allowed for a constant comparison of quality between all 20 studies. The checklist allowed for the appraisal of studies with respect to: (a) Study objectives; (b) Research design; (c) Research methods; (d)

Data analysis; (e) Results; (f) Discussion; and (g) Clinical implications. For the purpose of this review, if all 12 criteria were met, the study was considered to be of relatively high quality. If at least nine of the criteria (75%) were met, the study was deemed to be of relatively moderate quality. And, if less than nine criteria were met, the study was considered to be of relatively low quality.

Data extraction and synthesis

Each of the 20 papers was read in its entirety to extract specific data elements in order to create a matrix that would assist with data analysis (32). Articles were randomly assigned to two authors who completed data extraction independently (JD and NN). Data elements collected included authors, publication year, country of publication, study design, study purpose(s), age of participants (years), total *n*, intervention modality (individual, group, combined), intervention style (multidisciplinary, behavioural, and/or lifestyle), length of the intervention, attrition level (%), reasons for attrition, variables significantly associated with attrition, variables not significantly associated with attrition, type of data analysis performed (*e.g.,* descriptive + multivariate, multivariate only, or descriptive only) and limitations discussed in the study. Additional comments were added when appropriate.

A diverse number of predictors of and reasons for attrition were extracted from the research articles. To facilitate data analysis and interpretation, similar predictors were grouped together (where appropriate) to create categories based on *child*, *parent*, *family*, and *health services factors*. *Child factors* encompassed: (a) Age; (b) Sex; (c) Ethnicity; (d) Baseline weight status, which included weight,

BMI, BMI z-score, percentage over ideal weight, body fat %, body fat mass, and degree of obesity; (e) Longitudinal weight status, which included change in BMI reduction during treatment and mean 10-week weight loss; (f) Health status, which included the overall health status of the child and cardiometabolic health measures; and (g) Psychosocial/Behavioural/Lifestyle factors, which included motivation, internalizing and externalizing behaviours, self-reported depressive symptomology, self-concept, maladjustment, adaptive behaviour, participation in activities, self-reported social support for diet and exercise, adherence to treatment protocol, history of dieting, daily caloric intake, and daily breakfast routine. *Parent factors* consisted of: (a) Age; (b) Marital status; (c) Ethnicity; (d) Baseline weight status, which included BMI, mean BMI, weight status, and number of overweight parents; and (e) Psychosocial factors, which included motivation, self-reported psychological distress, and degree of marital satisfaction. *Family factors* were comprised of: (a) Sibling weight status; (b) Family functioning, which was measured using the Family Adaptability and Cohesion Evaluation Scales (FACES) to assess extremes of cohesion (including disengagement and enmeshment) and adaptability (including rigidity and chaos); (c) SES; (d) Insurance type, which included public (*e.g.,* Medicaid) or private; and (e) Home environment, which included single or dual parent household, family size, number of siblings, and family structure. *Health services factors* consisted of: (a) Travel distance from home to clinic; (b) Enrolment season; (c) Number of missed appointments; (d) Expectations of care; (e) Caregiver-rated quality of care; and (f) Treatment history. Additional details are reported in the data matrix where

necessary (refer to **Tables 2-3 and 2-4**), such as when an author explored more than one variable in a factor, for instance BMI and body fat % within children's baseline weight status factor, or when one or more variables were found to be significant (or not significant).

Reasons for attrition were grouped into five main categories: (a) *Physical barriers*, which included distance to the program, transportation difficulties, scheduling, parking, location, and time; (b) *Families' needs, wants, and/or expectations,* which included perceived need of treatment, children's desire to continue with the program, expectations of program services, and satisfaction with the care received; (c) *Costs,* which included clinical visit costs; (d) *Motivation/Readiness,* which included families' readiness to make healthy lifestyle changes; and (e) *Health services factors*, which included length of program, length of clinic visits, clinic environment, relationships with clinicians, and program educational content.

Three general types of statistical analyses were conducted in the studies included in this review: (a) Descriptive + multivariate; (b) Multivariate only; and (c) Descriptive only. Results from studies that analyzed variables using both descriptive and multivariate analyses were considered to be more rigorous and informative than results from studies that only conducted one type of analysis. Furthermore, multivariate analyses were considered to be more powerful and meaningful than descriptive analyses because analyses were indicative of predictors rather than associations. Additionally, how data analyses were conducted (*a priori* or *ad hoc*) was used as a method to differentiate between data.

This classification allowed us to determine the most rigorous data upon which to focus the review. To ensure a broad understanding of attrition, we included articles that used *ad hoc* analyses to explore this phenomenon, even if only descriptive analyses were conducted. Because there are many terms used to describe *attrition* in the literature (*e.g.,* non-return, premature termination, withdrawal from care, etc.), for consistency, this review will use the terms *drop out* and *discontinue care* interchangeably with *attrition*.

Results

Of the 20 articles in this review, 14 were investigated with *a priori* analyses and are shown in **Table 2-3** (10, 15, 17, 33-43). Articles in which predictors of attrition (no reasons were explored) were investigated in *ad hoc* analyses (n=6) can be found in **Table 2-4** (41, 44-48). C*hild*, *parent*, *family*, and *health services* factors from studies that used *a priori* analyses were investigated first, followed by studies that used *ad hoc* analyses.

The quality appraisal of studies revealed that four studies (20%) were of high quality, meaning they met all 12 quality criteria (39, 42, 44, 49). Thirteen studies (65%) were considered to be of moderate quality (10, 15, 17, 33-36, 40-41, 43, 45, 47-48). Overall, study details regarding research methods were most often not adequately described. For example, 37% of studies (7/19) did not report the reliability and validity of instruments used (when appropriate) (33, 35-38, 45, 48), 35% (7/20) of studies did not discuss ethical considerations (17, 34, 36-38, 45, 47), and 72% (13/18) of studies did not discuss statistical power (10, 15, 17, 33-35, 37-38, 41, 43, 46-48). Additionally, 25% (5/20) of studies did not discuss

the limitations of their research and design (10, 37-38, 40, 46). Lastly, three studies did not meet at least 75% of quality criteria (15%) and were considered to be of poor quality (37-38, 46). Irrespective of study quality, data from all reports were included in the review for inclusivity (50).

Overall, 15 studies were conducted in the United States (10, 17, 33, 35-39, 41-46, 49), two in the Netherlands (34, 47), and one each in Belgium (15), Canada (40), and Italy (48). Attrition levels ranged across studies from 4% to 73%. Eight studies (40%) delivered interventions at the individual/family level (17, 33, 35, 40-42, 45-46), six (30%) delivered group interventions (34, 37-39, 43-44), four (20%) delivered individual interventions with group components or group interventions with individual components (10, 47-49), and only one study (5%) provided either individual or group interventions based on the participant's age (15). The length of the intervention also differed greatly from study to study. Although each study defined attrition as the discontinuation of care, the length of treatment received before being classified as a *drop out* differed substantially between studies (*e.g.,* did not attend more than two appointments, did not complete the intensive phase of an intervention, or did not complete the entire study intervention). Additionally, all but one of the interventions (40) employed a multidisciplinary approach to care, involving a variety of clinicians including pediatricians, nurse practitioners, dietitians, physical therapists, exercise specialists, and/or psychologists. Lastly, the studies were predominantly quantitative in design, although there was one qualitative study (40) and one mixed methods study (17) included. The combination of quantitative and

qualitative methods and the varying definitions of attrition between studies meant a narrative analysis of the results was most appropriate.

Predictors of attrition

Child factors.

Three of the six studies that examined children's age found a positive correlation with drop out using *a priori* analyses (10, 15, 42). Two studies (10, 15), using both descriptive and multivariate analyses, indicated that older age was predictive of attrition. However, one study (42) reported that being a young male (< 6 years old) was a predictor of drop out, though the composite nature of this variable (age + sex) makes it difficult to confirm the independence of these factors. Conversely, two other studies (17, 33), both using descriptive and multivariate analyses, and one study (34) using only multivariate analyses, determined that age was not a significant predictor of attrition. Except for one study (47), *ad hoc* results also indicated age was not predictive of attrition (44, 46, 48-49).

Eight studies (10, 15, 17, 33-34, 39, 41-43) investigated the role of children's sex as a predictor of attrition; except for one study (42), sex was not significantly associated with attrition. For example, Cote *et al.* (17) analyzed the influence of children's sex using descriptive and multivariate analyses and concluded that sex was not predictive of attrition. One additional study (34) using logistic regression analyses, and six using descriptive analyses (23, 26, 31, 38, 41-42) corroborated this result. *Ad hoc* analyses, with the exception of one study

(46), also reported that children's sex was not significantly associated with drop out (35, 48-49).

Three of the five studies that examined children's ethnicity found that it was not predictive of attrition using multivariate *a priori* analyses (17, 39, 42). Investigators conducted bivariate analyses to corroborate this result (17). Conversely, one study (10), using descriptive and logistic regression analyses, indicated that children of African American descent were more likely to discontinue care. Tershakovec and Kuppler (41) substantiated this result through descriptive analyses. All three studies (45-46, 49) that examined ethnicity with *ad hoc* analyses found no association between children's ethnicity and attrition.

Children's baseline weight status (*e.g.,* BMI) was examined in eight studies (10, 15, 17, 34, 39, 41-43). Of these, seven determined children's baseline weight status was not predictive of drop out. For example, Cote and colleagues (17) used descriptive and logistic regression analyses to show that children's percentage over ideal body weight was not predictive of attrition. Four studies (10, 15, 39, 42) through multivariate analyses, and two studies (41, 43) using descriptive statistics corroborated these findings. Only one study (34) using logistic regression analyses reported that children with higher baseline BMI SDS (standard deviation scores) were more likely to discontinue care. *Ad hoc* results reported inconsistent findings about the association between children's baseline weight status and attrition. Four studies (45-46, 48-49) found no association between the two variables. However, two (44, 47) reported that individuals who discontinued care had a significantly higher baseline BMI than those who

continued with care. Furthermore, two studies also investigated the association of children's longitudinal weight status with attrition (46-47) and only one (47) indicated that families who were less successful in BMI-reduction during treatment were more likely to discontinue care.

Few studies examined children's health status as a predictor of attrition. Investigators (17) examined children's overall health status as a predictor of attrition, reporting no association between the two using descriptive and multivariate analyses. Furthermore, only one study examined the relationship between cardiometabolic health and attrition (10). Descriptive analyses showed low density lipoprotein, high density lipoprotein, and baseline blood pressure were not significantly associated with drop out. *Ad hoc* analyses indicated that cardiometabolic health measures were also not significantly associated with attrition (49).

There was substantial heterogeneity among the six studies that examined children's psychosocial/behavioural/lifestyle variables and their respective associations with attrition (10, 15, 34, 38-39, 43). Two studies (39, 43) did not find any of the variables they examined within this category to be predictive of drop out. However, the remaining four studies reported a variety of results. Braet *et al.* (15) and Zeller and colleagues (10) indicated that drop out was predicted by an internalizing behaviour problem at intake. Conversely, two studies used multivariate analyses to reveal that children exhibiting internalizing behaviour, externalizing behaviour, social problems and school problems in children were not predictive of attrition (10, 34). De Niet *et al.* (34) reported that children who

participated in fewer activities and did not have breakfast on a regular basis were more likely to discontinue care. Lastly, any degree of adherence to treatment protocols except extremely high adherence (38) was associated with attrition using descriptive statistics. Only one study used *ad hoc* analyses to report that children's psychosocial/behavioural/lifestyle factors were not associated with drop out (48).

Parent factors.

Two of the three studies that examined parents' baseline weight status (*e.g.*, BMI) found that it did not predict drop out using *a priori* analyses (15, 37). On the other hand, Jelalian *et al.* (39) reported that a higher parent BMI at baseline was a significant predictor of attrition in univariate and multivariate analyses. Only one study (48) examined parents' BMI using *ad hoc* analyses and found it was not predictive of drop out.

Only one study (15) found an association between parent psychosocial variables and attrition, revealing that parents of children who completed the treatment reported significantly higher motivation for treatment at intake. Low parental motivation for treatment remained a significant predictor of attrition in a logistic regression analysis. Furthermore, degree of marital satisfaction (37), and caregiver self-reported psychological distress (10) were not significantly associated with drop out.

Family factors.

Only two studies (34, 43) examined family functioning *a priori* and found contradictory findings. While de Niet and colleagues (34) found families who did not report a rigid adaptability structure (characterized by authoritarian parenting, lack of family evolution to change and very strict rules) were more likely to drop out using multivariate analyses, Williams *et al.* (43) revealed family rigidity and chaos were not associated with attrition also using multivariate analyses. Rather, these investigators (43) revealed family disengagement (characterized by close family boundaries, avoidance, an inability to ask for help from one another, and disloyalty) to be associated with drop out.

Four of the six studies that explored SES indicated that it was not predictive of attrition (15, 17, 34, 39) using *a priori* analyses. For example, one study (17) analyzed SES in bivariate and multivariate analyses to determine that it was not predictive of drop out. However, two studies using descriptive analyses reported that families who discontinued care were more likely to have a lower SES than those who completed care (37, 43). *Ad hoc* analyses indicated SES was not predictive of drop out (44).

Three of the four studies (10, 17, 42) that examined insurance type indicated that families with public insurance (*e.g.,* Medicaid) were more likely to drop out from pediatric weight management care compared to families with private insurance. For instance, Zeller *et al.* (10) examined this variable with descriptive and logistic regression analyses and found that families discontinuing care were more likely to be Medicaid recipients. Similarly, investigators (17, 42)

used multivariate analyses to determine that public insurance coverage was predictive of attrition. Only one study (41) found the association between private insurance and attrition to be not significant, but only used descriptive statistics in their analyses. A*d hoc* analyses (45) found no association between insurance type and attrition.

Three of the five studies that investigated the home environment (*e.g.,*. single or dual parent household) found that it was not predictive of attrition (10, 15, 34). Two of these studies (10, 15) also examined this variable in a logistic regression, but analyses revealed no association between the home environment and drop out. On the other hand, two studies (38, 43) used descriptive analyses to indicate that children from single parent households were more likely to discontinue care. Only one study (45) used *ad hoc* analyses to determine no association between single or dual parent households and attrition.

Health services factors.

Five studies examined a number of health services factors using *a priori* analyses (10, 15, 17, 35, 42) resulting in inconsistent findings. Investigators (42) used multivariate analyses to determine that enrolment during the summer months and a larger travel distance from the patient's residence to the clinic was predictive of attrition. However, Zeller and colleagues (10) determined through descriptive analyses that travel distance was not associated with attrition. Cote *et al.* (17) used descriptive and logistic regression analyses to reveal lower caregiver-rated quality of care predicted attrition. Furthermore, having more missed appointments (35) was significantly associated with discontinuing care.

However, expectations of group treatment and treatment history were not predictive of drop out (15). There were no *ad hoc* results reported to corroborate these findings.

Reasons for attrition

Physical barriers.

Kitscha, Brunet, Farmer and Mager (40) conducted a qualitative telephone survey to assess reasons for drop out in a dietitian-led pediatric weight management program. From this sample, 79% (n=11/14) of caregivers identified scheduling, parking, and location as reasons for attrition. Barlow and Ohlemeyer (33) explored parent reasons for attrition from weight management care, showing that 21% (n=9) of caregivers outlined scheduling conflicts in general as a barrier to care. This study also revealed that 28% (n=12) of parents expressed concern over children missing too much school, and 23% (n=10) said the program was too far from their home. Cote *et al.* (17) completed a telephone survey of caregivers to explore their clinical experiences. Overall, 18% (n=12) of participants described transportation difficulties as significantly impacting their continuation of care. Similarly, Hampl *et al.* (36) interviewed clinic administrators and indicated that children missing too much school (55%; n=13), transportation difficulties (59%; n=14) and the inability of caregivers to miss work (65%; n=16) were all commonly perceived barriers.

Families' needs, wants and/or expectations.

All five studies that explored reasons for attrition investigated families' needs, wants, and/or expectation. For instance, 37% of participants (n=16) described that the program was not what they were looking for (33) and 12% (n=8) of parents indicated that the clinic did not meet family expectations (17). Hampl and colleagues found that clinic administrators (n=7; 36%) perceived that families experienced little benefits from the clinic programs; the perceived relevance of treatment was also outlined as a barrier by parents who did not complete an intervention (15). Furthermore, 33% (n=22) of parents reported their child wanted to leave the program (17), and 7% (n=1) described no longer needing support from the clinic as a reason for discontinuing care (40).

Costs.

Three studies (17, 33, 36) reported that the cost of clinical visits was an important reason for drop out. In two studies, 33% (n=22) (17) and 21% (n=9) (33) of parents reported that they had difficulties with insurance coverage, which contributed to their discontinuing of care. Similarly, 23% (n=6) of clinic administrators at hospitals queried by Hampl *et al.* (36) outlined that the cost of clinic visits was a perceived barrier for families.

Motivation/Readiness.

Motivation/Readiness for change was addressed by two of the five studies (33, 40). Caregivers surveyed by Barlow and Ohlemeyer (33) reported that they withdrew from care because their child was not ready to make changes (16%;

n=7) or their family was not ready to make changes (5%; n=2). Additionally, 7% (n=1) of caregivers described motivation in general as an impediment to continuing care (40).

Health services factors.

With respect to health services factors, 14% (n=2) of caregivers outlined the clinic environment (lengthy appointments, lack of entertainment for children, small rooms), and 7% (n=1) described program educational content (patient focused counseling rather than family focused, previously learned information and skills) as reasons for drop out (40). Additionally, Barlow *et al*. (33) revealed that 12% (n=5) of caregivers described clinic visits were too infrequent and 7% (n=3) described clinic visits to be too frequent. Problems with appointment times were outlined as a reason for attrition by another study (15). Lastly, 6% (n=4) of caregivers in the study conducted by Cote *et al.* (17) reported that program participation took too much time, and an additional 6% (n=4) reported that appointment times were inconvenient.

Discussion

The purpose of this integrative review was to explore predictors of and reasons for attrition from pediatric weight management care. The quality of research involving attrition from pediatric weight management care was assessed and determined to be of moderate to high quality, meaning at least nine of the twelve quality criteria were met. Most studies adequately described the introduction, results, and discussion sections. Only three studies were rated to be

of poor quality (37-38, 46), which may be attributable to the older age of these studies (before the year 2000). Regardless of whether studies identified their intent to investigate predictors of attrition *a priori* or *ad hoc*, the quality of research conducted was still moderate to high and the findings were consistent across these types of studies. In fact, half of the studies rated as high quality (44, 49) investigated predictors through *ad hoc* analyses.

Our findings revealed that children's sex and baseline weight status were not significant predictors of attrition. However, insurance type was an important predictor of attrition; families who received public insurance (*e.g.,* Medicaid) were more likely to discontinue pediatric weight management care than families with private insurance. Additionally, the data reported inconsistent findings with respect to the remaining *child, parent, family, and health services factors.* The most commonly reported reasons for attrition, in the order of most reported to least, were physical barriers (*e.g.*, scheduling), the clinic failing to meet families' needs, wants, and/or expectations (*e.g.*, perceived need of care), costs (*e.g.*, cost of health services), a lack of child or parent motivation/readiness to change (*e.g.*, self-reported low motivation), and issues with health services factors (*e.g.,* problems with the length of appointments and/or programs).

The attrition data presented in this review were similar to those published by Skelton and Beech (18). Although attrition levels varied greatly in our review, upon further examination, it appears that the highest attrition levels were found among interventions that were delivered exclusively at the individual level or from group interventions that incorporated individualized components (15, 17, 33,

35, 40-42, 45-46). However, the intensity of clinic visits (*e.g.,* biweekly, monthly, or yearly) and the length of treatment most likely contribute to this observation. For example, three studies (34, 51-52) identified variables that predicted drop out at different stages of pediatric weight management interventions (*e.g.,* during the intensive phase or after a specified number of clinical visits). However, further research is needed to determine the best intervention modality (group, individual, or combined) and the treatment length that will produce the lowest attrition rates while still resulting in positive weight and health outcomes for children and their families. Additionally, the cost-effectiveness of interventions also needs to be taken into consideration; group interventions are more cost-effective than combined interventions (53). Because group interventions had the lowest levels of attrition in our study, it may be more appropriate to deliver group interventions instead of individual or combined treatments to minimize the risk of attrition.

With the exception of public insurance type, demographic variables of either children or parents, such as age, sex, and ethnicity, did not consistently predict attrition. A review examining attrition from adult weight management programs also concluded that demographic variables were not commonly associated with attrition (19). Because the majority of studies included in our review were conducted in the United States (the only wealthy industrializing nation in the world that lacks some form of universal health coverage (54)), it is not surprising that our results revealed public insurance type to be predictive of attrition. In the United States, direct public funding of healthcare is limited to Medicare, which covers eligible senior citizens and younger disabled adults, and

Medicaid, which provides health coverage to certain categories of low-income people, including children (55). Moreover, Medicaid enrollees have the highest prevalence of obesity (56) yet, as shown in this review, are at a greater risk for drop out from pediatric weight management care compared to those who are uninsured or privately insured. One plausible contributing factor is the lack of reimbursement from the government for the cost of obesity-related treatment (nutritional and behavioural therapy). In reality, only 10 states appear to reimburse Medicaid families for these health services (56), ultimately creating barriers to accessing care for families enrolled in Medicaid. Interestingly, the Centers for Medicare and Medicaid (CMS) services guidelines indicate that all necessary coverage exists for the treatment of pediatric obesity (57-58). However, states often do not recognize this or they create barriers to accessing this care, such as limiting the number of visits covered (58-59). Furthermore, as suggested by Rosenbaum *et al.* (57) "a strategy is needed for translating CMS guidelines into real service delivery action at the community level (p.44)." Therefore, the United States federal government needs to take action, such as clarifying with states that obesity-related services are covered (58), to ensure comprehensive coverage is being provided at the state level, thereby eliminating residence as a barrier to accessing care.

On the other hand, although public insurance type was predictive of attrition, the cost associated with clinic visits was not Medicaid and non-Medicaid families' main reason for discontinuing care. For example, in two studies (10, 17), Medicaid recipients were still more likely to drop out of care despite having

complete coverage for the program. Additionally, further examination of the results in one study (17) indicated that a greater proportion of families with private medical insurance reported cost as significantly impacting their decision to discontinue care. Therefore, families with private medical insurance may face more difficulties in paying for health services than individuals with public insurance in states where obesity-related treatment is in fact covered for Medicaid recipients. For example, the median third party payer reimbursement rate for pediatric weight management care at one program was only 11% (60). In the study by Cote and colleagues (17), when asked what clinics could do to facilitate families' return to the program, providing assistance with understanding and facilitating insurance coverage of the program was most frequently suggested. Interestingly, during the intervention, families were provided with individualized financial counseling and assistance with their medical insurance providers, indicating that rather than clinic-level modifications, government-level changes need to be made to effectively address this barrier. Because Medicaid recipients are still more likely to drop out of care, in order to promote retention among this population, Medicaid insurance programs can employ the use of incentives, such as gift certificates, for attending scheduled appointments for pediatric weight management (61). Additionally, private insurance companies need to incorporate reimbursement policies for pediatric obesity-related services, thereby eliminating families' financial status as barriers to obtaining health care services. Furthermore, because research suggests low initial uptake of new benefits,

insurance companies need to proactively educate providers on services newly covered, such as pediatric obesity-related treatments (58).

Moreover, characteristics specific to Medicaid recipients, in addition to financial status, may play a significant role in attrition. For instance, users of Medicaid tend to have a lower health status than individuals with private insurance coverage (55). Thus, children with poorer overall health may be at a greater risk of suffering from more serious co-morbidities that are more concerning to parents than their child's weight; parents may actively seek services for these more immediate health concerns, thereby putting these families at risk for attrition from pediatric weight management care (17). Additionally, because research suggests that users of Medicaid tend to be very poor (55), these families may also face more physical barriers such as a lack of transportation, child care and/or job security (43), making it difficult to commit to pediatric weight management care. Therefore, determining specific characteristics that contribute to Medicaid recipient families' discontinuation of care can help inform future interventions specifically tailored to this group in an effort to promote retention. Additionally, extra funding allotted to clinics from the government can help create targeted interventions, and can be used to alleviate barriers specifically faced by Medicaid recipients, such as providing transportation to and from clinics.

Although children's baseline weight status was not a significant predictor of attrition, children's longitudinal weight status may play a more important role. Weight loss during the initial phases of an intervention was related to weight loss and attendance during later weeks (39). It is likely that children experiencing

success early on in an intervention are more likely to continue and sustain this weight loss. In our review, Van den Akker *et al.* (47) reported the lowest attrition level – 4% after three months of intensive treatment – and children had a significant reduction in weight persisting until one-year follow up. Therefore, if shorter, intensive interventions are able to create positive weight and health outcomes for families compared to longer, less intensive interventions, future research should focus on promoting patient attendance in the early phases of treatment (43). It is conceivable that keeping families engaged in short-term interventions may be more feasible and cost-efficient than keeping families committed to long-term interventions. Furthermore, research also indicates that more frequent attendance during the initial phase of a treatment is correlated with better attendance during the follow-up phase of a treatment (43).

Unlike the results from our review, in adults, psychosocial and behavioural factors were more commonly associated with attrition than patient demographic or anthropometric characteristics (19). One explanation for the inconsistency in findings may be that the studies which investigated psychosocial factors often asked parents to report on their child's symptoms, rather than obtaining self-reports from children (43). For example, parents often reported less internalizing symptoms, such as their child being over anxious or depressed than what children actually reported (43, 62). Therefore, the extent to which psychosocial/behavioural/lifestyle factors truly play a role in drop out may have been weakened. Further research should focus on children's perspectives of their own psychological well-being and its association with attrition. Furthermore, to

improve retention in pediatric weight management care, clinical programs can incorporate screening for psychosocial and behavioural issues among children prior to initiating obesity treatment (10). For example, children deemed 'at risk' can then receive care from a psychologist before initiation or in conjunction with their obesity treatment. It is conceivable that once children no longer suffer from psychosocial or behavioural problems or have mental health issues better managed, they will be more likely to continue with care. However, further research needs to assess if incorporating treatment for psychosocial or behavioural difficulties will increase treatment demands for a group that may already be at risk for attrition (10).

Rather than the cost of clinic visits, families often reported physical barriers (*e.g.*, school, work and transportation) as reasons for drop out (17, 18, 33, 36, 40). Consistently missing school to attend appointments can cause children to fall behind, negatively impacting their learning. Furthermore, parents having to take time off work results in lost wages, which is especially taxing for lower income families. To alleviate the burden of physical barriers, clinics can offer appointments in the evenings or weekends to allow families with difficult schedules the opportunity to access weight management care (36). Furthermore, clinicians can educate families about alternative transportation options (36), such as the shortest bus route to the clinic. Lastly, additional funding from the government could help develop satellite clinics, outreach programs, and/or Telehealth networks (63-64) that allow for secure videoconferencing between families and clinicians, to provide care to families who live in rural or remote

areas. Although physical barriers have been reported by many families, it is important to note that these barriers are not exclusive to families who discontinue care; families who drop out from care do not perceive to experience more barriers that burden their ability to continue with weight management care compared to families who continue with care (15). This research suggests that families' perceptions of the care they receive may play a more important role in their decision to discontinue care than barriers faced.

Our review revealed many families discontinued care because their needs, wants, and/or expectations were not being met. It may be that the healthcare services delivered were not tailored to families' needs, resulting in little or no improvements in health and dissatisfaction with care, ultimately leading to attrition. On the other hand, families may no longer perceive any benefit from their treatment because they are already satisfied with their health outcomes, resulting in drop out that may be premature only from a clinician's or researcher's perspective (15, 36, 40). Future research should investigate matching treatment to patients' needs, wants, and/or expectations in an effort to reduce attrition and improve care (33). For example, if families wanted a greater focus on the child rather than the parent during clinical appointments, providing this approach to care may reduce attrition. Because families are often limited in the types and styles of programs they can choose from, understanding what kind of care families need by incorporating a screening tool, such as an educational needs assessment to identify healthy lifestyle knowledge and needs (40), can help improve the 'fit' between families and programs (33). Having a variety of

services for families to choose from (*e.g.,* individualized, group, Telehealth, and web-based) can also improve this 'fit'. Furthermore, clinicians can facilitate open communication by using active listening skills (65) and showing respect, interest, warmth, flexibility, and openness during clinical appointments (66); it is likely that families will be more willing to discuss their needs, wants, and/or expectations in a therapeutic environment.

Additionally, children wanting to leave the program was also outlined as a major reason for discontinuing care (17). It appears that children play a significant role in the decision-making process (18), warranting the need for retention methods to focus on children, such as using the Short Message Services (SMS), which has shown to keep children engaged in a weight management program (67). However, most research has only focused on parents' perceptions of pediatric care (68); more child-focused research is needed. Only two studies (33, 40) revealed insufficient child and parent motivation as a contributor to attrition, providing evidence that attrition should not be viewed exclusively as patient non-compliance (17). However, lack of motivation is a commonly faced barrier as perceived by clinicians providing pediatric weight management care (16). Therefore, identifying families at baseline who have lower motivation may be useful in determining when to use additional motivational strategies to enhance retention. One such strategy, which is consistent with clinical guidelines for obesity management (69), includes using patient-centered counseling, which emphasizes patient-physician collaboration (70). One form of patient-centered counseling is Motivational Interviewing (MI), which helps build patients'

motivation by working through their ambivalence about behaviour change (71-72). MI may also help improve the motivation of children and families not actively seeking treatment (*e.g.,* families that are extrinsically motivated by their physician) (16). Training in patient-centered counseling may help clinicians use this strategy more often (71). Additionally, further research on an appropriate methodological tool, such as a survey, to accurately assess motivation of families is also needed.

There are both strengths and limitations to this review. The key strength of this integrative review was the notable improvement with respect to the reporting of and methodological approach to the previous review conducted by Skelton and Beech (18). For example, the previous review only searched one database to find a total of 15 studies, of which only six were included in our review (because they met our inclusion criteria), whereas we searched five databases to retrieve 20 articles. We included more articles based on cogent but comprehensive inclusion and exclusion criteria; however, the inclusion and exclusion criteria used by Skelton and Beech are unclear. By examining the studies included in their review, it appears that the previous review did not limit their search to family-based structured interventions or clinical programs. Furthermore, Skelton and Beech inconsistently included studies that reported attrition data exclusively in the absence of predictors of or reasons for attrition. Additionally, unlike the previous review, we categorized our results based on the type of analyses conducted with respect to attrition data (*a priori* vs. *ad hoc*) and included a quality assessment. These steps ensured we were making conclusions based on the most rigorous data

available (*e.g.,* from moderate to high quality studies whose primary or secondary purpose was to explore predictors of or reasons for attrition from pediatric weight management care). Therefore, these methodological improvements enhance our confidence in the generalizability of our results.

This study also has several limitations. First, the heterogeneity in each of the data groups collected from studies (*e.g.,* ages of participants, lengths of interventions, intervention modalities, and definitions of attrition) limits the comparability of results. For example, comparing predictors of attrition from two different studies that utilized different intervention lengths may have resulted in misleading results. Second, attrition was conceptualized as a single category (17), regardless of when a family withdrew from care. It is likely that predictors of and reasons for families dropping out early in a program may be different than families who drop out later in the program. For example, early drop outs may have difficulty with insurance coverage whereas later drop outs may not have achieved their weight loss goals (17, 34). Third, because a criteria count was used to assess the quality of studies included in our review, key differences between the studies could not be conceptualized. Fourth, similar to adult literature (19), the majority of studies included in our review relied on data collected at baseline (*e.g.,* demographic, anthropometric, and psychosocial/behavioural/lifestyle information) rather than predictors chosen based on their empirical relationship with attrition. Lastly, because our research interests were primarily focused on attrition from family-based structured interventions or clinical programs delivered

in a research or clinic setting, we excluded school and community based interventions, which may have offered additional insight.

Future Directions

This review outlines the importance of patients' perspectives of their care. Predictors alone will not tell us the reasons why families drop out from care, making it difficult to make changes to minimize attrition. For example, insurance status, although predictive of attrition, did not corroborate with families' main reasons for drop out (physical barriers). Therefore, further research should focus on qualitative research methods to better understand factors that impact families' decisions to discontinue care (10, 15-16, 33, 36, 73). Additionally, most research to date has only examined parent reasons for attrition (17, 33, 40, 68). However, as indicated by our study, children also play an important role in the decision-making process. Therefore, gauging the child's perspective on his or her care will also be helpful in determining families' reasons for attrition from pediatric weight management care (17, 73). This information will help to optimize future delivery of health care services for this population. Additionally, because families' perspectives about their care was a significant reason for attrition, current programs should assess clinic-level barriers and subsequently incorporate quality-improvement measures to reduce attrition (36).

Conclusion

This study indicated that insurance status was predictive of dropout; families who received public insurance (*e.g.,* Medicaid) were more likely to discontinue pediatric weight management care. Additionally, the most commonly

reported reasons for attrition were physical barriers and families' needs, wants, and/or expectations not being met. To improve patient retention in pediatric weight management, clinic- and government-level changes are warranted, such as tailoring interventions specific to patient subgroups (*e.g.,* Medicaid recipients) and addressing clinic-level barriers as indicated by families. Additional research investigating child and parent reasons for their discontinuation of care is justified as child/family characteristics (*e.g.,* demographics) are not the primary contributors to patient drop out. Families' "perspective[s] [are] critical to developing effective strategies to promote patient completion of empirically supported programs (p.165) (17)." The variability in attrition levels and factors associated with drop out underscore the clear need to develop a global definition of attrition, which can then be used to guide future research and clinical decision-making in pediatric weight management care.

Table 2-1: Sample CINAHL, EMBASE, and MEDLINE search strategies

Concept 1		**Concept 2**		**Concept 3**
(weight or obesity or life-style* or lifestyle* adj2 (program* or clinic or clinics or center or centers or centre or centres)).mp.	AND	retention.mp. or attrition.mp. or exp Patient Dropouts/ or "drop out*".mp. or dropout*.mp. or success*.mp. or exp Patient Compliance/ or compliance*.mp. or non- return*.mp. or nonreturn*.mp. or non complian*.mp. or noncomplian*.mp or ("non adher*" or nonadher*).mp. or (prematur* adj end*).mp. or predict*.mp. or motivat*.mp. or enroll*.mp. or (discontin* or stop or disengag* or dis- engag*).mp. or "treatment refus*".mp.	AND	pediatric.mp. or exp Pediatrics/ or child.mp. or exp Child, Preschool/ or exp Child/ or minor.mp. or exp Minors/ or exp Adolescent/ or adolescen*.mp. or teen*.mp. or youth*.mp. or children.mp. or (limit set # to ("all infant (birth to 23 months”)) or "all child (0 to 18 years)") or ((pediatric* or paediatric* or peadiatric* or child* or teen* or adolesc* or youth or puberty). jn,jw,nj,nw.)

Table 2-2: Critical appraisal of scientific literature using Bowling's quality assessment tool (30), which was adapted by Desbourough *et al.* (31)

Checklist	**Israel *et al.* (37)**	**Israel *et al.* (38)**	**Sothern *et al.* (46)**	**Tershakovec & Kuppler (41)**	**Cote *et al.* (17)**	**Zeller *et al.* (10)**	**Barlow & Ohleymeyer (33)**	**Jelalian *et al.* (44)**	**Van den Akker *et al.* (47)**	**Jelalian *et al.* (39)**
Clearly stated aims & objectives	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Study design adequately described	✓	x	✓	✓	✓	✓	✓	✓	✓	✓
Appropriate research methods	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Appropriate use of instruments (reliability and validity)	x	x	✓	✓	✓	✓	x	✓	✓	✓
Adequate description of source of sample, inclusion/exclusion criteria, response rates	✓	✓	x	✓	✓	✓	✓	✓	✓	✓
Statistical power discussed	x	x	x	x	x	x	x	✓	x	✓
Ethical considerations discussed	x	x	✓	✓	x	✓	✓	✓	x	✓
Appropriate analyses (statistical or qualitative)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Results clear and adequately reported	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Discussion of results reported in light of study question & relevant literature	✓	x	x	✓	✓	✓	✓	✓	✓	✓
Limitations of research & design discussed	x	x	x	✓	✓	x	✓	✓	✓	✓
Implications of research discussed	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Checklist	**Skelton *et al* (45)**	**Vignolo *et al.* (48)**	**Kitscha *et al* (40)**	**Braet *et al.* (15)**	**Williams *et al.* (43)**	**De Niet *et al.* (34)**	**Halvorson & Skelton, (35)**	**Hampl *et al.* (36)**	**Savoye *et al.* (49)**	**Walker *et al.* (42)**
Clearly stated aims & objectives	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Study design adequately described	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Appropriate research methods	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Appropriate use of instruments (reliability and validity)	x	x	n/a	✓	✓	✓	x	x	✓	✓
Adequate description of source of sample, inclusion/exclusion criteria, response rates	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Statistical power discussed	✓	x	n/a	x	x	x	x	n/a	✓	✓
Ethical considerations discussed	x	✓	✓	✓	✓	x	✓	x	✓	✓
Appropriate analyses (statistical or qualitative)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Results clear and adequately reported	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Discussion of results reported in light of study question & relevant literature	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Limitations of research & design discussed	✓	✓	x	✓	✓	✓	✓	✓	✓	✓
Implications of research discussed	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Table 2-3: Overview of results from articles in which reasons and/or predictors of attrition were investigated with *a priori* analyses

Study	*n*	Age range (yrs)	Modality	Length	Attrition (%)	Definition of attrition	Reasons for attrition	Variables significantly associated with attrition	Variables not significantly associated with attrition
Barlow & Ohleymeyer, 2006 (33)	157	1-18	Individual	Open-ended	61%	Attended $\leq$ 2 visits	Physical barriers Families' needs, wants, and expectations Cost Motivation/ Readiness Health services factors		
Braet *et al.*, 2010 (15)	72	4-16	Individual or group	3 months	47%	Attended $\leq$ 6/8 sessions	Families' needs, wants, and expectations Health services factors	Older age of child* Child internalizing behaviour* Low motivation of parents*	Child sex Higher child BMI^ Motivation of child Parent age Parent baseline weight status Lower SES^ Family structure Higher family size^ Expectations of group treatment^ Treatment history

Cote *et al.*, 2004 (17)	120	5-17	Individual	21 months	55% after 3 months (intensive phase)	Did not complete intensive phase	Physical barriers Families' needs, wants, and expectations Cost Motivation/ Readiness Health services factors	Insurance type (public)^ Lower caregiver-rated quality of care*	Child age* Child sex* Child ethnicity* Child baseline weight status* Child health status^ SES*
De Niet *et al.*, 2011 (34)	248	8-14	Group	12 months	44%	Children dropped out during the total treatment period (0-12 months)		Higher baseline child BMI SDS^ Participated in fewer activities^ Did not have breakfast on a regular basis^ Non white mother^ Child did not live in family with a static adaptability structure^	Child age^ Child gender^ Internalizing behaviour^ Externalizing behaviour^ Social problems^ School problems^ Parent psychosocial factors Number of siblings SES
Halvorson & Skelton, 2011 (35)	194	2-18	Individual	12 months	57% after 4 months (intensive phase)	Did not complete the intensive phase		More missed appointments	
Hampl *et al.*, 2011 (36)	24	N/A	N/A	N/A	32% for follow-up visits	Did not attend a scheduled visit and did not call before the day of the visit to	Physical barriers Families' needs, wants, and expectations Cost		

						reschedule			
Israel *et al.*, 1986 (37)	111	8-13	Group	2 months	18%	Completed the initial assessment session but not the full program		Degree of marital satisfaction[§] Lower SES[§] Single parent household[§]	Parent baseline weight status Sibling weight status
Israel *et al.*, 1987 (38)	54	8-13	Group	6.25 months	26%	Withdrew from program or missed two consecutive sessions and did not attend the following session		Any adherence but extremely high baseline adherence to treatment protocols	
Jelalian *et al.*, 2008 (39)	76	13-16	Group	4 months	18%	Failure to complete the end of treatment evaluation (did not complete 16 weeks)		Higher baseline parent BMI*	Child sex Higher child BMI^ Ethnic minority status^ Child psychosocial/ behavioural/ lifestyle factors SES
Kitscha *et al.*, 2009 (40)	152	2-17	Individual	Open-ended	33%	Attended $\leq$ 2 clinic appointment	Physical barriers Motivation/ Readiness Health services factors		
Tershakovec & Kuppler, 2003 (41)	518	5-17	Individual	Open-ended	49%	Attended the initial assessment and intervention		African-American ethnicity Insurance type (private)[§]	Child sex Child baseline weight status

						session only			
Walker *et al.*, 2011 (42)	1080	0-17	Individual	6 months	38%	Did not return for any follow-up visit after the initial visit		Male, < 6 years^ Insurance type (public insurance)^ Living in a tertiary service area^ Enrolment during summer^	Baseline child BMI z-score ≥ 2.5^ Ethnicity^
Williams *et al.*, 2010 (43)	204	4-7	Group	24 months	32% at 6 months (intensive phase)	Attended ≤ 2 of total scheduled sessions		Ethnic minority Lower SES Single parent household Family disengagement^	Child sex Child baseline weight status Child psychosocial/ behavioural/ lifestyle factors Family chaos^ Family rigidity^
Zeller *et al.*, 2004 (10)	212	6-17	Individual	Open ended	55% at 4 months (intensive phase)	Completed ≥ 1 visit(s) but withdrew before completion of the intensive phase		Older age of child* African-American ethnicity* Little change in child BMI during treatment Child self-report depressive symptoms* Lower self-concept Insurance type (public)*	Child sex Higher child BMI/BMI Z-score^ HDL LDL Blood pressure Internalizing behaviour Externalizing behaviour^ Personal adjustment Clinical maladjustment Greater school maladjustment^ Adaptive behaviour Parent psychosocial

									factors Home environment^ Travel distance

*By descriptive and multivariate analysis
^By multivariate analysis only
§Approached significance
BMI: Body mass index
SES: Socio-economic status
HDL: High density lipoprotein
LDL: Low density lipoprotein

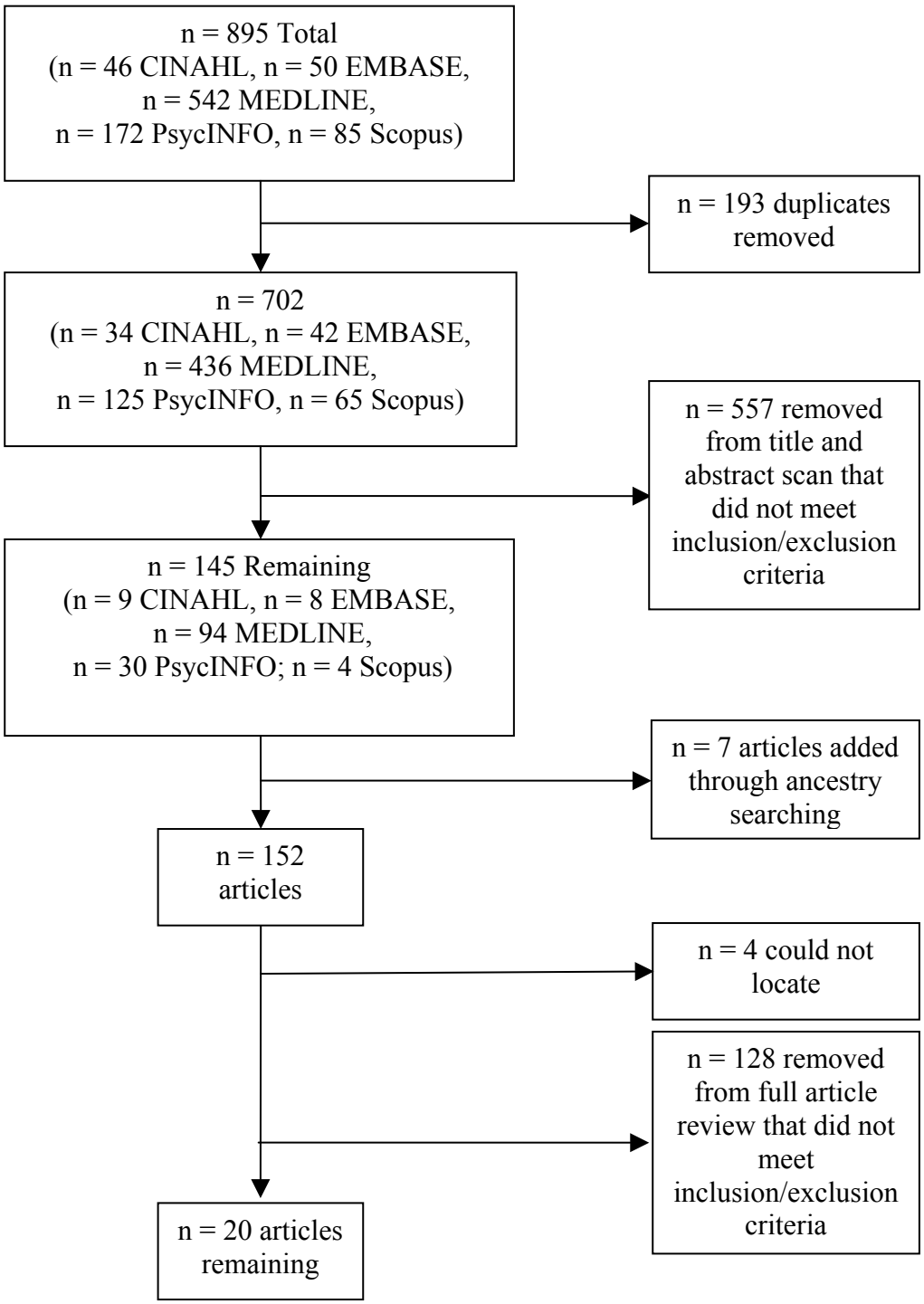
Table 2-4: Overview of results from articles in which predictors of attrition were investigated with *ad hoc* analyses

Study	*n*	Age range (yrs)	Modality	Length	Attrition (%)	Definition of attrition	Variables significantly associated with attrition	Variables not significantly associated with attrition
Jelalian *et al.*, 2006 (44)	76	13-16	Group	10 months	26%	Did not complete the study	Higher child BMI	Child age SES
Savoye *et al.*, 2011 (49)	209	8-16	Group with individual components	24 months	56%	Did not complete the study	Higher baseline diastolic blood pressure	Child age Child sex Child ethnicity Child baseline weight status Child health status
Skelton *et al.*, 2008 (45)	248	2-18	Individual	~12 months	73%	Did not complete the program during the study period		Child age Child sex Child ethnicity Child baseline weight status Insurance type Home environment
Sothern *et al.*, 1999 (46)	73	7-17	Individual	12 months	34%	Did not complete the study	Male	Child age Child ethnicity Child baseline weight status Child longitudinal weight status
Van den Akker *et al.*, 2007 (47)	73	8-15	Group with individual components	12 months	4% after 3 months (intensive phase); 33% after 12 months	Did not return at the end of the intensive phase or did not show up for follow-up visits	Older age of child Higher baseline child BMI-SDS Child less successful in BMI-reduction during treatment	

Vignolo *et al.*, 2008 (48)	31	6-12	Group with individual components	60 months	36%	Did not complete the study		Child age Child sex Child baseline weight status Child psychosocial/ behavioural/ lifestyle factors Parent baseline weight status

SES: Socio-economic status
BMI: Body mass index
SDS: Standard deviation scores

Figure 2-1: Integrative review search flow diagram



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Chapter 3: Understanding families' decisions regarding their (dis)continuation of pediatric weight management care

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Introduction

With the prevalence of obesity dramatically increasing over the past 25 years, obesity is now an epidemic among children in Canada (1-4). Many questions remain unanswered regarding obesity prevention and management, but the magnitude of obesity and obesity-related health risks is clear. The Canadian Health Measures Survey reported that between 1981 and 2007-2009, the average body mass index (BMI) of 12-year-old Canadians increased from 18.1 to 19.2 kg/m^2 in boys and 18.4 to 19.5 kg/m^2 in girls (1). Additionally, the proportion of boys aged 15-19 classified as overweight or obese increased from 14 to 31%; among girls, excess weight increased from 14 to 25%. These trends represent dramatic increases for both boys (+120%) and girls (+79%). Furthermore, childhood obesity is especially concerning because it is associated with increased morbidity in childhood (5) and increased mortality in adulthood (6-7). Therefore, specific interventions are needed to target the over two million Canadian children that meet eligibility criteria for weight management programs (2).

While pediatric obesity has emerged as a primary health concern, little research has been undertaken to explore how health services delivery can be optimized for obese children, youth, and their families. For example, a European study reported over 90% of children dropped out of weight management treatment over a 2-year period (8), emphasizing the need to improve care by addressing such significant attrition. Because intervention attendance and completion are correlated with improved health outcomes, individuals who drop out of care are unlikely to receive the full benefits of treatment (9-11). Furthermore, attrition

increases overall clinical expenses, results in an inefficient use of resources, and creates feelings of failure among both families and clinicians (12-13). Therefore, there is an urgent need to understand attrition in pediatric weight management care since even effective weight management interventions will have little impact on families who discontinue care (14).

To date, most research has focused on demographic, anthropometric and psychological factors that predict attrition in pediatric (13, 15-19) and adult (20) weight management programs. A literature review (14) exploring attrition from pediatric weight management care concluded that while some studies showed that ethnicity, socio-economic status, and levels of obesity were predictive of attrition, other studies did not. Although useful, this information does not address families' collective perspectives of their weight management care received. A few studies have also examined reasons for attrition from parents' (13, 16, 21-22) and clinicians' (12, 23) perspectives, most commonly reporting scheduling issues and treatment not meeting families' needs or expectations as primary issues. However, these studies failed to capture children's perceptions, which have been shown to play an important role in attendance (24). Furthermore, only three studies have used qualitative methodologies (12, 16, 21) to explore parents' perspectives, indicating that further research to understand *both* children and parents' perspectives of their reasons for their drop out is needed (12-13, 19, 22-23, 25). Consequently, the purpose of this study was to understand families' reasons for attrition by exploring qualitatively the factors that influenced both children's and parents' decisions to (dis)continue pediatric weight management.

Methods

Design

A qualitative case study methodology (26-27) was used in this study. This methodology is appropriate for two reasons. First, because relatively little is known about this area, a qualitative approach to inquiry allows for the exploration of families' perceptions, experiences, and needs when treatment is discontinued (28). Such rich data cannot be obtained through quantitative measures (*e.g.*, questionnaires). Second, a case study methodology is appropriate when studying 'bounded' social systems with specific rules and norms of social interaction (27-28). Furthermore, it is important that the topic of interest is represented within the case selected (26-27). In this study, the case was represented by a pediatric weight management centre, a 'bounded' system. This case provided valuable information and insight on families' decisions regarding their (dis)continuation of care.

It should be noted that this case study is part of a larger, on-going, multiple case study involving four pediatric weight management centres, each representing a case: the Centre for Healthy Weights in Vancouver, BC; the Pediatric Centre for Weight and Health in Edmonton, AB (the lead site); the Metabolism, Obesity and Health Program in Hamilton, ON; and the Healthy Weight Clinic in Montreal, QC. This larger case study will investigate reasons for (non)initiation and (dis)continuation from pediatric weight management care. Therefore, all data collection tools were designed with this purpose in mind. This paper included the data collected from the Edmonton site and focused on the (dis)continuation of care.

Sample

Sampling approach.

Participants included obese children or youth and their primary caregiver (*e.g.,* a parent) who received care at the Pediatric Centre for Weight and Health (PCWH) (Stollery Children's Hospital, Edmonton, Alberta, Canada). A purposeful sampling approach was used since it identifies cases that can provide the most relevant information to answer the question under study (29). For example, in our study, we specifically sampled participants that discontinued care to understand the factors that impacted families' decisions to drop out from care. Because of the qualitative nature of this study, a sample size calculation was not needed because the "validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information richness of the data and observational/analytical capabilities of the researcher than with the sample size (p.245) (29)." To maximize the information collected, although sample size was determined *a priori*, purposeful sampling was only terminated when data saturation was achieved, such that no new information was obtained from newly sampled data (30). Given the aims of this study, families were recruited based on whether they satisfied one of the following purposeful sampling criteria during recruitment:

1. *Continuers* (n=10): Families that were referred for weight management, regularly attended clinical appointments for weight management, and were active clients at the weight management centre.

2. *Discontinuers* (n=9): Families that were referred for weight management, attended any number of appointments for weight management, but were no longer active clients at the weight management centre.

Inclusion criteria.

Boys and girls were eligible if they: (a) Were referred for obesity treatment to the PCWH; (b) Were 10-17 years old at the time of the interview; and (c) Possessed an age-specific BMI $\geq 85^{th}$ percentile at the time of referral. Parents were eligible for this study if they self-identified as the primary caregiver of an obese boy or girl referred to the PCWH. The primary caregiver was defined as an adult, usually a parent, who assumed the principal role of providing care and attention to the child or youth. Because the PCWH provides care to blended families (*e.g.,* step-parents, step-grandparents, foster parents, *etc*.), families were in the best position to determine the adult who could, in their view, best represented their family's experiences and perceptions regarding pediatric weight management.

Exclusion criteria.

Families were not eligible for inclusion if they: (a) Could not fluently speak English, due to the language skills of our interviewers; (b) Had cognitive disabilities that impaired their ability to communicate with interviewers; and (c) Were discharged as a result of turning 18 years of age.

Recruitment.

Recruitment occurred between May 2011 and April 2012, after having received institutional approval from the Health Research Ethics Board at the University of Alberta (Edmonton, AB, Canada). Medical charts for *Continuer* families who attended at least one clinic visit since 2010, and medical charts for *Discontinuer* families who were discharged since 2010, were screened for potential study candidates. *Continuers* were contacted in-person about participating in this research during a scheduled clinical appointment by a member of the administrative staff at the PCWH. If families expressed interest, the lead researcher (JD) shared study promotional materials (found in **Appendix B**) with the family. If families expressed an interest in the study, follow-up for study participation was initiated by telephone or e-mail. For *Discontinuers*, study promotional materials were mailed to families with additional follow-up correspondence completed by the lead researcher (JD) by telephone or e-mail. Written informed consent and assent were provided by all parents and children. Copies of the consent and assent forms are found in **Appendix A**.

Because we anticipated the recruitment of *Discontinuers* to be difficult, to enhance our ability to successfully recruit families into both categories, we offered families $100 gift cards as an incentive to participate and as acknowledgement of their time and effort. However, a balance must exist between recruiting participants and avoiding the exploitation of families; the nature of this study (personal interviews) justified this level of compensation. As others have described (31), in the context of studies such as ours (*e.g.*, conducting one-on-one

interviews, collecting demographic and anthropometric/clinical data), incentives are generally innocuous.

Participants.

Initially, a total of 10 *Continuer* and 10 *Discontinuer* families were recruited from the PCWH. Of the 10 *Continuer* families, one child felt uncomfortable during the interview, so the interview was discontinued and his/her interview data were excluded from this study. Furthermore, one *Discontinuer* family (child and parent) did not provide consent for their interviews to be recorded. Although their data were collected (through writing rather than audio recording), because full consent was not provided, information from this family was excluded. Additionally, of the remaining nine *Discontinuer* families, one child did not attend the interview with his/her parent, so his/her interview data were not collected for this study; however, the parent still participated in the study. Therefore, a total of 10 *Continuer* and nine *Discontinuer* families were included in this study. More specifically, a total of 19 *Continuer* interviews (n=9 children; n=10 parents) and 17 *Discontinuer* interviews (n=8 children; n=9 parents) were included. The lead researcher (JD) conducted all 19 parent interviews and eight of the child interviews. Three other research assistants completed the remaining child interviews (n=9). Demographic, anthropometric, and health services data for both *Continuer* and *Discontinuer* groups are presented in **Table 3-1**.

Data collection

Socio-demographic variables.

Demographic and anthropometric/clinical information were collected from medical charts and directly from children and parents at the time of their interviews for contextual purposes. Evidence-based protocols for chart review research were adhered to (32-33). Demographic variables included: (a) Postal code (to determine the distance between the PCWH and family's residence); (b) Date of birth; (c) Sex; (d) Relationship of parent to child (*e.g.,* mother, father, *etc*.); (e) Country of birth; (f) Ethnicity; (g) Education level (parents only); and (h) Socio-economic status (SES). Anthropometric/Clinical variables included: (a) Weight; (b) Height; (c) BMI; (d) BMI percentile (children only); (e) BMI z-score (children only); (f) Date of referral; (g) Date of first clinical appointment; (h) Type of intervention received (individual, group, or both); (i) Number of clinical appointments attended; (j) Type of discharge (when applicable); and (k) Date of discharge (when applicable). A standardized case report form was developed with input from all team members from the larger, multi-centre study to enhance data collection. A manual was also created to provide clear protocols and guidelines to inform data collection. A copy of this protocol is provided in **Appendix B**.

Secondary data were collected from all families enrolled in the study. Children data from the family in which only the parent attended the interview were collected through self-report (by the parent). Once collected, data were entered into *LabKey*, a secure data management tool. The data in *LabKey* were audited by the lead researcher (JD), identifying a small level of error (0.5%).

Interviews.

Data were collected using personal, in-depth interviews. Each participant (children and parents) completed one individual interview. Children's interviews lasted, on average, 20 minutes and parents' interviews, 50 minutes. All interviews were digitally audio-recorded. The lead researcher (JD) received qualitative interviewing training by an expert (NLH) to ensure interviews were conducted appropriately. The lead researcher subsequently relayed this training to other interviewers involved in this study to maintain consistency. Throughout data collection, all interviewers involved in the larger multi-site case study maintained contact with each other to share the interviewing process and pertinent issues, ensuring the integrity, depth and breadth of data collection. If a new idea emerged (*e.g.,* impact of family orientation sessions), it was subsequently incorporated into each site's interview guide.

A semi-structured interviewing approach was used whereby the research team (site principal investigators, co-investigators, local research assistants) designed open-ended questions in advance of the interviews to address key issues. Minimal emphasis was put on the ordering of questions; rather, the interviewer followed the participants' interests and/or concerns, supplementing the questions with planned and unplanned probing questions (29). A semi-structured approach was appropriate because the research team knew enough about the phenomenon of interest to develop questions in advance of interviewing, but not enough to be able to anticipate the answers (28). Furthermore, because each participant was only interviewed once, developing highly focused questions served to establish

priorities for the single interview (29). Because several interviewers were involved in the interview process, developing carefully worded questions in advance also minimized variation in data collected (29).

The interview guide was based on an ecological framework. Questions were organized to start with a broad approach; probes and follow-up questions were then used to focus on specific aspects that needed further exploration (28). Specifically, child, parent, family, environment, clinic, and health system factors were investigated, including probes about perceptions, experiences, examples, and preferences involved in the (dis)continuation of care. In addition, expectations, needs, strengths, limitations, and areas for improvement regarding obesity-related health services were explored. Rapport was built based on the interviewer's ability to convey empathy and understanding without judgment (29). Both children and parents were asked similar questions; however, the vocabulary used during children interviews was adjusted to facilitate understanding. An example interview guide for both children and parents is presented in **Appendix B**. Following the interview, each interviewer completed a short reflection questionnaire (provided in **Appendix B**) describing their experiences with the interview, including rapport building, general observations, and key issues discussed.

Data analysis

Digitally recorded interview data were submitted electronically to the *Comma Police* (www.commapolice.com) for transcription. Subsequently, all identifying information was removed from transcribed data, and was entered

verbatim into *N-VIVO 9* (2011, QSR International; Melbourne, Australia), a qualitative data management software program. Data analysis commenced as soon as the first transcripts were received and continued in an iterative process throughout the study. The units of analysis were the family members who received weight management care (*e.g.*, child and parent dyads). Children's data were used to corroborate parents' data. These units of analyses were analyzed to produce an account of the key issues pertinent to the case.

Stake's (26-27) categorical aggregation approach for case study methodology was used. First, the lead researcher (JD) read through the transcripts and reflections (completed by all four interviewers) multiple times to gain a sense of the content and ensure full immersion in the data (34). During this review process, memos were used to record initial thoughts and preliminary interpretations of the data (29). Second, content analysis to identify key consistencies from the large amount of qualitative data was used to identify central meanings in the form of patterns and themes (29). The transcripts were coded, line-by-line, into meaningful segments of information and grouped by content into themes (34). As themes were identified, similar instances or occurrences were aggregated to create a basic coding schema. Rules of inclusion (*e.g.*, definitions) were created for each theme. Throughout the analysis, themes were continuously examined, questioned, and corroborated by the research team. The constant comparison technique was used to ensure that data included in each theme were similar to one another, but distinct from other themes (34). Analysis continued until data saturation was achieved, when all ideas were fully developed

and no new meanings emerged, even with the recruitment of additional participants (28). Finally, data were separated into the three core categories presented in the *Results* (*Family factors*, *Logistical factors*, and *Health services factors*). A written description was constructed to explain each category. The description of each category, in addition to the rules of inclusion for each theme, is found in **Table 3-2.**

Once all of the transcripts were analyzed, a data matrix was created to organize, compress and assemble the information to permit conclusion drawing (35). A summary of the data matrix created for this study is shown in **Table 3-3**, illustrating which themes were represented by *Continuer* and *Discontinuer* families. An expanded version of this data matrix is provided in **Appendix *C.*** Having aggregated similar data together, interpretations about the meaning of the descriptive categories were made. Key quotations from the categories and themes were used to describe the experiences of families who continued or discontinued care.

A broad ecological framework (36) was subsequently used to frame the analysis, enabling a multi-level evaluation of proximal and distal factors that underlie families' decisions regarding their (dis)continuation of care. Specifically, ecological theories hypothesize that behaviour is shaped by the interaction of individual factors with the broader social and environmental context (37). If a change is made at one level of influence, all other levels may be affected. The most proximal level in the ecological model is the *microsystem*. It consists of individual or interpersonal features and may include roles that a person plays

(*e.g.*, mother, father, child, *etc*.). This is the immediate setting within which individuals interact. Encompassing the *microsystem* is the *mesosystem*, in which organizational or institutional factors shape the environment within which the individual interacts. For example, the rules at a parent's workplace may influence the amount of time he or she can take off to attend clinical appointments. The *macrosystem* is composed of community level influences in which the individual is not required to be an active participant (*e.g.*, the health services delivery). The ecological framework has been extensively used in obesity research because of its ability to include a wide variety of factors at varying environmental levels (37-40). A sample of this framework, in the context of the categories presented in this study, is shown in **Figure 3-1**.

Methodological rigour

Verification refers to the mechanisms used during the research process to ensure reliability and validity, and thus, methodological rigour (41). Briefly, reliability requires that the same results will be obtained if the study were replicated, and validity requires that the results accurately reflect the phenomenon (28). Verification strategies also help the researcher identify when to modify, continue, or stop the research process to ensure rigor. As suggested by Morse, Barrett, Mayan, Olson, and Spiers (41), verification strategies should be integrated throughout the research process to identify and correct errors, rather than only using techniques at the end of the study when it is too late incorporate corrections. A number of techniques were used throughout the study to maintain rigour.

First, methodological coherence ensured the right fit between the method used in the study and the research question (41). Each method demands that the researcher think about the data in a specific way that matches the question, the data, and the analytic procedures (28). Careful selection of approaches to data collection (*e.g.*, individual interviews) and analysis strategies (*e.g.*, categorical aggregation), and reviewing these approaches with the research team throughout the study ensured methodological coherence.

Second, an appropriate sample was used, consisting of participants who were able to provide experiences related to the phenomenon of interest (28). Purposeful sampling ensured each of the 19 participants had experience with either continuing or discontinuing pediatric weight management care. Despite our *a priori* sample size goals, participant recruitment continued until data saturation was achieved.

Third, data were collected and analyzed concurrently from the beginning of the study, demonstrating the non-linear process of qualitative research (28). Findings were analyzed throughout the data collection period, which influenced decisions regarding the data collection instruments. For example, because several participants explained their experiences (unprompted) with the initial clinic orientation session, additional questions probing about this orientation session were added to the interview guide to maintain consistency. In addition, the use of the constant comparison technique ensured ideas were consistent across all data, and not just across the recently collected data.

Fourth, during data analysis, emerging ideas and themes were shared with the research team, enabling investigator triangulation (26). This ensured that new themes and patterns were thoughtfully examined and justified. Furthermore, obtaining data from multiple sources (*e.g.*, children and parents) also enabled the triangulation of findings (29).

Fifth, a reflexive journal was kept throughout the research process. It is important for the researcher to reflect on his/her previous knowledge about the phenomenon of interest and how it may impact the research in order to work inductively and learn from the data (29). Therefore, the primary researcher (JD) explicitly set aside her personal knowledge about attrition in pediatric weight management by writing in the journal. In addition, memos about important research decisions and events, links to literature, and ideas to consider in future analyses were also recorded in this journal, serving as an audit trail (28). Interview experiences were also shared with research team members at the other three sites. This documentation, in addition to the reflection questionnaire completed after each interview, provided justification for study findings and interpretations (28).

Results

The case: The PCWH

Launched in 2005, the PCWH is part of Weight Wise, Alberta Health Services' initiative focused on helping residents achieve healthy weights for healthy lives. With administrative and institutional support from Alberta Health Services, the Stollery Children's Hospital and the Department of Pediatrics at the

University of Alberta, the PCWH was established to become a centre of excellence in pediatric weight management. Currently, the PCWH provides weight management care to overweight and obese children and youth aged 8 – 17 years old using a family-centered approach. Because approximately 50% of patients present with significant co-morbidities (medical and mental health), the medical, psychosocial and family complexity of overweight and obese children and youth necessitates an integrative, interdisciplinary approach. Therefore, families attending the PCWH have access to a pediatric endocrinologist, psychologist, registered nurse, registered dietitians, and exercise specialists. The team also includes an outreach coordinator, secretary, research coordinator, an administrative assistant, and a program director. Additionally, the PCWH conducts practice-based research in a clinical setting, allowing all families receiving weight management care the opportunity to participate as research volunteers. This approach is unique among Canadian weight management programs and is used to inform what and how services are provided for families.

The PCWH receives numerous new physician referrals each month. Once referred, families are invited to attend an orientation session. Before attending the clinic, families attend this group orientation to learn about the PCWH and to ask questions about treatment options. If a family decides to enroll at the PCWH, the first step is to attend the clinic for initial assessments with the interdisciplinary team. These initial assessments include one appointment with the nurse, pediatric endocrinologist, and psychologist each, and two appointments with the registered dietitian and exercise specialist each. During these appointments, clinicians

discuss which treatment options are available to each family. Families have the option of accessing an individualized program in which the interdisciplinary team works one-on-one with families to make healthy changes. The frequency of appointments is based on each family's needs, and long-term follow-up support is provided. Families can also participate in group-based care. The *Parents as Agents of Change (PAC)* program involves parents of overweight 8 – 12 year olds. It is a 16-session clinical intervention (delivered weekly) that helps parents to become healthy role models for their families. Teenagers aged 13-17 can participate in the *Skills and Knowledge for Improved Lifestylez (SKILZ)* program. *SKILZ* is a 15-session (delivered weekly) clinical intervention that includes one-on-one lifestyle coaching and interactive group session. Additionally, families can also access both individualized and group-based care.

Following the completion of any group-based intervention, assessments with the interdisciplinary team are completed once again, and long-term follow up support is provided until the child reaches the age of 18. At this point, the child is transitioned into the community or the Adult Weight Wise program. At any point during the program (*e.g.*, before, during, or after completion of an individualized or group program), a family can withdraw from the clinic. Furthermore, if a family does not maintain contact with the PCWH once every six months, or if the child reaches the age of 18, the clinic will discharge the family from the program. Attrition, as a result of withdrawing or being discharged from the clinic, is a regular occurrence at the PCWH. A brief overview of a family's journey at the PCWH, situated with sampling criteria, is outlined in **Figure 3-2**.

Overview of results

The common themes across the *Continuer* and *Discontinuer* groups are presented with competing or contradictory data described where necessary. Data from *Continuer* families are marked by a "C" and data from *Discontinuer* families are marked by a "D" after the participant's study ID number. Below, similarities between the two groups are discussed first, followed by group-specific findings. The results are based on three main categories relating to the (dis)continuation of care: i) *Family factors*; ii) *Logistical factors*; and iii) *Health services factors*. **Table 3-3** summarizes these results.

Family factors.

Children and parents described a number of factors that impacted their decision to continue care. This category was created based on the themes of: (a) Motivating factors; and (b) Decision-making roles.

Motivating factors.

An improvement to their children's health was the main motivator for both *Continuer* and *Discontinuer* families. Some *Continuers* (n=4) were concerned with improving their children's pre-existing weight-related co-morbidities or avoiding developing co-morbidities that they were at a higher risk for; other families were primarily concerned about losing weight to look better. For example, when asked what motivates her to keep coming back, Parent 2C said:

> My biggest thing is I hate hearing those diabetes commercials on the radio…I don't ever want to be the one who has to take [Child

2C] to a diabetic clinic…it's health…her fat lipids and stuff weren't in the danger zone but they were up.

Interestingly, Parent 2C explained that her child's primary motivation to continue care at the clinic was to look better by losing weight rather than improving her medical condition(s): "She said this to [psychologist]…she wanted to be smooth…like her body shape. She wanted her body to be smooth instead of having wrinkles". Therefore, improving their children's health (including losing weight) was a motivator for families to continue care at the PCWH.

Some children (n=4) in the *Discontinuer* group who presented with weight-related co-morbidities stated that health was not a particular concern for them. Child 14D described it as, "I guess they would tell me…you have diabetes…but I didn't really feel like I…really have any of those. Just 'cause I don't know, I guess I was young, I didn't really care. I just wanted to do whatever". Parents whose children did not have any weight-related co-morbidities were motivated to initially continue care by a desire to lose weight. For example, Parent 21D said, "I was really worried about her weight…her pictures show that she was a chubby face…she had a big fit thick girth…I wanted her to grow up with the best possible chances of being normal, not ostracized by weight".

Both *Continuer* and *Discontinuer* families described seeing change(s) as motivating. For example, when Child 2C was asked what motivates her to continue care, she said, "the changes….I'm more active now and I'm aware of my portions, and I love the results…being physically fit and healthier". Similarly,

when asked what would help families adhere to the program, Parent 18D said, "Success. Seeing the pounds drop off…you have to see some of that". Reinforcing this point, some families said a lack of change discouraged them from continuing with the clinic. When asked why he decided not to come back to the clinic, Child 14D said:

> I guess falling off the track and feeling kinda disgusted, it really made me not wanna come here…Feeling like I wasted their time and my time just because of them tryin' to help me and I wouldn't do it sometimes. I'd just mess up and I'd feel like I don't wanna go there. They've been helping me, but I haven't really been using their instructions. So…I guess I really wasted their time and that they really wouldn't want me back.

Additionally, when asked how to reduce attrition, Parent 7C succinctly put it as, "I don't know what the results are for other people but I think…if people saw more results. And not even necessarily weight but just changes in patterns…then probably there would be a higher retention rate".

Additionally, both *Continuer* and *Discontinuer* families described having the program benefit the parent as additional motivation to continue with their care at the clinic. For example, when asked what the program did for him, Parent 6C said, "I actually lost weight during the program and for me it was mostly about eating. I became much more aware of what I was eating and how much. I probably lost between 10 and 15 pounds." Conversely, Parent 10C did not see any personal change: "Although I was included to a certain degree, if I'm not getting

any personal change out of it, then it's harder to stay motivated to do it. If I had got to see some change…it might have been different."

Furthermore, five *Continuer* families reported that coming to the clinic to have their progress evaluated and monitored helped provide motivation to continue care. For example, when asked what motivates her to keep coming back, Parent 5C said:

> 'cause I wanna see where he's at. Like if he would lost a lot of weight, I see him every day so I don't see any change…it's a varying thing that Ok you've lost a pound you're great. Oh you put on OK…we need to see what's going on.

Conversely, a few *Discontinuer* families (n=3) reported that they felt like they did not need the services provided by the clinic because they could 'do it on their own'. Child 17D explained her experience as, "I came to [Parent 17D] and I said you know I think I can do this by myself, I think I'm old enough. And she said OK…if you think you can do this by yourself, that's your decision".

Additionally, *Continuer* families (n=5) described the program as a commitment that they had to follow through. For example, when asked what makes her come back, Child 1C said, "Probably just 'cause I have to and it's a commitment…getting through and finishing the program". When the same question was asked to Parent 4C, she said, "I'm just the kind of person if I start something I finish it, you know". Having this mentality kept these families motivated to continue with their care.

Lastly, three *Discontinuer* families stated that they were no longer motivated to continue their care at the clinic simply because they had met their goals and felt they no longer needed the services provided by the clinic. Parent 21D explained it as:

> 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.

Reaching the goals this family set out to complete was the main reason why they discontinued care.

Decision-making roles.

Although most *Continuer* and *Discontinuer* families indicated that they shared their experiences at the PCWH with their extended family (*e.g.*, grandparents), these individuals did not play a role in their decision to continue with care. When asked if extended family members influenced her decision to attend the clinic, Parent 21D plainly put it as, "Grandparents, everybody [knows]. They were very supportive, but I don't think there was anything that they said that would've [made me] not come". Although some individuals received support from extended family members, the decision on whether or not to continue care remained directly within the family.

Similarly, most families from both groups also shared their experiences at the clinic with friends and/or co-workers. Families indicated that these individuals did not play a role in children and/or parents' decisions to continue with care.

For many *Continuers* (n=5), the parent played the most important role in the decision to continue care. When asked why she comes to clinical appointments, even though she does not want to, Child 1C said, "Well 'cause…my mom wouldn't be happy if I just up and quit". Similarly, when Parent 7C was asked whose decision it was to continue care, she said:

> The fact is that she's coming even if she doesn't want to. You know a lot of kids don't come. They quit coming. They refuse to come. And I'm like well I just tell her she has an appointment…so we're gonna go….Probably given the option, she wouldn't come…But it's not an option.

Parents also have a considerable influence on the decision to continue care in some *Discontinuer* (n=2) families. For example, one child wanted to continue with care at the clinic, but his parents did not. When asked who's decision it was to stop coming, Child 23D described it as, "It was more my mom and dad's decision…if it were up to me…I would still be coming here". Similarly, when Child 19D was asked if anyone could have changed his mind about leaving, he said, "If my mom wanted me to keep coming I'd be like OK fine, let's keep going. That's pretty much like the only person I think that would".

On the other hand, other *Discontinuer* families (n=5) gave their child the option of discontinuing care. When asked whose decision it was to stop coming, Parent 15D said:

> I'd say well we got to make an appointment and he's like no I don't want to go…I knew he wasn't interested in it and I didn't want to make it any worse…I'm disappointed, I wish he would…I believe it's like leading a horse to water, right?...It has to be his decision.

Because the child no longer wanted to attend the clinic, the parents decided to withdraw from the program.

Logistical factors.

Parents and children reported that a number of logistical issues impacted their decision to continue care. This category was created based on the themes of: (a) Parking costs; (b) Clinic location; (c) Scheduling; and (d) Weather conditions.

Parking costs.

Eleven families (seven *Continuers* and four *Discontinuers*) identified the cost of parking as an annoyance with obtaining care at the PCWH. For example, Parent 7C described her experience with parking as:

> Like for us. We're OK now. When we weren't OK like financially… 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…Financially it probably takes a toll even though they might not say it. 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.

Similarly, when asked what health care professionals could do to make it easier to continue care, Parent 25D responded, "Maybe not having to pay for parking…Some people probably can't afford it or don't have money on them or whatever and things like that." Although the parent did not identify the cost of parking as an issue relevant to her, she did recognize the impact the cost of parking can have on families with a lower socioeconomic status.

Distance.

Among the *Continuer* group (n=3), some families did not find the distance from their home to the clinic to be a barrier to care. For example, Parent 3C stated, "It's not that big of a deal. I'm willing to do whatever it takes to help her and if it means you know, driving a half hour, then I drive a half hour." In order to receive the services of the clinic, the family was willing to drive the distance. Conversely, other families (n=3) identified the location of the clinic as particularly inconvenient because they lived outside city limits. Parent 8C explained it as:

> It's at least an eight hour day shot there you know…The program itself is very good [for] a person who lives right here in the city and could come in more often it would benefit probably more. But…the distance is my biggest obstacle.

Nonetheless, the parent still continued with care at the clinic.

Among the *Discontinuer* group, six families found the location of the clinic to be inconvenient for them, with many stating it as a major drawback to continuing care at the clinic. For example, when asked what the main reason was for her discontinuation of care, Parent 20D responded with:

> I hate driving downtown so much. I get so stressed out and I think that was the biggest barrier. I mean it's great that it's in the middle of the city for 90% of the families that great…I just have issues driving downtown.

Although the parent recognized that the location would be convenient for many families, the downtown area was a big challenge. Additionally, Parent 21D said, "It's not convenient. It's not in our neighbourhood…if it was in our local community, maybe we would've gone more." Similarly, Child 23D described his experience as:

> I came here for my first appointment. Everyone's really nice…After the appointment…we just decided we couldn't come anymore because it was too far of a drive and my mom was getting tired of it… 'cause she doesn't like driving a whole lot so…I wish you guys were closer…Had a thing in Leduc or Beaumont or something.

Although the child had a positive experience at the PCWH, the distance was too great a barrier to overcome.

Scheduling.

All *Continuer* and *Discontinuer* families experienced difficulties with trying to schedule their days in order to accommodate clinical appointments. For example, when describing the challenges with attending appointments, Parent 14D described taking time off work to be an important obstacle:

> When I was doing this, I couldn't get the time off work…Evening appointments would be so nice…The difficulty to do it as a family is it's really hard if it's during the day, and you have to take time off of work to do it. And if you can't get the time off, it makes it very difficult to even become a part of it.

However, other families did not find taking time off work to be challenging. For example, Parent 2C said, "I'm lucky and so is my husband at work. We have the flexibility in terms of family responsibility, you know hours and stuff. It's more helpful than stressful." Similarly, Parent 17D worked in a very supportive environment, allowing her to take time off work to attend clinical appointments:

> I'd actually even talked to my manager at work about it 'cause she's heard my frustration about my kids and their weight, and so she was aware we were enrolled and I suggested that I might be missing some time off work and…it wasn't gonna be an issue.

Families also experienced anxiety with trying to fit clinical appointments into their daily lives. For example, when asked how he felt about the referral to the PCWH, Parent 6C said:

> As a family, we've got a son as well, and the both kids are in different activities and between the activities and the school and the homework and all that and the running around it doesn't leave much time…you know we're all tired and exhausted and it was one more thing to add into our lives. So at first, it was a bit like oh my God, how are we gonna do this you know.

Furthermore, attending clinical appointments in the daytime often required parents to take their children out of school early, creating further anxiety and frustration for families. Parent 3C described it as:

> It was frustrating that [Child 3] was missing a lot of school to make the appointments…She was missing school like half a morning at least every second week…And so if you have other things like doctor's appointments or something else going on now it's not only this but it's other appointments so now she's missing a lot more school. I think making it so it's a little bit more convenient for families to come.

Discontinuers were particularly concerned with their child missing school, highlighting it as a critical reason for their decision to discontinue care. For example, Parent 19D said:

> The reason we left was because he would miss a whole day of school coming here. And then, OK well, at least 1 day of school, I was homeschooling him at the time so it wasn't as bad. Now he

goes to the school. Missing a whole day of school when you're in a semester system is a big deal.

Most families (*Continuers* and *Discontinuers*) experienced difficulty in attending clinical appointments because of scheduling issues.

Weather conditions.

Of the families that reported their experiences with weather (when asked what factors did or did not impact their decision), all families stated that it did not impact their decision to attend clinical appointments.

Health services factors.

Children and parents highlighted a variety of clinic and service attributes that contributed to their decision to continue care. This category was created based on the themes of: (a) Access to care; (b) Facility attributes; (c) Program and appointment length; (d) Menu of services available; (e) Quality of services; (f) Relationships with clinicians; and (g) Care received meeting expectations.

Access to care.

Families that continued with care at the clinic did not experience any challenges accessing services, meaning families were able to participate in the services provided by the PCWH when they needed it. On the other hand, two *Discontinuer* families felt that they were discharged from the program too early, inhibiting their ability to access services. Parent 18D was very upset when she explained her discharge:

> They told us that they would not abandon us… it wasn't clarified that there were certain criteria to maintain. So maybe they have kicked us out prematurely. Maybe they can put us back in…I'm experiencing some success with [Child 18D]…and then all of a sudden, kabam. The hammer drops… Now he's bought in, now they've abandoned us.

Similarly, Parent 21D was confused when she was notified of her discharge:

> So when I got the official discharged letter…I thought it was really strange 'cause that was not how it was played out to me. It was said, if everything's fine, come and see us…but if there's every any point until she's 17, you can come back. So I was a little taken back that we were discharged because we didn't follow through.

From their perspective, these families felt the clinic abandoned them. Even though they still wanted care, these families felt they could no longer access it.

Facility attributes.

Most *Continuer* and *Discontinuer* families did not identify any aspects of the PCWH facility that contributed to their decision to (dis)continue care. Two *Discontinuer* families described wanting a larger gym.

Program and appointment length.

Six *Continuer* families did not express any concerns about the length of individual appointments. Families also valued the open-ended duration of the program provided at the PCWH. This was particularly important to Parent 2C:

"It's really important for us that we've never been told that our time is almost up…that's very comforting." On the other hand, three *Discontinuer* families reported that the program and appointment lengths were too long. For example, Parent 15D described it as:

> When we came it just seemed like we were here for more than an hour and half, two hours because we'd see more than one person. So you'd wait for that person, see that person, and then wait for another person. So it just took a long time to get through everything, so it was a little discouraging.

The time it took to attend clinical appointments discouraged this family from continuing with care.

Menu of services available.

Satisfaction with the flexibility the clinic provided in choosing individualized or group-based care was reported by five *Continuer* families. Each family had their own preference about the type of care they wanted; however, they emphasized the importance of being able to choose from more than one type of service:

> [Child 10C] did not take advantage of any of the group things…he much prefers the one-on-one attention so I think that's important for some people but that was not important for him…I'm glad we didn't have to go to a whole bunch of group things. I don't think we would have been there. (Parent 10C)

Similarly, Child 6C preferred group-based care and enjoyed meeting other children like her:

> I'm glad they sort of introduced [Active Start] to us…all the people there were like in PAC or something. And there was this one girl, she was my age, and she was like almost exactly like me and I was happy that I wasn't like alone in life or something.

Additionally, a few *Continuer* families (n=2) expressed a desire to incorporate a family group-based program to facilitate success. Parent 7C explained it as:

> Most of its just individuals that come here. But you have to remember they're part of families right? If we were all involved in activities and were invited to things, then you're more likely to have more success because you're doing it as a family.

Conversely, three *Discontinuer* families felt that the clinic lacked programs involving group-based care for younger children. The lack of group services for her child contributed to Parent 15D's withdrawal from care: "I thought the program there'd be other kids involved... Because kids…they see other kids doing something and they want to do it, so maybe that would help. But yeah, it wasn't like that". Parents wanted their children to meet other children who were also overweight or obese to facilitate friendship building, and to receive support and encouragement. Children also expressed this desire: "I would have preferred talking to other kids and seeing what they were doing in their home lives and how they were making changes so I could try them too" (Child 23D).

Quality of services.

Many *Continuer* (n=4) and *Discontinuer* (n=7) families outlined the interdisciplinary approach provided was a strength of the clinic. For example, when describing her experience at the PCWH, Parent 17D said, "I was just blown away that there was a team of four people with the dietitian and the doctor and the exercise therapist and the psychologist…I was impressed with that amount of support."

In addition, many families in both groups (six *Continuers* and seven *Discontinuers*) identified the information they received to be helpful and personalized. For example, Parent 20D described it as, "It was very helpful, very personalized. That was really important. We weren't just put in a big group and kinda hide in the crowd kinda deal. It was very personalized, it was wonderful." However, other families did not find the information they received to be useful. Parent 4C explained it as, " I don't know what else I can learn, right? I've taken nutrition…I've been on Weight Watchers, so I know how to eat…I know how important it is to exercise…I haven't been learning anything new".

Both *Continuer* and *Discontinuer* families also had varying levels of satisfaction with the amount of parental participation during clinical appointments. Some families (n=8) enjoyed having both individual and parent-child appointments. For example, Parent 21D said:

> We would do some [appointments] joined and some not…I think [Child 21] needs to have strategies that she deals with without me

being around and she needs to hear some of the things that I think but not all of them…so I liked the combination for sure.

On the other hand, some families (n=7) found that there was not enough child or parent involvement in the program. Parent 3C was particularly irritated with this aspect:

> At the beginning I was really frustrated with the program because I found that…we got constantly split. So I couldn't understand [Child 3] and she didn't know where I was coming from…still to this day the child is separated from the parents…The conversations with the psychologist and with the exercise person and with the dietitian are separate…so how do you manage a family dynamic?

Although this family was continuing with care at the time of the interview, this parent stated that she was considering withdrawing from the program because of her ongoing frustrations, indicating the high value some families place on addressing issues collectively.

The PCWH program emphasizes creating manageable family goals, an attribute that four *Continuer* families recognized. For example, when asked what they liked about the program, Parent 8C said:

> Every time we've come in we seem to go out with a new goal. It's not to lose X number of pounds or anything … It's like switching to Crystal Light from pop…Every time there's little steps right. At no point did they want us to throw everything out the window and just go cold turkey.

This experience highlights that attending clinical appointments to progressively build on goals was helpful for families.

Additionally, a couple *Continuer* families (n=2) expressed a desire to have more accountability involved in the program by incorporating measurements of success (*e.g.*, weighing their child on every visit). Parent 7C explained it as:

> We come in, we don't weigh, we don't measure, we don't do anything. We sit down, we talk, [Child 7C] goes home with her paper, she doesn't look at them again until it's time to come back…And then we come back and we just kinda do the same thing over and over again…I think to make her accountable is important.

Furthermore, three *Discontinuer* families reported clinical appointments to be boring. Children wanted more interactive appointments a chance to meet other children like them:

> I think it needs to be more exciting here. And kind of like more kids around so you could meet new people… 'Cause I didn't get to know any of the people…And I think it would just be cool if it was more exciting here…and it would be always fun to come here instead…it's kind of a waste of my time. (Child 21D)

For this family, sitting through uninteresting appointments was the main reason why they chose to discontinue care.

Relationships with clinicians.

Six *Continuer* and four *Discontinuer* families described the atmosphere of the clinic as upbeat, non-judgemental, and friendly. For example, when asked to

describe the atmosphere of the clinic, Parent 8C said, “It’s very positive and upbeat and I haven’t seen any [judgement]…it’s definitely easier to come into a positive atmosphere and everybody wants to help you and encourage you versus if it was negative, I think we would probably quit.” Coming to a welcoming environment made it easier to continue with care.

Additionally, nine of ten *Continuer* families were happy with the amount of encouragement and support received from clinicians. For example, Parent 5C said:

> They were helpful. If they would have been kinda OK well we don’t really care, then you know we wouldn’t have come. But they all sincerely care…[Dietitian] is always happy to see even a little bit of an improvement. Like to me it’s like oh gee, that’s not really much…but she makes him feel good.

In addition, children had positive relationships with the clinicians. Child 19D described it as, “The people are actually really cool…they were just always positive if you did something wrong…I remember, especially the gym one was my favourite…She was always pumped…it’s actually fun with her ‘cause she actually listens to you.” Having this support from clinicians bettered the family’s relationship with the clinicians at the PCWH.

Conversely, three *Discontinuer* families described their experiences with the clinicians as negative, reporting that they did not receive enough encouragement or support. For example, when asked if she received adequate encouragement from the clinicians, Parent 18D said:

> Yeah it was definitely lacking…Some people need to be told what to do…I think they've got the wrong approach putting the client in charge as opposed to…saying you signed up for the program, this is what it's about, let us give you a little bit more direction and you follow it.

This family wanted more directed support, creating tension between the family and clinicians, ultimately contributing to their decision to discontinue care.

Care received meeting expectations.

Most parents reported that they did not have any particular expectations of the care they were to receive. A few parents reported that they had expectations of receiving specific services. For example, Parent 25D described her expectations as, "I don't know what I was hoping for, maybe somebody to hold my hand…I was expecting a little more out of the fitness part of it. I think it's huge." Because her expectations were not met, she chose to discontinue care at the clinic.

Children (from both groups), on the other hand, expected the clinicians to be judgemental about their weight. When asked if she ever wanted to stop coming to the clinic, Child 2C said:

> Probably like the first two months of the whole thing…I didn't like being under a microscope 'cause I know I'm not used to being judged and I hated it. I guess I didn't wanna be here because I thought they would judge me but it's far from it.

Similarly, when Child 19D was asked a similar question, he responded with:

> At the beginning I was like ah I don't really wanna be here. You know who wants to the hospital all the time?...I guess I was uncomfortable in the beginning because you had to come here…you know overweight clinic…being big…And I was like I don't know if I like that.

Although children had negative expectations of the clinic, over time, they were able to see that there was no judgement from the clinicians.

Additionally, children expected the clinicians to be 'bossy'. When asked what expectations he had of the clinic, Child 7C said, "[I thought] that they'd tell me what to do…So they'd just boss me around…like I wouldn't get a chance to say what kind of stuff I eat…they'd just say you have to eat this and this to lose weight." However, because his negative expectations of the clinic were not met, it made it easier to continue with care.

Discussion

The objective of this study was to examine factors that contributed to attrition following commencement of a pediatric weight management program. Three main categories relating to the (dis)continuation of care emerged from the data: (1) *Family factors*, which included motivating factors and decision-making roles; (2) *Logistical factors*, which included parking costs, distance, scheduling, and weather; and (3) *Health services factors*, which included access to care, facility attributes, program and appointment length, menu of services available, quality of services, families' relationships with clinicians, and care received meeting expectations. All three categories considerably influenced families'

decisions to (dis)continue pediatric weight management care. Specifically, families that continued care described more positive experiences with motivating factors and the menu of services available; families that discontinued care reported more negative experiences with motivating factors, decision-making roles, distance, access to care, the menu of services available, and the quality of services received. Both groups highlighted positive relationships with clinicians and scheduling barriers as factora that contributed to their decision to (dis)continue care.

This study makes an important contribution to the literature, such that the findings reinforced that a broad ecological model (*e.g.*, Bronfenbrenner (36)) can be used to conceptualize reasons for attrition from pediatric weight management care. Previously, McCurdy and Daro (42) determined that parental decisions to enrol and remain in family support programs were shaped by a variety of factors at different "levels" of influence including the individual characteristics of the parent and family, provider attributes, program characteristics and neighbourhood characteristics. The use of the ecological model allowed for the analysis of interactions across these levels to better explain participants' decisions. The ecological model was also proposed by Marcellus (43) to describe research participant attrition from longitudinal research studies. Although attrition from research studies is likely a different phenomenon than attrition from clinical care, attrition in its broadest context is an issue impacted by many levels rather than just participant or provider characteristics. Because each of the three categories (family factors, logistical factors, health services factors) outlined in this study

represent a different environmental/ecological level, this study is among the first to support the application of the ecological model to examine attrition specifically from pediatric weight management care.

Both *Continuer* and *Discontinuer* families described improving their children's weight or health as their primary motivator to receive treatment. Compared with *Continuers*, *Discontinuers* described not needing clinical services and not seeing improvements in their children's health and/or weight as reasons for discontinuing care. Conversely, *Continuer* families described viewing their involvement with the clinic as a commitment and seeing health and/or weight changes as reasons for continuing care. Consistent with clinicians' perceptions (12), our research suggests that families who experience success during their treatment are more motivated to continue with their care. However, even setbacks experienced by *Continuers* were still described as providing further motivation to continue with care. Because of these differing perceptions, it is likely that families' motivation for treatment and readiness to change play a more important role in families' desire to continue with care. Consistent with literature, a lack of child and/or parent motivation was also described as a barrier to treatment by both parents and clinicians (12, 14, 21, 44-45). Because individuals tend to be more highly motivated by actions that produce tangible benefits than by those that do not, providing monetary incentives to families who would benefit from healthier behaviours (also known as pay for performance for patients) may improve health outcomes (46). In adult weight management programs, the use of monetary incentives (*e.g.,* monetary deposits) was associated with reduced attrition rates

(47-49); however, a monetary penalty for failure to attend or lose weight was associated with increased attrition (50). Furthermore, a systematic review reported that financial incentives (*e.g.,* cash, vouchers, lottery tickets, or gifts) improved patient compliance with medication, medical advice, or medical appointments (51). However, long-term behaviour maintenance once incentives are removed still needs to be determined as the impact of incentives may diminish over time (46). Future research should focus on different incentive programs (*e.g.*, how incentives are delivered, how often they are delivered, and how big they are), their cost-effectiveness, and their ability to reduce drop out and achieve positive health outcomes, especially in families enrolled in pediatric weight management clinics.

In addition to increasing motivation, clinicians should be aware of families' readiness to participate in a healthy lifestyle intervention. The concept of *readiness to change* was first described by the transtheoretical model, where behaviour change can be thought of as occurring as a progression through a series of stages (52-53). According to this theory, a person may initially be unaware or not intending to change a problem (*pre-contemplation* stage), then move to being aware of the problem, but having no plans to address it in the future (*contemplation* stage), then move to planning a new behaviour (*preparation* stage), then actually beginning a new behaviour (*action* stage), and finally, maintaining a new behaviour for at least six months (*maintenance* stage). Parents of obese children often are not aware of their child's condition (54) or do not view it as a significant health threat (16, 55). Thus, families who withdrew from care were most likely not in the *action stage* either when they were referred for

treatment or during treatment because of a failure to achieve treatment goals. Consistent with expert recommendations for pediatric obesity management (44), clinicians should help families move along these stages, rather than prescribing a new behaviour to families who are not ready (*e.g.*, in the *pre-contemplation*, *contemplation* or *preparation* stage*s*).

To enhance the transition between stages, clinicians can use Motivational Interviewing (MI), which uses active listening and non-judgemental questions to help build patients' motivation by taking into account their readiness to change (44, 56-57). Research indicates that MI can also help build rapport, improve patient-physician collaboration (44, 58), and improve health outcomes of obese children enrolled in pediatric weight management interventions (57). Primary care clinicians can use MI to help families with low motivation progress to the *action* stage before referring them to a structured, multidisciplinary, pediatric weight management program (44). In this way, limited resources are utilized only by families who are highly motivated to continue with care. Encouragement provided by physicians can also motivate some families to change their behaviour and receive weight management treatment (12). Additionally, clinicians working at pediatric weight management clinics can use MI with families who exhibit low motivation at presentation to transition them to the *action* stage before implementing formal weight management care. In order to identify children and parents who have low motivation at baseline, further research should focus on creating and testing a survey to assess families' readiness to change (59), thereby facilitating the most efficient use of resources, which means that weight

interventions are provided to families who are ready to make changes to their lifestyle. Past research has only focused on demographic factors *(e.g.*, children's age) and parental perceptions (*e.g.*, perception of children's weight) associated with being in the *preparation* and *action* stages of change (54). Additionally, clinicians can use MI with families who become discouraged because of lack of progress during treatment. When families encounter challenges, clinicians can assist families with problem-solving and developing potential solutions (57). Consistent with expert recommendations, it is important that clinicians working in pediatric weight management be trained in MI techniques (44) and actively utilize these techniques during clinical appointments (58).

It is important to note that three families withdrew from care not because they were not motivated to attend, but because they felt they no longer required the services of the clinic (*e.g.*, achieved their treatment goals). However, families' perceptions of success may be different than clinicians' perceptions of success; the decision to discontinue care may have been premature from a clinician's point of view (13, 21, 23). Interestingly, the BMI of children who continued or discontinued care were very similar, suggesting either that families who continued with care were heavier at intake, or families who withdrew from care were still implementing healthy lifestyle changes at home. Future research should explore the extent to which families engage in health lifestyle practices after (prematurely) discontinuing pediatrics weight management care.

Our research indicated that only children referred for weight management and their parents played a role in the decision-making process. Specifically,

Continuer families often indicated that it was parents' decision to continue with care, regardless of children's desires. Therefore, children may have been extrinsically motivated by their parents to continue care. However, *Discontinuer* families described their children as wanting to the leave the program as their main reason for discontinuing care, suggesting that children play an active role in determining their care. On the other hand, parents' perceptions of the willingness of their child to receive treatment may have also influenced families' continued involvement in pediatric weight management care (16). Future research should examine if specific parenting styles (*e.g.,* permissive) are predictive of attrition; to date, only family functioning has been studied and mixed results have been reported (17-18). Clinicians may need to provide more support in addressing the optimal involvement of children in health care decisions based on the child's developmental status (16). Furthermore, because children play an important role in attrition (16, 45), clinicians should focus on employing retention strategies specifically to this group. For example, using a Short Message Service (text message) maintenance treatment during a lifestyle intervention is an effective way for improving adherence to follow-up appointments in obese children, with limited time investment from treatment providers (60). However, although these text messages were acceptable to obese children, research indicates that they need to be carefully constructed, such as avoiding acronyms (*e.g.,* LOL) that are considered too informal for messages from healthcare providers (61). Furthermore, adolescents in particular should be targeted, as parents will often allow older children to play more of a central role in the decision-making process

about their care (24). Strategies aimed at parents, such as providing weight management treatment for obese parents concurrently with their children, should be further explored.

Experiences with logistical barriers were not exclusive to families who discontinued care; both *Continuers* and *Discontinuers* described similar difficulties, with *Discontinuer* families reporting the distance between their residences and the clinic as a barrier to a greater extent than *Continuer* families. However, demographic data indicated that compared with *Continuers,* more *Discontinuers* resided less than 20 kilometers from the clinic, indicating that perception of distance may play a more important role than actual traveling distance. Distance to access health services was reported to be a barrier for families when investigated qualitatively (16) and quantitatively (62), which is especially concerning because families who live in rural or remote areas tend to be more obese (63). Therefore, rather than in-person contact, alternative forms of communication (*e.g.*, videoconferencing, e-mailing) may be more feasible for families and clinicians to stay connected (63-66). For example, the PCWH offers families who live a considerable distance away with the opportunity to attend clinical appointments through Telehealth, a secure videoconferencing network that allows families to interact with clinicians. Although available, additional funding from the government could help to expand this program to include all families who report distance as a perceived barrier to care, regardless of actual travel distance. However, the effectiveness of e-health interventions in improving health outcomes especially in the area of childhood obesity still needs to be

determined. Additionally, clinicians in rural areas should be given the opportunity to receive additional training on how to effectively prevent, assess, manage, and treat pediatric overweight or obesity in the primary care setting (44). This way, clinicians can provide services to families who are unable to travel the distance to receive interdisciplinary pediatric weight management care.

All families described scheduling issues as the most important logistical factor impacting their decision to (dis)continue care, which is consistent with other research (21-23). In particular, families expressed that clinical appointments were inconvenient because they conflicted with school and work commitments. Consistently missing school to attend appointments can cause children to fall behind, negatively impacting their learning. In addition, parents having to take time off work results in lost wages, which is especially taxing for lower income families. To minimize the burden of scheduling difficulties, clinics can offer appointments in the evenings or on weekends to allow families with difficult schedules the opportunity to access weight management care (23). Further, children who are involved in making their own appointments are more likely to attend these appointments (24). Therefore, an online process to facilitate appointment bookings may enhance attendance of families. In this way, families can also easily cancel or reschedule their appointments, decreasing delays in accessing care for those waiting for treatment (16). Similar to a study conducted by Braet *et al*. (13), in our study, the degree to which families perceived experiencing scheduling difficulties did not differ between *Continuers* and *Discontinuers*. Demographic data further corroborated this finding, reporting

similar household incomes and mean ages of children (and likely, school schedules) between the two groups. Therefore, it is likely that other factors, rather than the number of barriers perceived, may play a more important role in attrition. For example, *Continuers* may be more motivated than *Discontinuers* to attend clinical appointments or may have developed better strategies to minimize logistical issues that impede their ability to access care, such as scheduling clinical appointments when children had a half-day at school. These families may be more *resilient* than *Discontinuers. Resilience* refers to a "dynamic process encompassing positive adaptation within the context of adversity (p.543) (67)" and reflects the interaction between risk factors and protective factors. In our study, although families who continued or discontinued care perceived to face the same logistical barriers, some families were able to overcome this adversity and remain engaged with their care. These protective factors can be categorized as individual attributes, family qualities, and supportive extra-familial systems, mirroring the social ecological framework (68-69). To date, research has investigated factors that promote weight resilience, defined as maintaining a healthy body weight despite living in an obesogenic environment, in adolescents (69). For example, self-efficacy for eating (70) and physical activity (71) (individual factors), parenting behaviours (72) (family factors), and availability of healthy food (73) (extra-familial factors) have all been shown to be weight protective in youth. Within the context of pediatric weight management care, further research should investigate multi-level protective factors (*e.g.,* child and

parent motivation) that foster the development of resilience to attrition to ascertain which families are more likely to continue with care at presentation.

Both *Continuer* and *Discontinuer* families reported that their experiences of their health care services were important factors in their decision to (dis)continue care. Families' perceptions of their health care services predominately influence their attrition from care (16). In our study, although both groups generally reported positive relationships with clinicians, families who withdrew from care indicated that their treatment needs, wants and/or expectations were not being met. In particular, families felt that they were discharged by the clinic prematurely or the services provided by the clinic were lacking. For example, many families indicated that they wanted a group-based intervention for their young child, a program that the PCWH does not currently offer. However, research indicates that omitting obese children from actively participating in lifestyle interventions (*e.g.,* "parents as agents of change" programs (74)) may be beneficial for the promotion of healthy lifestyles and weight loss (75). Although matching programs to parent preferences may reduce attrition, the health benefits of this approach need to be further examined (22). Another common critique of the services provided by the clinic was that families felt that the information they received was redundant, contributing to their drop out. Other families chose to discontinue care because they were unaware that the services they were looking for were in fact available at the clinic. These instances underscore the need to determine how to best assess families' needs, wants, and/or expectations to provide optimal care. For example, clinics can incorporate

a screening tool, such as a healthy lifestyles educational and treatment needs assessment at initial appointments (21) to determine patients' needs, wants, and/or expectations. In this way, clinicians can tailor treatments specific to each patient, which is consistent with family-centered care, ultimately reducing attrition and improving care (22). Furthermore, although individuals interviewed for our study were primarily of Caucasian ethnicity, research indicates that there may be a mismatch between the standard weight management treatment approach and perspectives of patients from different ethnicities, resulting in poorer treatment outcomes or attrition (19, 76). Therefore, incorporating such a tool can also help to identify patients' ethnic treatment needs (*e.g.*, cross-cultural communication). Disseminating clinic-specific information to all families before enrolment at the clinic (*e.g.,* by providing details about services provided at the PCWH to primary care health care providers who refer overweight/obese children for pediatric weight management care) will help inform families regarding realistic expectations of their care. Lastly, clearly communicating the clinic's discharge policies will reduce the number of families who perceived they were prematurely discharged.

In our study, although both groups described valuing their positive relationships with clinicians, families were unable to express their treatment needs to their healthcare providers, which contributed to attrition. A key feature of weight management counselling is the negotiation of care (77), in which decision-making is reciprocal between families and clinicians (78). Families in our study may have been hesitant to provide feedback to clinicians because they viewed

them as the 'experts' (78). Interestingly, families were willing to share their frustrations with researchers, indicating that communication between health care providers and families can be improved. Furthermore, *Discontinuer* families were engaged with the program for a fairly long time (approximately 20 appointments), indicating that families had ample opportunity to address their treatment needs with clinicians, indicating the therapeutic relationship can be enhanced. Therefore, clinicians can improve the patient-provider relationship by using rapport-building strategies to facilitate communication and increase the ease with which families share their treatment needs (79-80). Clinicians who are reassuring, supportive, warm, respectful, empathetic, and approachable are more likely to improve client trust, communication and rapport (80-81). Additionally, clinicians can facilitate open communication by incorporating skills such as listening, responding, open questioning, reflecting, paraphrasing, and summarising, in their clinical encounters with families (82). As indicated earlier, because a third of *Discontinuer* families interviewed in our study felt they were prematurely discharged by the clinic, communication to families about discharge practices also can be improved, as suggested earlier. Ultimately, taking a family-centred care approach by facilitating collaboration between families and clinicians will help develop mutually agreed upon goals (44). Because families are often limited in the types and styles of programs they can choose from, understanding families' treatment needs, wants, and/or expectations can help improve the 'fit' between families and programs (22).

There are both strengths and limitations to this research. A strength of this research included capturing the perceptions of families receiving care, or who once received care, at a pediatric weight management clinic. There is compelling research that the perspective of target populations should be obtained to inform interventions (83). Previous research has investigated parents' (13, 16, 21-22) and clinicians' (12, 23) perspectives on attrition, but ours is the first qualitative study to obtain rich, contextual information to investigate reasons for attrition from both children and parents in an interdisciplinary pediatric weight management program. Although parents' perspectives are important, given differences in age and development, important concerns for parents may not resonate with children, and *vice versa*. Furthermore, because both children and parents are involved in the decision-making process (16), it is important to explore all family members' reasons for attrition. Lastly, the methodological rigour used in this study is a strong point. To sum, the key strengths of this paper included understanding families' (children's *and* parents') perspectives about their care and strong methodological rigour.

A study limitation is that the findings in this study provide detailed information about only one case, limiting its generalizability. Families' reasons for attrition may be attributable to characteristics specific to the PCWH. However, qualitative studies are considered to have an element of naturalistic generalizability (84), meaning that the findings might be relevant to similar types of situations to those studied here, such as attrition in other pediatric weight management centres. This research can also serve as a starting point for further

investigation to explore reasons for attrition at the other pediatric weight management centres participating in this multi-centre study. Sampling bias may have also been introduced into the study whereby families who had overly positive or negative experiences at the clinic were more willing to participate in the research study. Because it is difficult to engage families for research participation at the clinic once they have already withdrawn from care, it was deemed appropriate to gather data from any family who was willing to participate. Furthermore, findings from the other cases involved in the larger study can help corroborate our findings, thereby reducing sampling bias.

Conclusion

Family, logistical, and health services delivery factors all influenced families' decisions to (dis)continue pediatric weight management care. Most notably, our study indicated that families who continued with care exhibited more motivation to attend clinical appointments and valued the variety of services provided by the clinic; families who discontinued care exhibited lower motivation to continue with care, indicated that their child no longer wanted to attend clinical appointments, perceived distance from their residence to the clinic as a main barrier, and were unsatisfied with the care received (*e.g.,* access to care, menu of services available, quality of care) because their treatment needs, wants, and/or expectations were not met. Furthermore, both groups placed considerable importance on their relationships with health care providers and indicated scheduling to be a significant barrier to continuing with pediatric weight management care. Consistent with the ecological framework, our data highlighted

several multi-level strategies that clinicians can employ to potentially reduce attrition by having a positive impact on modifiable factors (*e.g.,* using MI to enhance families' desire to continue with care, offering Telehealth to provide care to families who live a remote or rural areas, and using rapport-building strategies to facilitate communication about families' treatment needs). Because a change at one level of influence may impact all other levels, implementing these changes may successfully reduce attrition; however, further intervention research is needed to examine the effectiveness of these approaches in not only reducing program attrition, but also creating positive health outcomes for families (*e.g.,* improvements in children's weight).

Table 3-1: Characteristics of participants

Variables:	***Continuers* (n=10 families)**		***Discontinuers* (n=9 families)**	
	Parent	**Child**	**Parent**	**Child**
Demography:				
Age (y)	44.8 ± 4.5	13.8 ± 2.3	44.6 ± 8.2	14.8 ± 2.3
Sex:				
Male	n=2	n=3	n=0	n=8
Female	n=8	n=7	n=9	n=1
Ethnicity:				
Caucasian	n=9	n=9	n=8	n=7
African-American	n=0	n=1	n=0	n=0
Latino	n=0	n=0	n=1	n=1
Other	n=1	n=0	n=0	n=1
Country of birth:				
Canada	n=10	n=10	n=8	n=9
Other	n=0	n=0	n=1	n=0
Household income:				
≤$29,999	n=0	N/A	n=1	N/A
$30,000-49,000	n=1		n=0	
$50,000-69,000	n=1		n=1	
$70,000-89,999	n=2		n=2	
$90,000-99,9999	n=1		n=2	
≥$100,000	n=4		n=2	
Prefer not to say	n=1		n=1	
Highest level of parental education:				
No high school	n=0	N/A	n=0	N/A
Some high school	n=0		n=0	
High school diploma	n=2		n=2	
University/College	n=7		n=6	
Post-graduation	n=1		n=1	
Other	n=0		n=0	
Prefer not to say	n=0		n=0	
Distance from home residence to clinic:				
≤ 20km	n=5		n=7	
> 20km	n=5		n=2	
Anthropometry:				
Weight (kg)	92.7 ± 33.4	80.8 ± 28.7	77.9 ± 15.5	89.2 ± 30.0
Height (cm)	167.3 ± 7.8	156.2 ± 12.0	161.4 ± 7.9	165.8 ± 11.7
Body Mass Index (BMI; kg/m^2)	32.8 ± 11.4	32.4 ± 8.5	30.3 ± 8.0	32.0 ± 8.1
BMI Percentile	N/A	98.6 ± 1.8	N/A	97.6 ± 3.6
BMI Z-score	N/A	2.85 ± 1.1	N/A	2.83 ± 1.3
Number of overweight/obese parents*	n=8	N/A	n=7	N/A
Health services:				
Weight management intervention type:				
Individual	n=4		n=6	
Individual + Group	n=6		n=3	
Number of clinical appointments attended	37 ± 15		20 ± 16	
Wait time from referral to first clinical appointment (months)	3.5 ± 1.0		4.7 ± 2.5	

N/A, not applicable; *Overweight/obese = BMI ≥ 25

Table 3-2: Rules of inclusion for categories and themes

Name of Code	Rule of Inclusion
1. Family Factors	*Family discusses child and parent level factors that have impacted their decision to (dis)continue care.*
a) Motivating factors	The child or parent discusses factors that have motivated or de-motivated them to continue with their care (*e.g.*, community supports, health, seeing changes, willingness to come, *etc.*).
b) Decision-making roles	The child or parent discusses who played a role in their decision to (dis)continue care.
2. Logistical Factors	*Family discusses factors that play a role in the organization and management of attending clinical appointments.*
a) Parking costs	Family discusses if parking costs associated with attending clinical appointments impacted their ability to (dis)continue care.
b) Distance	Family discusses if the location of the clinic impacted their ability to attend clinical appointments.
c) Scheduling	Family discusses their challenges and successes when trying to schedule their day in order to accommodate clinical appointments.
d) Weather	Family discusses whether or not the weather impacted their ability to attend clinical appointments.
3. Health Services Factors	*Family discusses characteristics and their opinions of the programs and services at the clinic that have contributed to their (dis)continuation of care*
a) Access to care	Family discusses if their ability to access the care provided at the PCWH (or services provided for PCWH patients at other locations) impacted their decision to (dis)continue care.
b) Facility attributes	Family discusses if the physical attributes of the clinic impacted their ability to (dis)continue care.
c) Program and appointment length	Family discusses if the length of the program and/or appointments impacted their decision to (dis)continue care.
d) Menu of services	Family discusses if their ability to choose from the variety of services provided at the clinic impacted their decision to (dis)continue care.

e) Quality of services	Family discusses if their satisfaction with the clinic and the services they received (*e.g.*, specific characteristics, atmosphere of the clinic, strengths and weaknesses, amount of parental involvement during appointments, quality of information received, *etc*.) impacted their decision to (dis)continue care.
f) Relationships with clinicians	Family discusses the interactions they have had with the clinicians, the support and encouragement received, their opinions of the clinicians, and if these factors played a role in their decision to (dis)continue care.
g) Care received meeting expectations	Family discusses the expectations they had of the clinical services provided at the PCWH, and if having them met or unmet influenced their decision to (dis)continue care.

Table 3-3: Data matrix of participants' responses

Factors that Impact the (Dis)Continuation of Care at the PCWH														
		Family Factors		**Logistical Factors**				**Health Services Factors**						
	ID	**Motivating factors**	**Decision-making roles**	**Parking costs**	**Distance**	**Scheduling**	**Weather**	**Access to care**	**Facility attributes**	**Length**	**Menu of services**	**Quality**	**Relationships with clinicians**	**Care *vs.* Expectations**
CONTINUERS	P1	+	+	+	+	+	+	-	+	+	+	+	+	+
	C1	+	+	-	-	-	-	-	-	+	-	+	+	+
	P2	+	-	+	-	+	+	+	-	+	+	+	+	+
	C2	+	+	-	-	-	-	-	-	-	-	+	+	+
	P3	+	+	-	+	+	-	-	-	-	+	+	+	+
	C3	+	+	-	-	+	-	-	-	-	-	+	+	-
	P4	+	+	+	+	+	+	-	-	-	+	+	+	+
	C4	+	-	-	-	-	-	-	+	-	-	+	+	+
	P5	+	+	+	+	+	-	-	-	+	+	+	+	+
	C5	+	+	+	-	+	-	-	-	+	+	+	+	+
	P6	+	+	+	+	+	+	-	-	+	-	+	+	+
	C6	+	-	-	-	-	-	-	-	-	+	+	+	+
	P7	+	+	+	-	+	+	-	-	-	+	+	+	+
	C7	+	+	-	-	+	-	-	-	+	+	+	-	+
	P8	+	-	-	+	+	+	-	-	-	+	+	+	-
	C8													
	P9	+	+	+	-	+	+	-	-	-	+	+	+	+
	C9	+	+	-	-	+	-	-	+	-	-	-	+	+
	P10	+	+	+	-	+	+	+	+	-	+	+	+	+
	C10	-	+	-	-	+	+	-	-	+	-	-	+	+
	n	*18*	*15*	*9*	*6*	*15*	*9*	*2*	*4*	*8*	*12*	*17*	*18*	*17*
DI	P14	+	+	+	-	+	-	+	+	+	-	+	+	+
	C14	+	+	-	-	-	-	-	-	-	-	+	+	+
	P15	+	+	-	-	+	-	-	-	+	+	+	+	+
	C15	+	+	-	-	-	-	-	-	+	+	+	+	-

S	P17	+	+	+	+	+	-	+	-	-	-	+	+	+
C	C17	+	+	-	-	-	-	-	-	-	-	+	+	-
O	P18	+	+	+	+	+	-	+	-	-	+	+	+	+
N	C18													
T	P19	+	+	+	+	+	+	-	-	-	+	+	+	+
I	C19	+	+	-	+	+	+	-	-	+	+	+	+	+
N	P20	+	+	+	+	+	+	-	-	-	-	+	+	+
U	C20	+	+	-	-	+	-	-	-	+	-	+	+	+
E	P21	+	+	-	+	+	-	+	-	-	-	+	+	+
R	C21	+	-	-	-	+	-	-	+	-	+	+	-	+
S	P23	+	+	-	+	+	-	-	+	-	+	+	+	+
	C23	+	+	-	+	+	-	-	+	-	+	+	+	+
	P25	+	+	+	-	+	-	-	-	+	-	+	+	+
	C25	-	+	-	-	-	-	-	-	-	-	+	-	+
	n	*16*	*16*	*6*	*8*	*13*	*3*	*4*	*4*	*6*	*8*	*17*	*15*	*15*
	Total n	**34**	**31**	**15**	**14**	**28**	**12**	**6**	**8**	**14**	**20**	**34**	**33**	**32**

The plus sign (+) indicates the presence of a response in the theme
The negative sign (-) indicates a lack of response to the theme

Figure 3-1: A diagrammatic representation of the ecological framework

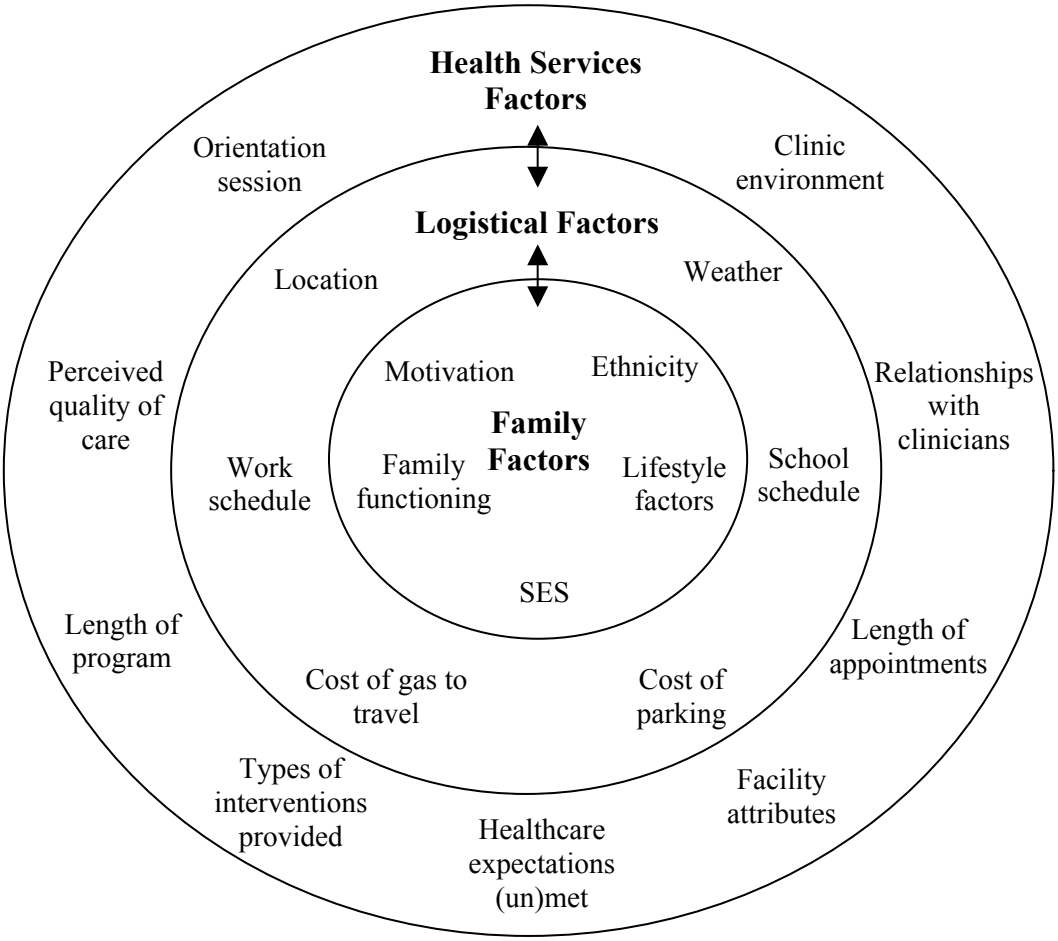
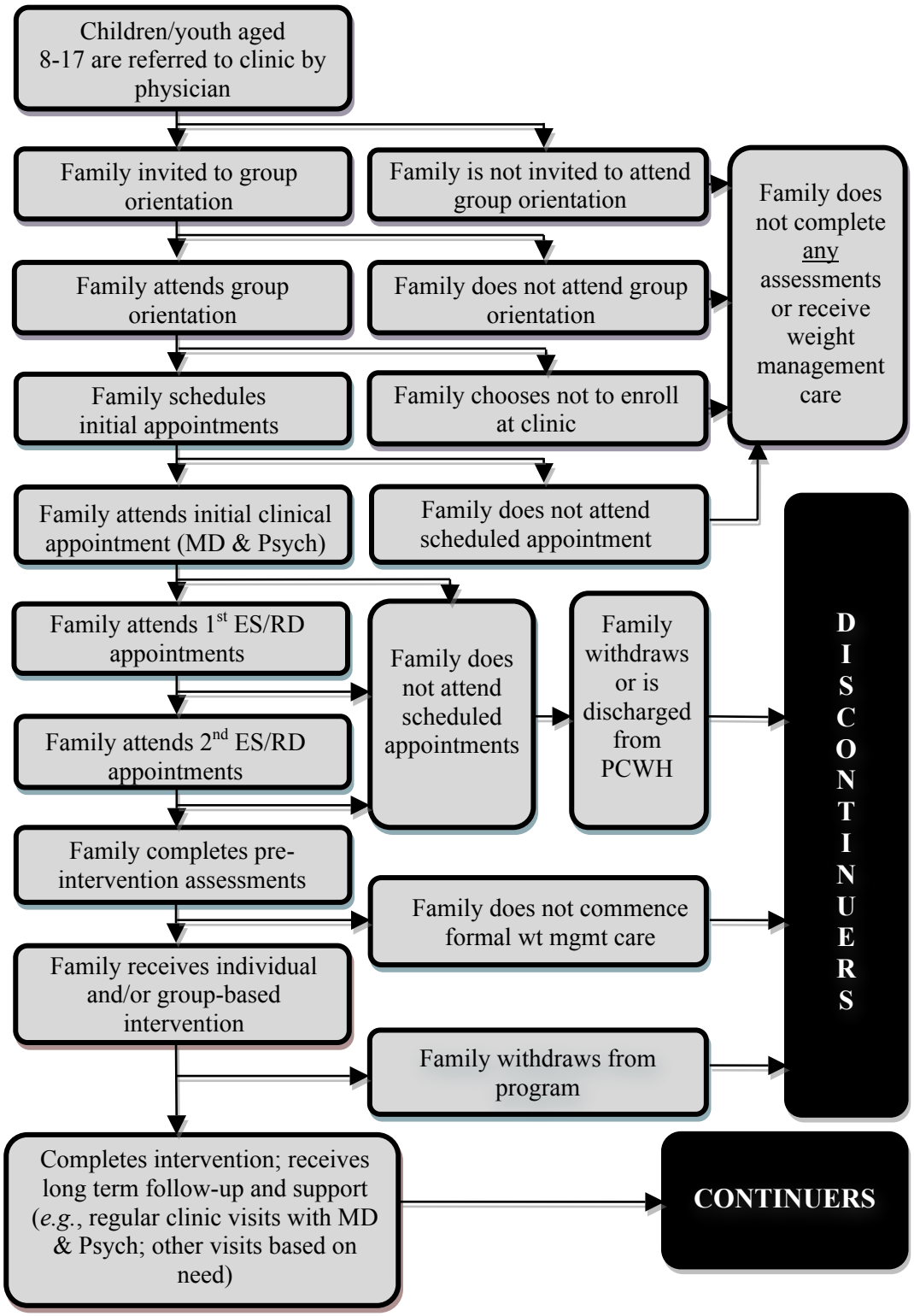


Figure 3-2: Family journey at the PCWH



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Chapter 4: Conclusion

Major Findings

Integrative review

My integrative review demonstrated that relatively few research studies have explored predictors of and reasons for attrition from pediatric weight management care. Results indicated that insurance type was an important predictor of attrition; families who received public insurance (*e.g.,* Medicaid) were more likely to discontinue care than families with private insurance. Results were inconsistent with respect to a number of other *child*, *parent*, *family*, and *health services* factors. In the order of most commonly reported to the least, physical barriers (*e.g.,* scheduling), clinic failing to meet families' needs, wants, and expectations (*e.g.,* perceived need of care), costs (*e.g.,* cost of health services), a lack of family motivation/readiness to change (*e.g.,* self-reported low motivation), and issues with health services factors (*e.g.,* problems with the length of appointments and/or programs) were given by families as reasons for discontinuing care. These findings highlighted the importance of understanding predictors of attrition to help health care providers identify families at risk for attrition at presentation. Subsequently, interventions can be tailored to at-risk groups of families to minimize attrition. Additional research investigating child and parent reasons for their discontinuation of care is justified as child/family characteristics (*e.g.,* demographics) were not the key contributors to drop out; rather research indicated that families' perspectives of their care (*e.g*., how the

clinic met families' treatment needs, wants, and/or expectations) were fundamentally important reasons for discontinuing care.

Qualitative study

My qualitative study sought to provide an understanding of factors that influenced families' decisions to (dis)continue care after commencing pediatric weight management care at the Pediatric Centre for Weight and Health (Stollery Children's Hospital, Edmonton, AB). Data analysis revealed three main contributors to attrition: (1) *Family factors*; (2) *Logistical factors*; and (3) *Health services factors*. Families who continued care described more motivation to attend clinical appointments and valued the menu and quality of services provided by the clinic. In comparison, families who discontinued care exhibited lower motivation to attend clinical appointments, indicated their child influenced their decision to discontinue care, perceived distance from their residence to the clinic as a barrier, and were unsatisfied with the care received (*e.g.,* access to care, menu of services, quality of services received) because their treatment needs, wants, and/or expectations were not met. Both groups of families highlighted their relationships with clinicians and scheduling barriers as factors contributing to their decision to (dis)continue care; weather, facility attributes, and program and appointment lengths did not greatly influence families' decisions. These findings demonstrated the importance of families' perceptions of their care (compared to reality) when deciding to (dis)continue care. Consistent with the ecological framework, our data highlighted multi-level strategies to reduce attrition. However, intervention research is needed to examine the effectiveness of these approaches in

simultaneously reducing program attrition and creating positive health outcomes for families (*e.g.,* improvements in children's weight).

Future Directions

Identifying predictors of and reasons for attrition can help shape future interventions in three ways. First, gaining a better understanding of predictors can help identify families at risk for drop out at baseline. In these circumstances, clinicians can provide additional support (*e.g.,* incorporate motivational interviewing into clinical appointments) for these families to promote retention during the beginning stages of an intervention. Second, determining reasons for attrition can facilitate clinic-level changes needed to enhance retention. Third, this research can inform decision-making about which families ought to be included or excluded from participating in pediatric weight management programs (1-2). By excluding families that are likely to drop out, clinicians can focus their resources on families who are more likely to continue with care, and thus are more likely to receive the benefits of treatment. De Niet and colleagues (3) revealed that older children were more likely to drop out from an intervention, and subsequently changed the inclusion criteria to participate in an intervention from 8-14 years old to 7-12 years old. From our perspective, because we still do not have a complete understanding of attrition, it would be hasty to exclude families entirely from receiving care based on preliminary results. Clinical endeavors and future research should focus on the effectiveness of providing support to promote retention among families at risk for attrition rather than excluding families who may be at increased risk for drop out.

The key to gaining a better overall understanding of predictors of and reasons for drop out lies with how we conceptualize the phenomenon of attrition. As indicated in my thesis, a broad range of definitions were used to characterize attrition, making it difficult to compare results across studies. As Garfield (4) has emphasized, "the use of varying definitions and criteria of dropouts or premature terminators makes it difficult to compare studies and to secure meaningful generalizations…Even though individual investigators may clearly define their dropout group…, the extreme variability among these operational definitions leads to chaos. Unless we agree about the phenomenon we are studying, we cannot hope for any systematic progress (p.168)." One way to address this knowledge gap is to convene an expert panel consisting of clinicians and researchers who have a comprehensive understanding of attrition from pediatric weight management. The appropriateness of attrition being characterized solely by duration of treatment received (as it has been done thus far) should be critically examined. For example, are patients who withdraw from treatment after only attending initial assessment appointments different from patients who withdraw during an intervention? Furthermore, it is important to recognize that because attrition is a patient phenomenon, patients' perspectives need to be taken into consideration when defining attrition Since the definition of attrition can differ between families and clinicians (5-8), perspectives from families who have discontinued pediatric weight management care should also be explored (*e.g.,* by including families in the expert panel).. Ultimately, having a clear understanding

of attrition can help us make clinical changes to effectively address drop out from pediatric weight management care.

Lastly, it is important to acknowledge the differences between families' perceptions of their care versus objective measures of their care. In my integrative review, one study (9) showed that families that discontinued care wanted support to understand and utilize their insurance policy; in reality, the clinic offered individualized insurance support to each family. Similarly, in my qualitative study, some families that discontinued care perceived that the clinic did not provide services they were looking for (*e.g.,* group interventions for their adolescents), when it reality, such services were available to families. These examples suggest that families perceive their care differently than the reality of care received, or clinicians may not be delivering the same quality of services to each family. Therefore, future research should focus on understanding how children's and parents' perceptions of their care are similar or different to the reality of care received from clinicians' perspectives. Determining factors involved will help ensure equitable healthcare to all.

Concluding Remarks

My thesis examined the phenomenon of attrition within the context of pediatric weight management. My first paper (**Chapter 2**) sought to explore what was already known about this topic using an integrative review approach. Results indicated that while many studies have investigated predictors of attrition that can help identify families at greater risk for dropout at presentation, very few studies have explored families' reasons for attrition, providing an incomplete

understanding of the phenomenon of attrition. Furthermore, most research focused exclusively on clinicians' or parents' perspectives of attrition. This underscored the clear need for additional research to determine *family* specific reasons for the discontinuation of care, providing justification for my qualitative study. In **Chapter 3**, my qualitative case study further explored factors that influenced children's *and* parents' decisions regarding their (dis)continuation of care following commencement of a pediatric weight management program. Findings from this study identified family, logistical, and health services factors as main reasons for attrition. Most notably, families who discontinued care reported more negative experiences with motivating factors, decision-making roles, distance, access to care, and the menu of services available. Overall, the combination of a review and qualitative data in this thesis provided a more complete understanding of attrition than either approach alone. Not only did my qualitative paper corroborate the findings from my integrative review paper, such that motivation (family factors), distance and scheduling (logistical factors), and health services issues and treatment needs, wants, and/or expectations not being met (health services factors) were outlined as key barriers, but it also provided additional insights about why children *and* parents chose to discontinue care (*e.g.,* children were involved in the decision-making process). Taken together, these two studies explored attrition from a number of different perspectives (child, parent and clinician). These findings suggest that changes at multiple levels (*e.g.,* clinic, government) are needed to minimize attrition from pediatric weight management care by having a positive impact on modifiable factors. However,

intervention research is required to examine the efficacy and effectiveness of different approaches outlined in my two papers to minimize program attrition.

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Appendix A: Ethics Forms

PARENT INFORMATION SHEET AND CONSENT FORM

Title of Project:	**Should I Stay or Should I Go? Understanding Overweight Children and Their Families Referred For and Discontinuing Weight Management Care**	
Principal Investigator:	Dr. Geoff Ball	Phone: 780 342-8465
Co-Investigators:	Dr. Nicholas Holt	Dr. Arya Sharma
	Dr. Jean-Pierre Chanoine	Dr. Rebecca Gokiert
	Dr. Katherine Morrison	Dr. Laurent Legault

What is the purpose of this study?

To interview children and youth (and their parents) to better understand their experiences, expectations, and needs related to weight management.

Why is this study happening?

There is very little information on families' decisions regarding their experiences related to weight management care. To provide the best care possible, we need to learn from families. For example, some families are referred for weight management, but never attend a clinical appointment. Others get referred and decide to enrol in weight management interventions that can last for months or years. In this study, we hope to better understand why some families choose not to initiate care while other families initiate care and continue receiving help and support for a long time.

Understanding families' views on these issues will help us to develop the best possible weight management programs. This study includes families referred to weight management programs in Edmonton (at the Pediatric Centre for Weight and Health, PCWH), Vancouver, Hamilton and Montreal. By learning from children and parents at all of these programs, we hope to learn from a wide variety of families and get a national view of families' thoughts and decisions about weight management.

What information is collected? How is it being collected?

Background Information

We may ask you some questions and do some measurements or collect some information about your family from your child's medical chart at the PCWH. Background information we will collect for this study includes things like your / your child's sex, date of birth, and ethnicity. Physical information such as height, weight, and waist circumference will be collected, too.

Individual Interviews
For this study, you and your child will each be interviewed. Interviews will include a number of questions. The following examples are similar to the kinds of questions we will ask you and your child:

> *"Who referred you / your family for weight management?"*
> *"Did you attend a clinic appointment for weight management?"*
> *"If you attended an appointment, what issues helped you decide to attend?"*
> *"If you didn't attend an appointment, why issues helped you decide not to attend?"*
> *"If you've been in a weight management program for awhile, what keeps you going?"*
> *"If you attended a weight management program for awhile, but stopped going, what helped you decide to stop?"*

How we word these questions may vary so parents and children can understand. Your to these types of questions will help us to learn about your (and your child's) experiences related to weight management. Interviews will be 30 (child) to 60 (parent) minutes long and will be digitally recorded to help us analyze your information. During the interviews, we may also take some notes to help us stay organized. Most likely, the interviews will take place at the PCWH. However, if it's more convenient for your family, we can meet at another location (ex. your home, a quiet coffee shop, or office at the University of Alberta or in the Stollery Children's Hospital).

Are there any possible benefits of this study?
This study will help the researchers and health professionals at the PCWH (and other programs in Vancouver, Hamilton, and Montreal) develop the best possible weight management programs for children and families. It will also give your family a chance to talk about issues that relate to your family's weight management experiences. In our experience, this can help families better understand how they communicate with each other.

Are there any possible risks of this study?
In volunteering for this study, we do not believe your family is at any physical risk. However, some of the interview questions may bring up strong feelings and emotions. If you desire, please let us know if you'd like to speak with the PCWH Psychologist. She may be able to help you with any family or emotional issues that arise.

How is information kept confidential?

By signing the consent form, you allow the research team to access your health information that is kept at the PCWH (in your child's medical chart). The information we collect will be entered into a computer to help us analyze the data. Information on the computer will be protected with a password. All paper copies of your family's information will be stored in a lockable filing cabinet in the Research Office at the PCWH. All the information will be kept for a minimum of five years. The results of this study may be published in a scientific journal or presented at a conference. However, all of your family's information will be kept private. Also, your name and your child's name will never be used in any report or presentation (only group information will be presented). Your family's information may be combined with information from other families who are participating in this study from Vancouver, Hamilton and Montreal. Again, only group information will be reported.

Are we free to withdraw from this study?

Your participation in this study is completely voluntary. If you decide that you do not want to participate in this study, it is OK. You may withdraw from the study at any time. If you decide to withdraw or not take part in this study, it will not affect the care you and your child receive at the PCWH.

Is there an independent office we can contact if we have concerns about this study?

If you have any concerns about this study, you may contact the Health Research Ethics Board at 780-492-0302. This office has no connection with the study researchers.

PARENT CONSENT FORM

Title of Project:	**Should I Stay or Should I Go? Understanding Overweight Children and Their Families Referred For and Discontinuing Weight Management Care**	
Principal Investigator:	Dr. Geoff Ball	Phone: 780-342-8465
Co-Investigators:	Dr. Nicholas Holt Dr. Jean-Pierre Chanoine Dr. Katherine Morrison	Dr. Arya Sharma Dr. Rebecca Gokiert Dr. Laurent Legault

Please circle your answers:

Do you understand that you and your child have been asked to be in a research study?	Yes	No
Have you received and read a copy of the attached Information Sheet?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Have you had an opportunity to ask questions and discuss this study with the researchers?	Yes	No
Do you understand that you are free to refuse to participate or withdraw your child from the study at any time? You do not have to give a reason. Refusing to participate or withdrawing will not affect the medical care your family receives.	Yes	No
Has the issue of confidentiality been explained to you?	Yes	No
Do you understand we will be accessing your family's information collected at the Pediatric Centre for Weight and Health including personally identifiable health information?	Yes	No
Do you agree to be contacted for future research studies?	Yes	No

My Child's Name: _____

I agree to take part in this study: YES ¨ NO ¨

I agree for my child to take part in this study: YES ¨ NO ¨

Signature of Parent or Guardian:_____ Date: _____

Printed Name: _____

Signature of Witness:_____ Date: _____

Printed Name:_____

Signature of Researcher:_____ Date: _____

Printed Name:_____

CHILD INFORMATION SHEET AND ASSENT FORM

Title of Project:	**Should I Stay or Should I Go? Understanding Overweight Children and Their Families Referred For and Discontinuing Weight Management Care**	
Principal Investigator:	Dr. Geoff Ball	Phone: 780-342-8465
Co-Investigators:	Dr. Nick Holt	Dr. Arya Sharma
	Dr. Jean-Pierre Chanoine	Dr. Rebecca Gokiert
	Dr. Katherine Morrison	Dr. Laurent Legault

What is this study about?

For this study, we will interview children and parents to learn about their decisions for attending a weight management program such as the Pediatric Centre for Weight and Health (PCWH). This information will help us to make the program better for other children and their families.

What do I have to do?

We will have two interviews. One will be with you, and the other will be with your mom or dad. We will ask you some questions and tape-record your answers. We might also take some written notes during your interview to help stay organized. The interview should last about 30 minutes. Some of the questions we might ask you are:

> *"Did a doctor tell you to come to a weight management program or did you decide yourself?"*
> *"If you went to a weight management clinic, what did you hope to learn?"*
> *"If you went to a weight management clinic for awhile, but stopped going, why did you stop?"*
> *"What things did you like about the clinic?"*
> *"What things didn't you like about the clinic?"*

Along with the interview, we may also take some measurements (such as height and weight) from you and your mom or dad. If these measurements were done recently at the PCWH, we might collect this information from your medical chart instead of measuring you again.

Will any measurements or tests hurt me?

None of the measurements will hurt you. Some of the questions we ask in your interview might be hard to answer. However, we will give you lots of time to think. Also, there are no wrong answers. We just want to know about your thoughts and experiences.

Can I quit the study?
If you don't want to, you don't have to sign up for this study. Also, you can quit at any time. No one will be mad at you if you decide you don't want to do this, or if you decide to stop part way through.

Do I have to autograph anything?
If you agree to sign up for this study, you have to sign this form. Also, your mom or dad will sign another form. This is so both of you agree for you to sign up for the study.

What if I have questions about this study?
You can ask your mom or dad about anything you don't understand. You can also talk to the researchers. They can answer any questions you have about the study. If you have questions at any time, you can contact Jasmine Dhaliwal (780-342-8449), Kathryn Ambler (780-342-8409) or Dr. Geoff Ball (780-342-8465). All of them are involved with this study.

I agree to take part in this study.

Signature of Child:_____
Date :_____

Signature of Witness:_____
Date :_____

Signature of Researcher:_____
Date :_____

RECRUITMENT LETTER

Dear [insert family name]: [Date]

We want to improve the weight management care we provide to families like yours. To do this, as part of a new research study, we want to interview your family (your child and one parent). These interviews will help us to understand families' experiences, expectations, and needs about weight management. The information we learn will also help us to improve the healthcare we offer families like yours.

So you know, similar interviews are taking place with families living in Vancouver, BC, Hamilton, ON, and Montreal, QC. We will take information from all of these interviews to learn from families living in different parts of Canada.

This information from families from across the country we help us to make our weight management programs as good as possible.

We plan to interview three groups of families. This will help us to learn from families who have had a variety of experiences with our clinic. For your information, we plan to interview families with:

- Children who were referred for weight management but did not attend a clinical appointment.
- Children who were referred for weight management, attended some clinical appointments but are no longer active clients at our clinic.
- Children who were referred for weight management and are attending scheduled clinical appointments for weight management.

We would love for your family to participate in this important research. If you are interested, please contact Jasmine (see below for details). Otherwise, we will be in touch with you in the near future to discuss this study in more detail.

Kind Regards,

Dr. Geoff Ball, Assistant Professor
Department of Pediatrics
University of Alberta

Jasmine Dhaliwal, Graduate Student
Department of Pediatrics
University of Alberta
780-342-8449 (ph)
dh4@ualberta.ca (email)

CHILDREN (AND THEIR PARENTS) REFERRED TO THE PEDIATRIC CENTRE FOR WEIGHT AND HEALTH (PCWH)

Can you help us to make our weight management program as good as possible?

WHAT: A new research study is exploring families' reasons for attending (or not attending) a weight management program.

WHY: Learning from families will help us to improve our program as well as other programs across the country.

WHO: Children (and their parents) who were referred to the PCWH.

WHERE: Wherever is most convenient for you! At the PCWH, at the U of A, or even at your home.

TIME: Child interviews take about 30 minutes; parent interviews take a bit longer (about 60 minutes).

DETAILS:

For this study, families like yours who were referred for weight management are being recruited in Vancouver, Edmonton, Hamilton and Montreal. We want to ask you about your experiences and needs related to weight management. We also want to learn about what influenced your decision to attend (or not attend) the PCWH. Your answers will help us to make our program as good as possible, and will also help families who attend our program in the future

For participating in this study, your family will receive a **$100 gift card** as a token of our appreciation.

Interested in participating? Questions?
Please contact Jasmine Dhaliwal (Graduate Student):
dh4@ualberta.ca or 780-342-8449

Principal Investigator: Dr. Geoff Ball, Asst Professor, Dept of Pediatrics, University of Alberta; 780-342-8465 (phone); gdball@ualberta.ca

Appendix B: Study Protocol

STUDY PROTOCOL

STUDY GROUP DEFINITONS

1. **Continuers (n=10 families/site)**

   Families that were referred for weight management, have regularly attended clinical appointments for weight management, and are active clients at the weight management centre.

2. **Discontinuers (n=10 families/site)**

   Families that were referred for weight management, attended any number of clinical appointments, but are no longer active clients at the weight management centre.

1.0 RECRUITMENT

1. View “Attendance FIS 8-12”, “FIS Teen Attendance” for 2010 and 2011 (both found in G:\Family Information Session\Attendance) and “2010 onwards Client Intake Tracking” (found in G:\Client Intake Tracking) to generate potential participant list (starting from January 2010).

Re-Recruitment to target specific groups:.

A. To identify Initiators, view latest “Discharged Patients” (found in G:\Client Intake Tracking\Active and Discharged Client Lists”. Start with patients who have been discharged in 2011 and work backwards.

2. Copy patient’s name and group classification into most recent “List of Potential Participants” (found in Z:\Personal\JasmineDhaliwal\Thesis Work\Recruitment\Participant Tracking).

3. Locate patient’s referral information on “Copy of all Ped WW referral 2010-05 to 2011-02” (or appropriate referral information according to date of referral) (Z:\Personal\JasmineDhaliwal\Thesis Work\Referral Info) or chart (if applicable) or Webview to obtain full contact information (full name, address, postal code, city, postal code, province, phone number, email address).

4. Copy this contact information into most recent “List of Potential Participants”.

5. Highlight individuals that are under 10 years of age (born after April 2001) in red – exclude them from this study.

6. Go through list and check to see if there are any siblings. If so, highlight the younger one in green and exclude him/her from this study.

7. Go through list to see if there are any individuals who did not give consent to participating in future studies at the PCWH. If so, highlight those in yellow and exclude from this study.

8. Circulate potential participant list to clinicians at study to identify inappropriate patients. Remove those patients from the list.

9. Using contact information, create Recruitment Packages for each participant.

a. Recruitment package (found in Z:\Personal\JasmineDhaliwal\Thesis Work\Recruitment\Recruitment Package) consists of the most recent versions of "Recruitment Letter" and "Recruitment Poster".

10. Mail *Discontinuers* their recruitment packages. Keep *Continuers'* packages for when they attend next scheduled clinic visit

<u>Steps 11 – 18 apply only to *Discontinuers:*</u>

11. Indicate date (DD/MM/YYYY) the Recruitment Package was sent on most recent "List of Potential Participants".

12. Indicate if response was received (Y/N?), and on what date, on most recent "List of Potential Participants".

13. If an email response is received, respond by asking them to provide some times that you could phone them to talk about research study. Respond to any questions as necessary.

14. If a telephone response is received, read the "Telephone Script" (found in Z:\Personal\Jasmine Dhaliwal\Thesis Work\Recruitment\Telephone Script) to participant. Indicate date (DD/MM/YYYY) telephone script was read, and by whom, on most recent "List of Potential Participants".

15. Provide participant with a list of available dates to schedule an interview appointment. Record this date (DD/MM/YYYY), time and location on most recent "Patient Tracking Sheet". Record interview date (DD/MM/YYYY) on CRF.

16. Ensure you have confirmed who will be attending the appointment and their relationship to the child. Record on CRF.

17. Provide participant the option of receiving PCWH location information (either through email or mail). Explain parking information (information found in Z:\Personal\Jasmine Dhaliwal\Thesis Work\Recruitment\Recruitment Package).

18. Three business days before interview, call participant and confirm date, time and location. At this time, give family parking information and explain how to get to clinic from within building (information found in

Z:\Personal\Jasmine Dhaliwal\Thesis Work\Recruitment\Recruitment Package).

19. If required by family, reschedule interview.

    Steps 20 – 23 apply only to *Continuers:*

20. Record participant's next three scheduled appointments (in DD/MM/YYYY format) in "List of Potential Participants".

21. Coordinate with clinic team to attend one of these appointments (either before or after) in order to recruit participant.

22. Once at appointment, give participant a brief overview of the project. A sample script to follow (called "Continuer Template Verbal Script") can be found in Z:\Personal\JasmineDhaliwal\Thesis Work\Recruitment\Continuer Template Script.

23. Give participant Recruitment Package and indicate you will follow up with them within 3-5 days. Ask them their preferred method of contact and record in "List of Potential Participants". Indicate date (DD/MM/YYYY) recruitment package given on most recent "List of Potential Participants".

24. Call or email participant by following steps 8 – 14.

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25. Assign study ID for parent and child (in XX-YYY-ZZ format) and subject ID from Active and Discharged Client lists (if applicable). Record ID numbers in "List of Potential Participants", "Participant Tracking Sheet". On top right hand corner of CRF, record child and parent's ID numbers. Also record local child and parent ID numbers on CRF.
    a. XX – Study Centre ID (01: Vancouver, 02: Edmonton, 03: Hamilton, 04 – Montreal)
    b. YYY – Assign participants number from 0 to 100 consecutively
    c. ZZ – Only assign to parents of children. A key of codes to assign can be viewed below.

    Example: First family enrolled in study in Vancouver. Parent identifies herself as the adoptive mother.

    Child is assigned as 01-001; Parent is assigned as 01-001-05

Codes for Parental Relationships

Relationship	01	Mother	09	Sister
	02	Father	10	Brother
	03	Step-Mother	11	Grandmother
	04	Step-Father	12	Grandfather
	05	Adoptive Mother	13	Aunt
	06	Adoptive Father	14	Uncle
	07	Foster-mother	15	Cousin
	08	Foster-father		

26. Before interview, record family's contact information and group classification onto CRF from "List of Potential Participants".

27. View client's referral information on Webview or in their clinic chart to obtain child's DOB (DD/MM/YYYY), date of referral (DD/MM/YYYY), date of first clinic appointment (DD/MM/YYYY), and type of intervention provided (if applicable), Record this information under "Referral Information" on the CRF.

28. Use RISE to determine the total number of clinic appointments attended by *Discontinuers* and *Continuers.* The appointments recorded on RISE do not include group-based interventions attended by patients. Record this number under "Referral Information" on the CRF.

29. For families who completed (or withdrew) from the PAC program, record the number of sessions attended using "PAC Pilot Data-Brad-MR_14May10-ATTRITION_KA_17DEC10.xls". If the family cannot be located using this file, go into the G drive\PAC and look for patient specific notes under the year in which they were enrolled in the program. If the patient still cannot be found, ask Kathryn Ambler. Record this information under "Referral Information" on the CRF and into "Participant Tracking Sheet".

30. For families who completed (or withdrew) from SKILZ, go into G drive\SKILZ Program (teen)\Chart Notes & Attendance and look for patient specific notes on attendance. Record this information under "Referral Information" on the CRF and into "Participant Tracking Sheet".

31. Add together the number of individual and group-based appointments attended and record the total under "Referral Information" on the CRF.

32. For *Discontinuers*, discharge information is located in G:\Dr. Referral Letters\Child Letters and G:\Dr. Referral Letters\Teen Letters. Locate

patient's file by name, open up discharge letter and look for reason for discharge. Indicate reason and date (DD/MM/YYYY) on CRF.

33. If the patient is an *Initiator*, take out any questions on the interview guide related to the continuation of care.

2.0 DATA COLLECTION

1. On day of interview, pick up interview package from PCWH. Ensure all items (listed on front of package) are contained within the package. Electronic copies can be found in Z:\Personal\JasmineDhaliwal\Thesis Work\Interviews\Interview Package. Check to see if there is enough battery in recorder for interview. Replace "Child Assent Form" with "Mature Minor Consent Form" if child is 17 years of age or older.

2. Meet with participants at predetermined location and give introduction.

3. Give family consent and assent forms and go through them, line by line.

4. Leave room for 5 minutes for discussion.

5. Come back to room and answer any questions they may have.

6. Get parent and child to sign ALL consent/assent forms and bear witness to signing.
    a. If parent does not give consent for child to interview, still collect information from parent.
    b. Ensure that parent has circled "Yes" for all questions

7. Confirm first page of CRF with parent.

8. Give parent "Demographic Information" section of CRF to fill out (ensure it is complete when they give it back to you).

9. Collect anthropometric information from parent and child. Follow most recent "SISOSIG Height and Weight Measurement Protocol". Record numbers on CRF. Indicate who collected these measurements.

10. Test recorder to ensure it is recording before conducting interview.

11. Follow group-specific "Interview Guide" and conduct interview. If two interviewers are available, conduct child and parent interviews simultaneously in separate rooms. If only one interviewer is available, conduct interviews in the order the family prefers.

12. Give parent "Post Interview" sheet from CRF and go through points.

13. Give parent their gift card and record gift card number. If they did not receive it, indicate why.

14. Conclude interview

15. Complete “Field Note Template”. Record any other thoughts in field note book.

16. Mark interviews as complete/incomplete on most recent “Participant Tracking Sheet”.

17. Record gift card and request for results on most recent “Participant Tracking Sheet”.

18. Record gift card number and who received it in Z:\Personal\JasmineDhaliwal\Thesis Work\Interviews\Gift Card Information.

19. Set up a debriefing session with PI/Co-PI/other RA.

20. Obtain PI/Co-PI’s signature on consent/assent forms.

21. Create copies of consent/assent forms. Create double sided copy for child assent form. Put original into PCWH Study Binder under “Consent/Assent Forms” tab. Mail copy to family. Record in most recent “Participant Tracking Sheet”.

22. Indicate on client’s chart that they have given assent/consent and participated in our study. Record this information on client’s Research Chart Note (brown sheet).

23. Calculate BMI information using height and weight found in “Anthropometric Information” in CRF. Record this data on CRF.

24. Place completed CRF into PCWH Study Binder under “Completed CRF” tab. Mark CRF as complete in most recent “Participant Tracking Sheet”.

25. Place completed “Field Note Template” into PCWH Study Binder under “Field Note Templates” tab. Mark as complete on most recent “Participant Tracking Sheet”.

26. Upload audio file into Z:\Personal\JasmineDhaliwal\Thesis Work\Data Collection\Audio Files. Create a spreadsheet in Excel which will record the file name and the study participant ID.

27. Also upload the file to *CommaPolice* for transcription. Mark as uploaded on most recent "Participant Tracking Sheet". A detailed outline of how to upload files can also be found in the document called "*CommaPolice* Information" under the "IT Info" Tab in the Study Binder.
    a. Go to www.commapolice.com
    b. At the top right hand corner, click on "Login"
    c. Type in username and password
    d. On right hand side of Internet Explorer browser, click on "Page", and then click "Open FTP Site in Windows Explorer".
    e. Enter username and password information again.
    f. A folder called "ftp://ftp.commapolice.com/ - Microsoft Internet Explorer" should appear.
    g. Open up site specific folder.
    h. Drag audio file into site specific folder. Repeat with next audio file.
    i. Wait until it has completed uploading before closing the window.
    j. Email Lauren (Lauren@commapolice.com) telling her you have uploading X number of files.

28. Mark date (DD/MM/YYYY) audio file sent for transcription on CRF.

29. Immediately enter CRF data into *LabKey* database using the "Lists" created in your folder.

    a. Numbers following each question/response indicate the number you should enter into LabKey
    b. If a field is not applicable to the participant, enter 9999 into the appropriate field.
    c. Double check data entry to ensure no fields are left blank.

30. Replace used forms in Recruitment Package with new ones.

3.0 DATA ANALYSIS

1. Regularly check *CommaPolice* for transcribed files. Mark date (DD/MM/YYYY) transcript was received on most recent "Participant Tracking Sheet".

2. Go through transcript and replace all names with pseudonyms (i.e. Site 1, Child 1 or Site 1, Parent 1). Record names and pseudonyms in "Pseudonym Key" found in Z:\Personal\JasmineDhaliwal\Thesis Work\Data Collection.

3. Mark date (DD/MM/YYYY) transcript analyzed on most recent "Participant Tracking Sheet" and on CRF

4. Analyze data using content analysis method.

4.0 SECURITY

1. Password protect “List of Potential Participants”, “Pseudonym Key”, and “Participant Tracking Sheet”.
    a. To do this, click “Save As”. At the bottom right hand corner of the window, click on “Tools” and then “General Options”. Create your passwords. Store them in a secure area.

2. Store Study Binder in a secure area (i.e. locked filing cabinet).

DATA COLLECTION FORM

GROUP CLASSIFICATION (Please check only one):

☐ **DISCONTINUER** (1)
Families that were referred for weight management, attended a few clinical appointments, but are no longer active clients at the weight management centre.

☐ **CONTINUER** (2)
Families that were referred for weight management, have regularly attended clinical appointments for weight management, and are active clients at the weight management centre.

Local Child ID #: _____
Local Caregiver ID #: _____

FAMILY INFORMATION

Caregiver's Relationship to Child/Youth:
☐ Bio Mother (1) ☐ Step-Mother (3) ☐ Adoptive Mother (5) ☐ Grandmother (7)
☐ Bio Father (2) ☐ Step-Father (4) ☐ Adoptive Father (6) ☐ Grandfather (8)
☐ Other (9) (please specify): _____

Caregiver Study ID #: _____

Caregiver's Postal Code (enter as A#A #A#): _____

INTERVIEW INFORMATION

Date of Interview (YYYY-MM-DD):_____

Interview Site (1-Vancouver, 2-Edmonton, 3-Hamilton, 4-Montreal):
_____

Interviewer Name:
_____

☐ Interview Data Sent For Transcription
Date (YYYY-MM-DD): _____

☐ Interview Data Analyzed
Date (YYYY-MM-DD): _____

ANTHROPOMETRIC INFORMATION

Were child anthropometrics measured?

☐ Yes (0) By: _____
☐ No (1) Reason:_____
☐ Self-Report (2)

Were parent anthropometrics measured?

☐ Yes (0) By: _____
☐ No (1) Reason:_____
☐ Self-Report (2)

CHILD

Weight (to nearest 0.1kg): ☐☐☐.☐ kg

Height (to nearest 0.1cm):

Trial 1: ☐☐☐.☐ cm Trial 3: ☐☐☐.☐ cm

Trial 2: ☐☐☐.☐ cm Average: ☐☐☐.☐ cm

BMI (to nearest 0.1kg/m^2): ☐☐☐.☐ kg/m^2

Calculated using Anthropometric Calculator:

BMI Percentile (to nearest 0.1): ☐☐☐.☐

BMI Z-Score (to nearest 0.01) ☐☐☐.☐☐

CAREGIVER

☐☐☐.☐

Weight (to nearest 0.1kg): . kg

Height (to nearest 0.1cm):

Trial 1: ☐☐☐.☐ cm Trial 3: ☐☐☐.☐ cm

Trial 2: ☐☐☐.☐ cm Average: ☐☐☐.☐ cm

BMI (to nearest 0.1kg/m^2): ☐☐☐.☐ kg/m^2

REFERRAL INFORMATION

Date of Referral (YYYY-MM-DD):_____

Date of First Clinic Appointment (excluding information sessions)
(YYYY-MM-DD): _____

Type of Intervention Provided:

- ☐ Group (0)
- ☐ Individual (1)
- ☐ Both (2)

Number of Clinic Appointments (excluding information sessions):
_____

Type of Discharge:
_____

Date of Discharge (YYYY-MM-DD):_____

DEMOGRAPHIC INFORMATION

CHILD
DOB (MM-YYYY):_____
Sex: ☐ Male (0) ☐ Female (1)

CAREGIVER
DOB (MM-YYYY):_____
Sex: ☐ Male (0) ☐ Female (1)

People living in Canada come from many cultural and racial backgrounds. Is the **child**:

☐ White (1)
☐ South Asian (e.g. East Indian, Pakistani, Sri Lankan) (2)
☐ Southeast Asian (e.g. Cambodian, Indonesian, Laotian, Vietnamese) (3)
☐ West Asian (e.g. Afghan, Iranian) (4)
☐ Arab (5)
☐ Chinese (6)
☐ Filipino (7)
☐ Japanese (8)
☐ Korean (9)
☐ Latin American (10)
☐ Black (11)
☐ Aboriginal (Canadian First Nation, N. American Indian, Métis, Inuit) (12)
☐ Other (13), please specify:_____

In what country was the **child** born?

☐ Canada (1)
☐ China (2)
☐ France (3)
☐ Germany (4)
☐ Greece (5)
☐ Guyana (6)
☐ Hong Kong (7)
☐ India (8)
☐ Italy (9)
☐ Jamaica (10)
☐ Netherlands/Holland (11)
☐ Philippines (12)
☐ Poland (13)
☐ Portugal (14)
☐ United States (15)
☐ Vietnam (16)
☐ Sri Lanka (17)
☐ United Kingdom (18)
☐ Hungary (19)
☐ Other (20), please specify: _____

People living in Canada come from many cultural and racial backgrounds. Is the **caregiver**:

☐ White (1)
☐ South Asian (e.g. East Indian, Pakistani, Sri Lankan) (2)
☐ Southeast Asian (e.g. Cambodian, Indonesian, Laotian, Vietnamese) (3)
☐ West Asian (e.g. Afghan, Iranian) (4)
☐ Arab (5)
☐ Chinese (6)
☐ Filipino (7)
☐ Japanese (8)
☐ Korean (9)
☐ Latin American (10)
☐ Black (11)
☐ Aboriginal (Canadian First Nation, N. American Indian, Métis, Inuit) (12)
☐ Other (13), please specify:_____

In what country was the **caregiver** born?

☐ Canada (1)
☐ China (2)
☐ France (3)
☐ Germany (4)
☐ Greece (5)
☐ Guyana (6)
☐ Hong Kong (7)
☐ India (8)
☐ Italy (9)
☐ Jamaica (10)
☐ Netherlands/Holland (11)
☐ Philippines (12)
☐ Poland (13)
☐ Portugal (14)
☐ United States (15)
☐ Vietnam (16)
☐ Sri Lanka (17)
☐ United Kingdom (18)
☐ Hungary (19)
☐ Other (20), please specify:_____

Please indicate which category best represents the total annual **household** income from all sources:

☐ Less than $29,999 (1) ☐ $30,000-49,000 (2) ☐$50,000-69,000 (3) ☐ $70,000 – 89,999 (4)
☐ $90,000 – 99,999 (5) ☐ $100,000+ (6) ☐ Prefer not to say (7)

POST INTERVIEW

Would you like to be contacted about the results of this study?

☐ Yes. Please provide your email address: _____

☐ No.

Did you receive your gift card?

☐ Yes.

Parent Signature: _____

Date: _____

Researcher Signature: _____

Date: _____

Card number: _____

☐ No. Why not? _____

Interview Guide for Parents and Children

QUESTIONS:	PARENT	CHILD
Factors Related to the Initiation of Care		
Intro	- What do you know about the clinic? - How long have you been at the clinic? - What program are you in? - How are you liking it?	- What do you know about the PCWH? - Have you been here before?
Q1. Referral	-First of all, I would like you to think back to when <insert child's name> was referred to <insert clinic name> - What prompted the referral? - Who referred you? What did they say? - Did you know about the clinic beforehand? Where did you learn about it? - Did your physician know about the clinic? - Do you remember anything else about your discussions with your health care professional? - What information did you receive about the referral and next steps? - What happened after the referral?	- Okay, first I want you to think back to the time when you were told you needed to attend the <insert clinic name> -Who told you that you needed to go? (or Who told your mom/dad that you needed to go?) - What did they say? - What did your mom/dad say? - Did the doctor make it clear to you what to do to begin the program? - Do you remember how they told you about the <insert clinic name>? Did they show you a website, brochure, pictures, or did they just tell you?

	- How helpful was the Family Information Session? - How long did you have to wait between your first clinic appointment and the information session? - How did they share this information with you (verbal, brochure, email, website, etc)? - What kind of information would be most helpful for you and your family? -During the referral, how did you feel at that moment? *Probe for examples* -Was there anything positive or negative about the referral process that stood out to you? -*Probe for details and reasons* - Was there anything that your health care professional could have done better? If they didn't follow up, was there anything they could have done to change your mind?	- How did you feel when you got referred? *Probe for examples*
Q2. Child	-How did your child respond to the referral process? *Probe for examples* - Did <insert child's name> behaviour change in any way?	- How did you feel about starting here? *Probe for examples* - What did you think about it? - How did you cope? Did you try anything

		that helped you cope? - Did your mom/dad do anything that helped you cope? *Probe for examples*
Q3. Parent	- Was it your decision, or your child's, to come to the clinic? - Was he/she reluctant to come to the clinic? -Please describe why you decided (or not) to go to <insert clinic name> - What influenced you? Was there something or someone? Where there any personal or individual factors that influenced your decision? How motivated were you to come to the clinic? Were you ready to make healthy lifestyle changes at home? Did you have any expectations before coming to the clinic?	- What were your reasons for wanting to be in this program? - What made you want to come? -Who made the final decision – you or your mom/dad? - Could anyone have changed your mind? (for non-initiators and initiators) *Probe for examples* - - Were you ready to make changes to your lifestyle? Why or why not? *Probe for details* - What did you think the program could help you with? *Probe for details*
Q4. Family Members	- Did you tell other family members that <insert child's name> was referred to <insert clinic name>? - Why or why not? *Probe for details*	- Did you tell anyone that you were told to go to <insert clinic name>? - Did you tell your brother/sister about it? - What about conversations with your

	- What were their reactions? *Probe for examples* - Did any of them affect your decision?	mom/dad? - Why or why not? *Probe for details* - What did they say? How did they react? *Probe for examples*
Q5. Parent History	- I'd like you to describe your own experiences with making healthy lifestyle change before coming to the clinic -What have you tried in the past? Did it work? - Was there anything else you could have done? - What challenges did you face on your own when trying to make healthy lifestyle changes? *Probe for examples* - What challenges did you face as a family when trying to make healthy lifestyle changes? *Probe for examples*	Have you tried anything in the past to lose weight? Did it work? - Did you try to make any healthy lifestyle changes at home? - What were the most challenging things about that? *Probe for details* - Did you get support from other people? Did it make it easier or harder? *Probe for details*
Q7. Overview	- In your opinion, what do you think would help other families want to attend <insert clinic name>? *Probe for examples* - Is there anything about the <insert clinic name> that you'd like to change? What would	- What do you think would help other children want to attend <insert clinic name>? *Probe for examples* - Can the doctors do a better job? Is there anything about your doctor that you'd like to change?

	make your experience at <insert clinic name> better? *Probe for examples* - Are there things that health care professionals could do to make it easier to initiate care? *Probe for examples*	*Probe for examples* - Is there anything about the <insert clinic name> that you'd like to change? What would make your experience at <insert clinic name> better? *Probe for examples*
Factors Related to the Continuation of Care		
Q8. Challenges/ Successes	- Was it your decision to continue care at the clinic, or your child's? - What motivated you to keep coming back? - What motivated <insert child's name> to keep coming back? - Did your child experience any challenges during the program that influenced your decision to continue care? *Probe for examples i.e. about achieving goals* - Were there times where you really didn't want to come to the clinic? - Where there times where you really did want to come to the clinic? - Did your child experience any successes that influenced your decision to continue care? *Probe for examples* - Did your family experience any challenges	- Can you explain what you've done here? How have the clinicians helped you? - Did you experience any challenges or successes that made you want to continue/discontinue care? - What were the staff at the clinic like? How were they helpful? - Did your family members affect your decision to continue/discontinue care? - Did your friends affect your decision to continue/discontinue care? - Were there other things, like having too much homework, the weather, being sick, etc, that made it hard for you to come to the clinic? *Probe for details* - Were there times when you didn't want to come? How come?

	that influenced your decision to continue care? - Did your family experience or successes that influenced your decision to continue care? - Did new health care concerns or improvements influence your decision? - Did any weight gain or loss influence your decision? - Did any occupation changes influence your decision? - Did moving influence your decision? - Did the amount of free time you have at home influence your decision? - Did the people at <insert clinic name> influence your decision to continue? - Did you have any positive or negative interactions with the clinic staff? *Probe for examples* - Did the people at <insert clinic name> influence your child's decision to continue? *Probe for examples* - Did any family members influence your decision to continue? How?	

	Probe for examples - Did any family members influence your child's decision to continue? How? *Probe for examples* - Have you told your co-workers or friends about <insert child's name> being referred to the clinic? - What were their reactions? - Have they influenced your decision to continue? How? *Probe for examples* - Has <insert child's name> told her friends about her coming to the clinic? Have they influenced his/her decision to continue care? How? *Probe for examples* - Were there other factors like work, weather, timing, parking, child's homework, weight loss progress, etc that affected your decision? How? *Probe for examples* - Were there other factors like work, weather, timing, child's homework, weight loss progress, etc that affected your child's decision? How? *Probe for examples*	

Q9. Strengths/Weaknesses	- What were the strengths of the program? - Could you describe the atmosphere of the clinic. - Did you think you received enough information during the program? During one-on-one sessions? - What kind of educational resources did you receive? - Did you like them? Did they teach you anything? What did they teach you? - Have you tried implementing this information at home? Did it work? - Would you have liked additional information? About what? - Have you had a lot of support from the clinicians? How have they supported you? Have they encouraged you or <insert child's name>? How? - Have you experienced any health benefits (real or perceived) from being at the clinic? Has your child experienced any health benefits? Were your expectations met?	- What did you like about the program when you were in it? *Probe for examples related to educational resources, professional support and relationships, positive rapport, encouragement, health benefits (real or perceived), expectations (met and unmet), etc.* - What didn't you like about the program? *Probe for examples related to the lack of educational resources, professional support and relationships, positive rapport, encouragement, health benefits (real or perceived), expectations (met and unmet), etc.*

	-What were the weaknesses of the program (probe for examples)? Was there anything you were unhappy with? *Probe for examples related to the lack of educational resources, professional support and relationships, positive rappart, encouragement, health benefits (real or perceived), expectations (met and unmet), etc.*	
Q10. Overview	- In your opinion, what do you think would help other families want to stick with the program? - Is there anything the people at <insert clinic name>, or your doctor, could have done to make it easier to stay in the program for a long period of time? *Probe for examples regarding timing and duration of appointments, parking, transportation, additional resources, etc*	-What do you think would help other children want to keep attending the program? -Is there anything the people at <insert clinic name> or your doctor could have done to make you want to stay longer?
Summary	- Is there anything else you would like to add about what influenced your decision to come to the clinic?	Is there anything else you would like to add?

Reflection Questionnaire

Date: _____Time: _____

Location: _____

File you recorded the interview (EG. Folder A, File 1, 2, 3): _____

Who did you interview? _____

The conversation from the initial phone call to set up the interview:

The conversations that took place before and after the interview:

Description of the surroundings during your interview:

Questions asked by the participant.:

Your feelings about how well you were received:

Any emerging feelings about the interview experience in general:

Observations you think are important to highlight for this study:

Notes for next time:

Appendix C: Data Matrix of Results from Qualitative Study

Data results from *Continuers* organized by theme

Family Factors

ID#	Motivating Factors	Decision-Making Roles
02-001 (Child)	Coming to the clinic is a commitment	Receives support from family members Does not share clinic experiences with siblings Child attends clinic because his/her parent wants them to
02-001-01 (Parent)	Progress provides motivation	Shared clinic experiences with co-workers/friends but did not impact decision-making Shared clinic experiences with family; received support but did not impact decision-making Parent's decision to continue care at the clinic
02-002	Progress provides motivation Main reason to attend is to become healthy Evaluating progress provides motivation	Shared clinic experiences with friend(s) but did not impact decision-making
02-002-01	Progress provides motivation Main reason to attend is for child to become healthy	
02-003	Coming to the clinic is a commitment Motivation to attend is to prove to parent he/she is healthy	Did not share clinic experiences with friend(s) Does not share clinic experiences with siblings Child attends clinic because his/her parent wants them to
02-003-01	Child is not overly resistant to coming to the clinic Lack of progress (no weight loss) makes it difficult to continue care Continue care in the hope "it will click" Main reason to attend is for child to become healthy Program benefits parent	Did not share clinic experiences with co-workers/friends but did not impact decision-making Shared clinic experiences with family; received support but did not impact decision-making Parent's decision to continue care at the clinic
02-004	Progress provides motivation Evaluating progress provides motivation	
02-004-01	Coming to the clinic is a commitment Child is not overly resistant to coming to the clinic Main reason to attend is for child to become healthy Progress provides motivation	Shared clinic experiences with co-workers/friends but did not impact decision-making Shared clinic experiences with family; received support but did not impact decision-making
02-005	Progress provides motivation Evaluating progress provides motivation	Did not share clinic experiences with friend(s) Does not share clinic experiences with siblings
02-005-01	Progress provides motivation Evaluating progress provides motivation	Shared clinic experiences with co-workers/friends but did not impact decision-making Shared clinic experiences with family; received support but did not impact decision-making Parent's decision to continue care at the clinic
02-006	Coming to the clinic is a commitment Progress provides motivation Evaluating progress provides motivation	
02-006-02	Progress provides motivation	Shared clinic experiences with co-workers/friends but did not impact

	Program benefits parent	decision-making Shared clinic experiences with family but did not impact decision-making Parent's decision to continue care at the clinic
02-007	Child is not overly resistant to coming to the clinic Progress provides motivation Main reason to attend is to become healthy	Shared clinic experiences with friend(s) Does not share clinic experiences with siblings Shared clinic experiences with family but does not receive support Parent's decision to continue care at the clinic
02-007-03	Coming to the clinic is a commitment Child is not overly resistant to coming to the clinic Lack of progress (no weight loss or changes in behaviour) makes it difficult to continue care Continue care in the hope "it will click"	Shared clinic experiences with family but does not receive support and does not impact decision-making Parent's decision to continue care at the clinic
02-008		
02-008-02	Child is not overly resistant to coming to the clinic Progress provides motivation	
02-009	Progress provides motivation	Child attends clinic because his/her parent wants them to
02-009-01	Child is not overly resistant to coming to the clinic Main reason to attend is for child to become healthy Progress provides motivation Program benefits parent Evaluating progress provides motivation	Shared clinic experiences with co-workers/friends but did not impact decision-making
02-010		Shared clinic experiences with friend(s) Did not share clinic experiences with family Coming to the clinic was the child's decision
02-010-01	Child is not overly resistant to coming to the clinic Progress provides motivation for child Program doesn't benefit parent so it makes it difficult to continue care	Did not share clinic experiences with family

Logistical Factors

ID#	Parking Costs	Distance	Scheduling	Weather
02-001 (Child)				
02-001-01 (Parent)	Parking is expensive Use strategies to deal with cost	Location is inconvenient for family (≥1hr drive)	Child had to miss school to attend clinic Appointments have not negatively impacted child's schooling Work provides flexibility for taking time off to attend appointments Family has to juggle home life Prioritizing Care	Did not impact family even when weather conditions were not ideal
02-002				
02-002-01	Parking is expensive Use strategies to deal with cost		Changes to days/times clinic is held Child is not in traditional school system	Did not impact family even when weather conditions were not ideal
02-003			Changes to days/ times clinic is held Child had to miss school to attend clinic	
02-003-01		Location is convenient for family	Child had to miss school to attend clinic Appointments negatively impacted child's schooling Family has to juggle home life Prioritizing Care	
02-004				
02-004-01	Parking is expensive Use strategies to deal with cost	Location is inconvenient for family (≥1hr drive) Recognizes that location is convenient for families in city	Child had to miss school to attend clinic Appointments negatively impacted child's schooling Work provides flexibility for taking time off Family does not find it difficult to juggle home life Prioritizing Care	Did not impact family even when weather conditions were not ideal
02-005	Parking is expensive		Parents' work hours make it difficult to attend appointments	
02-005-01	Parking is expensive	Location is convenient for family Recognizes that location may be inconvenient for families located out of town	Changes to days/times clinic is held Appointments have not negatively impacted child's schooling	
02-006				
02-006-02	Cost of parking is not an issue	Location is convenient for family	Child had to miss school to attend clinic Appointments have not negatively impacted child's schooling Parents' work hours make it difficult to attend appointments Family has to juggle home life Prioritizing Care	Did not impact family even when weather conditions were not ideal

02-007			Prioritizing Care	
02-007-03	Parking is expensive Use strategies to deal with cost		Child does not miss school to attend clinic Family has to juggle home life Prioritizing Care	Did not impact family even when weather conditions were not ideal
02-008				
02-008-02		Location is inconvenient for family (≥1hr drive)	Child is not in traditional school system Prioritizing Care	Did not impact family even when weather conditions were not ideal
02-009			Parents' work hours make it difficult to attend appointments	
02-009-01	Parking is expensive		No changes to days/times clinic is held Family has to juggle home life Prioritizing Care	Did not impact family even when weather conditions were not ideal
02-010			Child had to miss school to attend clinic Appointments negatively impacted child's schooling	Did not impact family even when weather conditions were not ideal
02-010-01	Cost of parking is not an issue		Changes to days/times clinic is held Work provides flexibility for taking time Prioritizing Care	Did not impact family even when weather conditions were not ideal

Health Services Factors

ID#	Access to care	Facility attributes	Program & appointment length	Menu of services available	Quality of Services	Relationships with clinicians	Care *vs.* expectations
02-001 (Child)			Open-ended duration		Enjoys parental involvement No change needed to program Manageable steps towards achieving goals Received helpful personalized information	Clinicians are encouraging Clinicians provided extra support Good relationship with clinicians	Becoming healthier
02-001-01 (Parent)		Aesthetics of building are not important Elevators take a long time	Appointment length is fine	Enjoys flexibility in individual vs group care	Multidisciplinary approach to care Generates awareness of healthy behaviours Clinicians worked as a team Lack of feedback from clinicians to family Received helpful personalized information	Clinicians provided extra support Good relationship with clinicians	No prior expectations Becoming healthier (weight loss, positive medical changes) Positive expectations met
02-002					Generates awareness of healthy behaviours Wants kid involvement in PAC Received helpful personalized information	Clinicians are encouraging Games used as teaching tools Good relationship with clinicians Clinicians made child feel safe	Expected clinicians to be judgemental
02-002-01	Did not know family could have access to clinicians during PAC		Open-ended duration	Was not aware individualized care alone existed Wants group option for child	Positive clinic atmosphere PAC was generic Received helpful personalized information	Psychologist was important Clinicians are encouraging Good relationship with clinicians Clinicians emphasize small improvements Clinicians provided extra support	No prior expectations Becoming healthier (positive medical changes) Positive expectations met
02-003					No change needed to program Manageable steps towards achieving goals	Good relationship with clinicians	

					Received helpful personalized information		
02-003-01				Lack of group services for child outside city	Not enough parental involvement Desires more structure to the program Clinicians did not work as a team Did not receive helpful information Lacking measurements of success	Psychologist was important Clinicians are supportive Accountability towards clinicians provides motivation Clinicians made child feel safe	More psychological counselling Positive expectations were not met Child expected clinicians to be judgemental
02-004		Enjoys fitness room			Manageable steps towards achieving goals	Clinicians made child feel safe	Expected clinicians to be judgemental
02-004-01				Enjoys group care Lack of group services for child outside city	Too much parental involvement Positive clinic atmosphere Did not receive helpful information Wants kid involvement in PAC PAC was generic	Clinicians are encouraging Clinicians are supportive	More focus on child rather than child and parent Becoming healthier (weight loss) Positive expectations were not met
02-005			Long appointment length	Enjoys flexibility in individual vs group care	No change needed to program Manageable steps towards achieving goals Received helpful personalized information	Clinicians are encouraging Clinicians are supportive Accountability towards clinicians provides motivation	Becoming healthier (weight loss, positive medical changes) Positive expectations met
02-005-01			Frequency of appointments is fine	Want more services available for family rather than child alone Wants group services for child to meet other children Support services involving success stories	Manageable steps towards achieving goals Received helpful personalized information	Clinicians are encouraging Good relationship with clinicians Clinicians emphasize small improvements Clinicians are supportive Accountability towards clinicians provides motivation	Support Positive expectations met

02-006				Enjoyed Active Start and meeting other children like her	Dislikes blood tests Generates awareness of healthy behaviours Wants kid involvement in PAC	Psychologist was important Good relationship with clinicians Clinicians are supportive Clinicians made child feel safe	Being told what to do Becoming healthier (weight loss) Expected clinicians to be judgemental
02-006-02			PAC program was long		Child dislikes blood tests Positive clinic atmosphere Generates awareness of healthy behaviours Multidisciplinary approach to care PAC was generic	Clinicians are supportive	No prior expectations
02-007			Frequency of appointments is fine	Enjoys cooking classes Enjoys meeting other children	Received helpful personalized information		Being told what to do, boring Negative expectations were not met
02-007-03				Want more services available for family rather than child alone	Not enough parental involvement More options/feedback for blended families Did not receive helpful information Lacking measurements of success Lacking accountability	Psychologist was important Clinicians were not encouraging Wants more support from clinicians Tense relationship with clinicians	Becoming healthier (weight loss) Positive expectations were not met
02-008							
02-008-02				Enjoys flexibility in individual vs group care	Enjoys parental involvement Positive clinic atmosphere Manageable steps towards achieving goals Multidisciplinary approach to care Received helpful personalized information	Clinicians provided extra support Accountability towards clinicians provides motivation	
02-009		Elevators take a long time				Clinicians are encouraging	Group with other kids Positive expectations not met

02-009-01				Enjoys flexibility in individual vs group care	Positive clinic atmosphere Received helpful personalized information Generates awareness of healthy behaviours PAC was generic	Clinicians provided extra support	Support Positive expectations met
02-010			Appointment length is fine			Clinicians are encouraging Good relationship with clinicians	More focus on exercise
02-010-01	Wanted clinicians to push to see all clinicians	Aesthetics of building are not important		Prefer weight services for adults Enjoys flexibility in individual vs group care	Enjoys parental involvement Positive clinic atmosphere Greater use of technology Clinicians worked as a team Received helpful personalized information	Clinicians are encouraging Clinicians provided extra support Accountability towards clinicians provides motivation	Multidisciplinary Positive expectations met

Data results from *Discontinuers* organized by theme

Family Factors

ID#	Motivating Factors	Decision-Making Roles
02-014 (Child)	Child resistant to coming to the clinic because of embarrassment Wasn't aware of health conditions and how losing weight could help with that Lack of progress (no weight loss) made it difficult to continue with care Wanted to do it on his/her own	Shared clinic experiences with family; received support and impacted decision-making Didn't share clinic experiences with friends
02-014-01;02-014-02 (Parent)	Lack of progress (no weight loss) made it difficult to continue with care Coming to the clinic was not a commitment for child Child motivation lacking Child wanted to do it on his/her own	Shared clinic experiences with family; received support and did not impact decision-making Parent's decision to come Shared clinic experiences with co-workers but didn't impact decision-making Child's decision to discontinue care
02-015	Was willing to come to clinic	Shared clinic experiences with friends but did not impact decision-making Mom's decision to come Parent-child decision to discontinue
02-015-01	Main reason to attend is for child to become healthy (lose weight) Lack of progress (no weight loss) makes it difficult to continue care Felt they could do it on their own Child lacking motivation	Shared clinic experiences with family; didn't always receive support but did not impact decision-making Shared clinic experiences with friends but did not impact decision-making Parent's decision to continue care Parent-child decision to discontinue
02-017	Wanted to do it on his/her own	Does not share clinic experiences with siblings Didn't share clinic experiences with friends Child's decision to discontinue care
02-017-01	Main reason to attend is for child to become healthy Lack of progress (no weight loss) makes it difficult to continue care Child's motivation was lacking Child wanted to do it on his/her own	Didn't share clinic experiences with family because child felt embarrassed Shared clinic experiences with co-workers/friends but did not impact decision-making Father doesn't know about clinic – would not let child come to clinic Does not share clinic experiences with siblings Parent's decision to continue care Child's decision to discontinue care
02-018		

02-018-01	Coming to the clinic is a commitment Child's motivation was lacking Lack of progress (no weight loss) makes it difficult to continue care Benefits parents	Shared clinic experiences with co-workers but did not impact decision-making Child didn't share clinic experiences with siblings Shared clinic experiences with family; received support but did not impact decision-making
02-019	Main reason to attend is to become healthy Child willing to come Felt they didn't need program anymore (losing weight and blood pressure in control) Parent-child decision to discontinue care	Shared clinic experiences with friends; received support but didn't impact decision-making Mom's decision to continue care
02-019-01	Main reason to attend is for child to become healthy Felt they didn't need program anymore (losing weight and blood pressure in control)	Didn't share clinic experiences with co-workers and didn't impact decision-making Child didn't share clinic experiences with friends Parent's decision to discontinue care
02-020	Lack of progress makes it difficult to continue care	Shared clinic experiences with friends; didn't receive support and didn't impact decision-making Mom's decision to discontinue care
02-020-01	Child willing to come Felt they didn't need program anymore (losing weight) Mother's motivation was lacking because of depression	Shared clinic experiences with family; didn't receive support and didn't impact decision-making Mom's decision to continue care Parent's decision to discontinue care
02-021	Child was not willing to come Program benefits parents Felt they didn't need program anymore (losing weight)	
02-021-01	Main reason to attend is for child to become healthy (lose weight) Child didn't see weight as a problem Felt they didn't need program anymore (lost enough weight) Child was not willing to come Program benefits parents	Shared clinic experiences with family; received support and didn't impact decision-making
02-023	Child was willing to come	Didn't share clinic experiences with siblings Didn't share clinic experiences with friends Parent's decision to discontinue care
02-023-01	Child was willing to come	Shared clinic experiences with family; received support and didn't impact decision-making
02-025		Didn't share clinic experiences with siblings
02-025-01	Didn't think program could help Parent lacking motivation	Parent-child decision to discontinue care

Logistical Factors

ID#	Parking Costs	Distance	Scheduling	Weather
02-014 (Child)				
02-014-01;02-014-02 (Parent)	Cost of parking is not an issue Use strategies to deal with cost		Work does not provide flexibility for taking time off to attend appointments Changes to days/time clinic is held (evenings) Family has to juggle home life Child had to miss school to attend clinic Appointments have not negatively impacted child's schooling Prioritizing care	
02-015				
02-015-01			Attending other appointments made it difficult to come Child had to miss school to attend clinic Booking appointments together	
02-017				
02-017-01	Parking is expensive Cost of parking is not an issue	Location is inconvenient for family (≥1hr drive)	No changes to days/time clinic is held Work provides flexibility for taking time off to attend appointments Child did not have to miss school to attend clinic Appointments have not negatively impacted child's schooling	
02-018				
02-018-01	Parking is expensive Use strategies to deal with cost	Location is convenient for family	No changes to days/time clinic is held Work provides flexibility for taking time off to attend appointments Appointments have not negatively impacted child's schooling	
02-019		Location is inconvenient for family	Child had to miss school to attend clinic Appointments have negatively impacted child's schooling	Did not impact family

02-019-01	Parking is expensive Use strategies to deal with cost	Location is inconvenient for family	Child has to miss school to attend clinic Appointments have negatively impacted child's schooling Booking appointments together Changes to days/time clinic is held (evenings) Does not work Family has to juggle home life Prioritizing care	Did not impact family
02-020			Child did not have to miss school No changes to days/time clinic is held	
02-020-01	Parking is expensive	Location is inconvenient for family Recognizes location is convenient for families living in the city	Does not work No changes to days/time clinic is held Family has to juggle home life Child is not in traditional school system so has flexibility Does not work Depression	Did not impact family even when weather conditions were not ideal
02-021			Child had to miss school to attend clinic	
02-021-01		Location is inconvenient for family	Work does not provide flexibility for taking time off to attend appointments Child had to miss school to attend clinic Prioritizing care	
02-023		Location is inconvenient for family (≥1hr drive)	Child had to miss school to attend clinic Mom is sick	
02-023-01		Location is inconvenient for family (≥1hr drive)	Child had to miss school to attend clinic Appointments did not negatively impact child's schooling Changes to days/time clinic is held (evenings) Cancer treatment	
02-025				
02-025-01	Parking is expensive		Changes to days/time clinic is held (evenings) Work does not provide flexibility for taking time off to attend appointments Family has to juggle home life Child did not have to miss school to attend clinic	

Health Services Factors

ID#	Access to care	Facility	Program & appointment length	Menu of services available	Quality of services	Relationship with clinicians	Care *vs.* expectations
02-014 (Child)					Wanted more structure (i.e., meal plans) More info about consequences	Good relationship with clinicians	Expected clinicians to be judgemental
02-014-01;02-014-02 (Parent)	Earlier enrolment	Want bigger gym	More frequent appointments		Wanted more parental and family involvement Received helpful personalized information More specific exercise information wanted Multidisciplinary Psychology wasn't family based Neutral clinic atmosphere	Clinicians provided extra support Clinicians are encouraging Wanted friendlier relationship with clinicians	No prior expectations Expectations were met
02-015			Too long	Wants group option for kids	Boring	Clinicians provided support	
02-015-01			Appointments were too long	Wants group option for child Support services involving success stories	Too much parental involvement Child found it boring Didn't receive helpful personalized information Too much research based Lack of success rates Lack of feedback Positive clinic atmosphere Didn't like multidisciplinary	Clinicians were not encouraging Good relationship with clinicians	Child expected immediate results Expected more group activities were kids Expected more direct support from clinicians Positive expectations were not met
02-017					Positive clinic atmosphere	Clinicians provided support	
02-017-01	Earlier enrolment (from duration info)				Received helpful personalized information Multidisciplinary No change Positive clinic atmosphere	Clinicians are supportive Good relationship with clinicians	No prior expectations Child expected immediate results
02-018							

02-018-01	Premature discharge			Enjoyed Active Start	Wanted more parental involvement Had problems with how Active Start was run Received helpful personalized information Multidisciplinary Child dislikes blood tests PAC was not helpful Lack of success rates	Wanted more directed care Clinicians were not supportive	Child becoming healthier
02-019			No changes to frequency of appointments	Liked being able to work out alone at the clinic gym	Received helpful personalized information Manageable goal setting More information directed at kids No change	Clinicians are supportive Good relationship with clinicians	Becoming healthier (blood pressure) Expectations were met
02-019-01				Child liked being able to work out alone at the clinic gym	Received helpful personalized information Multidisciplinary Didn't want to see psychologist	Clinicians are supportive Didn't receive extra support Clinicians are encouraging Good relationship with clinicians	No prior expectations
02-020			Appointments were too long		Received helpful personalized information	Clinicians are supportive Good relationship with clinicians clinicians made child feel safe	Expected clinicians to be judgemental
02-020-01					Enjoyed level of parental involvement Received helpful personalized information Multidisciplinary Positive clinic atmosphere	Clinicians are supportive Psychologist was not helpful Didn't receive extra support Clinicians are encouraging Good relationship with clinicians	Learning healthy behaviours
02-021		Old building		Wants more group option for kids	Boring		No prior expectations Expected clinic to be busier

02-021-01	Premature discharge				Enjoyed level of parental involvement Received helpful personalized information Multidisciplinary PAC was helpful Family oriented Positive clinic atmosphere	Clinicians are supportive Received extra support	Expectations were met
02-023		Enjoys "fancy" equipment		Wants more group option for kids	Awareness of healthy behaviours Boring	Child hesitant to attend clinic initially but clinicians made child feel safe	Expected to lose weight
02-023-01		Want bigger gym		Wants more group option for kids	Enjoyed level of parental involvement Received helpful personalized information	Good relationship with clinicians	No prior expectations
02-025					Boring		Expected clinicians to tell you what to do
02-025-01			Time consuming		Enjoyed level of parental involvement More focus on parent Not enough accountability Did not receive helpful personalized information Multidisciplinary Greater focus on exercise Wanted more structure (i.e., plans) Boring	More males Didn't receive enough support	More support More fitness Expectations were not met