

Enrollment in Multidisciplinary Clinical Care for Pediatric Weight Management:
Predictors, Reasons, Facilitators, and Recommendations

by

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Abstract

Background: One-third of Canadian children meet the criteria for overweight or obesity. While multidisciplinary clinical care (MCC) can be effective to manage pediatric obesity, many eligible children are not referred to this level of care and many of those who are referred do not enroll in treatment. This is of concern given the limited effectiveness of alternative options to address obesity in children and the long-term, adverse consequences of excess weight.

Objectives: (i) determining the proportion and the predictors of enrollment in children referred to MCC for pediatric weight management (PWM) (study 1), (ii) exploring parents' reasons for (non)enrollment and facilitators of enrollment in MCC (studies 2 and 3), and (iii) exploring parents' recommendations to enhance enrollment in MCC.

Methods: Studies 1 through 4 were completed between 2013–2017 and applied multiple methods. Study 1 was quantitative and included 2–17 year olds referred to three multidisciplinary clinics for PWM in Alberta between 2013–2016. Studies 2, 3, and 4 included qualitative designs with data collected from parents of children with overweight and obesity referred to MCC for PWM in Vancouver, Edmonton, Hamilton, and Montreal. For study 1, analyses included generalized linear mixed models and multivariate logistic regression; studies 2–4 applied content and thematic analyses.

Results: Study 1 showed that approximately two out of every five children (total n=2,014) referred to MCC for PWM enrolled in treatment. Most children referred and enrolled had severe obesity, were 2–12 years old, and lived in urban areas. Treatment clinic and time between the orientation session attended and the initial appointment booked predicted enrollment. Children's BMI z-score negatively predicted enrollment in children with severe

obesity, but not with their leaner peers. In study 2, parents' (n=18) reasons for not enrolling their children in MCC for PWM were related to not perceiving the need for weight management (*e.g.*, not recognizing a weight problem), not perceiving the need for further actions (*e.g.*, believing that the child already had a healthy lifestyle), perceiving that the recommended care was not the most suitable option (*e.g.*, preferring self-management to address the weight issue), and facing internal and external enrollment barriers (*e.g.*, having scheduling issues). In study 3, reasons for enrollment were related to parents' (n= 65) concerns about their children's weight, health, and emotional well-being, perceived need for external support, and the benefits attributed to the recommended care (*e.g.*, comprehensive assessment of children's physical and mental health). Facilitators of enrollment were related to initiator of the referral (*e.g.*, families asking physicians to refer them to an obesity program), treatment motivation (*e.g.*, physicians highlighting the comparative advantages of the recommended care), and control over enrollment barriers (*e.g.*, parents being able to overcome their children's lack of interest in the recommended care). In study 4, parents (n=79) made several recommendations to enhance enrollment such as increasing enrollment opportunities (*e.g.*, allowing families to self-refer), informing families and primary care providers about availability and characteristics of obesity services (*e.g.*, using websites and brochures to inform the public on obesity services), motivating families for treatment (*e.g.*, sharing successful stories of weight management), avoiding discouragement and making obesity services more appealing to parents and children, and improving families' access to weight management services (*e.g.*, offering families convenient appointment time options).

Conclusions: Many children who can benefit from MCC for weight management are not referred in a timely manner or do not enroll in treatment. Strategies to improve enrollment

should enhance and be tailored to families' readiness for treatment, capitalize on facilitators of enrollment, and address individual, family and contextual barriers to enrollment. The feasibility and effectiveness of parents' recommendations to enhance enrollment in MCC for PWM remain to be examined empirically.

Preface

This thesis is an original work by Arnaldo Jaime Pérez García. The research project, of which this thesis is part, received ethics approval from the University of Alberta Health Research Ethics Board: Project Name “Should I Stay or Should I Go? Understanding Overweight Children and Their Families Referred For and Discontinuing Weight Management Care”, Pro00017713, approved on January 26, 2011; and “Predictors of treatment enrollment in children referred for pediatric weight management in Alberta”, Pro000 58385, approved on March 16, 2016.

Chapter 2 of this thesis is ready to be submitted as Perez A, Kebbe M, Yaskina M, Maximova K, Peng C, Patil T, Nielsen C, Holt N, Ho J, Luca P, Connors A, Bennett T, Brunet Wood K, Baron T, LaFrance R, Godziuk K, Ball G. Predicting enrollment in children referred to multidisciplinary clinical care for weight management in Alberta, Canada. Target journal is Pediatrics. Alongside the mentorship of G. Ball, I was responsible for (i) designing the study, (ii) coordinating data extraction and cleaning, (iii) analyzing the data, and (iv) writing the study manuscript.

Chapter 3 of this thesis has been published as Perez A, Holt N, Gokiart R, Chanoine JP, Legault L, Morrison K, Sharma A, Ball G. Why don't families initiate treatment? A qualitative multicentre study investigating parents' reasons for declining paediatric weight management. Paediatr Child Health 2015;20:179-84. Alongside the mentorship of G. Ball, I was responsible for (i) defining the research question, (ii) designing the study, (iii) analyzing and interpreting the data, and (iv) writing the study manuscript.

Chapter 4 of this thesis has been published as Perez A, Avis J, Holt N, Gokiart R, Chanoine JP, Legault L, Morrison K, Sharma A, Ball G. Why do families enroll in pediatric

weight management? A parental perspective of reasons and facilitators. *Child Care Health Dev.* 2016;42(2):278-87. Alongside the mentorship of G. Ball, I was responsible for (i) defining the research question, (ii) designing the study, (iii) analyzing and interpreting the data, and (iv) writing the study manuscript.

Chapter 5 of this thesis has been submitted for publication as Perez A, Kebbe M, Holt NL, Gokiert R, Chanoine JP, Legault L, Morrison KM, Sharma AM, Ball GDC. Parent recommendations to enhance enrollment in multidisciplinary clinical care for pediatric weight management. *Obesity Research & Clinical Practice* (In Review). Alongside the mentorship of G. Ball, I was responsible for (i) defining the research question, (ii) designing the study, (iii) analyzing and interpreting the data, and (iv) writing the study manuscript.

Appendix A of this thesis has been published as Perez A, Ball GDC. Paradoxically speaking about engagement in pediatric weight management. *Pediatr Obes.* 2017 Feb 16. doi: 10.1111/ijpo.12207. [Epub ahead of print]. Alongside the mentorship of G. Ball, I was responsible for writing this perspective article.

Appendix B of this thesis has been published as Perez A, Ball GDC. Beyond ‘oblivobesity’: Seven myths about parental misperceptions of children’s weight. *Childhood Obesity* 2015;11(6):735-737. Alongside the mentorship of G. Ball, I was responsible for writing this letter to the editor.

Appendix C of this thesis has been published as Ball GDC, Perez Garcia A, Chanoine JP, Morrison KM, Legault L, Sharma AM, Gokiert R, Holt NL. Should I stay or should I go? Understanding families’ decisions regarding initiating, continuing, and terminating health services for managing pediatric obesity: A qualitative study protocol. *BMC Health Services*

Research. 2012;12:486. Alongside the mentorship of G. Ball, I was responsible for writing the first draft of the protocol manuscript.

Dedication

I dedicate this dissertation to my mother Cira D García who wanted me to study medicine and become a doctor. I am sure I honor her memory by having a doctoral degree in medical sciences in the field of pediatrics.

I also dedicate this thesis to my wife Anaida Osoria, my daughter Daniela Pérez, my father Arnaldo Pérez, and my sisters Inelda Pérez, Nilda Hernández, and Ivonne Hernández for their unconditional support, patience, and love.

I will forever be thankful to my supervisor Dr. Geoff Ball for his mentorship and the opportunities for professional growth throughout my PhD studies.

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List of Abbreviations

AHS	Alberta Health Services
BMI	Body Mass Index
CA	Central Access
CIHR	Canadian Institutes of Health Research
MCC	Multidisciplinary Clinical Care
OW	Overweight
OB	Obesity
PCWH	Pediatric Centre for Weight and Health
PWM	Pediatric Weight Management
SO	Severe Obesity
Team ABC ³	Team to Address Bariatric Care in Canadian Children
WCHRI	Women and Children's Health Research Institute

Chapter 1

Introduction

1.1. Overall View of the Research Dissertation

Data from my PhD were derived from two larger, CIHR-funded, multi-center studies. First, the Team to Address Bariatric Care in Canadian Children (Team ABC³) which is an ongoing study that includes 8 inter-related research projects intended to enhance the understanding and management of severe obesity in Canadian children (the Team to Address Bariatric Care in Canadian Children, 2017). Second, the Should I Stay or Should I Go (SISOSIG) study which included 6 inter-related research projects intended to understand and improve the enrollment and retention of physician-referred families in multidisciplinary clinical care (MCC) for pediatric weight management (PWM) across Canada (Ball et al., 2012). My dissertation focuses on *actual enrollment* at this stage of care, operationally defined as attending at least one clinical appointment, excluding the orientation session families are invited to participate to learn about the services that weight management clinics offer. Unlike *intended enrollment* (intention to enroll), which is a common proxy indicator of enrollment in the literature, actual enrollment indicates whether patients actually commenced treatment. Indeed, many families who show interest in obesity interventions do not actually enroll in care (Nguyen et al., 2012).

I conducted four related studies on enrollment (**Table 1.1**) – one quantitative (Study 1) and three qualitative (Studies 2, 3, and 4). Study 1 examined the enrollment of patients referred to MCC for managing pediatric obesity in the province of Alberta from April 2013 to April 2016 and demographic, anthropometric, procedural, and contextual predictors of enrollment. Study 2 explored parents' reasons for not enrolling their children in MCC after being referred to a weight management clinic, while study 3 explored parents' reasons for enrolling their children in MCC

and the factors that facilitated their enrollment. Lastly, study 4 explored parents' recommendations to enhance children's enrollment in MCC for managing pediatric obesity, which is a novel approach given that previous recommendations to enhance enrollment had been primarily made by researchers and did not incorporate families' perspectives.

The four original studies that comprise this paper-based dissertation include two published (Perez et al., 2016; Perez et al., 2015a), one submitted (chapter 5), and another manuscript ready to be submitted (chapter 2). Additionally, three published papers including a perspective article on engagement in PWM (Perez and Ball, 2017), a letter to the editor on weight misperceptions (Perez and Ball, 2015b), and the protocol paper (Ball et al., 2012) are included in appendices.

Throughout this dissertation, readers are advised to pay attention to terminology. For example, in the second study, the term *initiation* was used because this was the term employed in the published protocol paper (Ball et al., 2012) that provided the methodological framework to my doctoral research. In the other studies, the term *enrollment* was used because it referred to a process *versus* a point in time and is more aligned with the literature on patient engagement in PWM. Likewise, the term *tertiary-level care* for pediatric weight management used in initial studies was gradually replaced by *multidisciplinary care* or *multidisciplinary clinical care* to be consistent with the staged approach for treating and managing pediatric obesity (Barlow et al., 2007). In many instances throughout this dissertation, *pediatric weight management* is also employed to refer to multidisciplinary clinical care for managing childhood obesity. Additionally, in my studies, children were referred for MCC for PWM by a number of different health care professionals including physicians (mostly general pediatricians, sub-specialty pediatricians, and family physicians), nurse practitioners, and dietitians. While the terms may vary slightly, in general, I refer to these professionals as 'referral providers' or 'referring clinicians'.

In this introductory chapter, I provide background information about obesity as a chronic condition, obesity management, and patient engagement in obesity interventions, especially enrollment in care, which I understand as an engagement issue along with care-seeking, referral-making, and treatment retention and adherence. I also comment on the ontological, epistemological, and theoretical underpinnings of my doctoral research as well as on the rationale for the studies conducted. This introduction ends with a definition of the overreaching objectives of my dissertation.

1.2. Background

1.2.1. Obesity¹ Etiology, Prevalence, and Consequences

Obesity is a chronic condition characterized by an excess of body fat that results from a disruption of the balance between energy intake and energy expenditure (Lustig, 2001). Dietary, activity, and metabolic factors may cause the disruption of this balance (Sharma & Padwal, 2010), which can originate early in life (Ogden et al., 2012). Any factor that increases energy intake (*e.g.*, saturated fat, large portion size, sugar-sweetened beverages) and decreases energy expenditure (*e.g.*, lack of physical activity, excess sedentary behavior) may cause obesity in the long term (Ebbeling et al., 2002). For practical reasons, excess weight in children (<18 years of age), which includes overweight and obesity, is commonly defined on the basis of age- and gender-specific body mass index (BMI, kg/m²) percentiles as a proxy measure of adiposity. According to these metrics, approximately one-third of children in Canada and the United States are either overweight or obese (BMI \geq 85th percentile) (Rodd & Sharma, 2016; Ogden et al. 2016). Obesity disproportionately affects older, ethnic minority, and low-income children, and has increased in all

¹I appreciate the difference between overweight and obesity, but for the sake of simplicity, I will use the terms “obesity” and “obese” throughout my thesis, and I will differentiate them when necessary.

obesity classes (Skinner et al., 2016). Gender differences have been also reported in the prevalence of obesity. For example, in Canada, boys aged 5 to 11 years are three times more likely to be obese than girls (Roberts et al. 2012).

Higher BMI is associated with increased risk for type 2 diabetes, cardiometabolic risk factors (e.g., high blood pressure, insulin resistance), some types of cancer, joint problems, and respiratory diseases (Ebbeling et al., 2002). Children with obesity are also at higher risk for depression, isolation, negative self-image, low self-esteem, sub-optimal quality of life, and weight stigmatization (Puhl et al., 2013; Modi et al., 2008; Latner & Stunkard, 2003). The high prevalence of obesity also represents a tremendous economic burden for families and health care systems (Withrow & Alter, 2011) and may have contributed to the societal normalization of overweight so that children who meet the criteria for overweight are increasingly viewed as normal weight (Jeffery et al., 2005). Changes in weight norms may be a consequence and a cause of the high prevalence of obesity since weight misperception (Lundahl et al., 2014) has been found to be associated with lack of weight concern and perceived need for weight management (Finne et al., 2009), which negatively affects utilization of weight management services. Because obesity in children is likely to persist into adulthood (Singh et al., 2008) with worsening health consequences (Reilly et al. 2003), the health care system has an important role to play in addressing this issue.

1.2.2. Healthcare Services for Obesity Management: The Staged Approach

While obesity prevention is fundamentally important, especially because efforts to treat obesity have yielded moderate weight outcomes (Reinehr, 2011), my doctoral research focused on obesity management within the health care system. To manage obesity successfully, energy balance must be adjusted so that energy output exceeds energy input for a sustained period of time, which is followed by weight maintenance by remaining in energy balance. However, restoring this

balance is challenging for at least three reasons. First, the environments that most children in developed countries live in promote a sedentary lifestyle and consumption of energy dense foods (August et al., 2008). Second, human physiology is designed to store fat so that any attempt to lose weight will likely activate a series of physiological and neurological mechanisms to regain the weight lost (Greenway, 2015). Third, lifestyle behaviors are modifiable, but once established, are difficult to change (van't Riet, 2011).

Multiple, coordinated levels of care are required to address the complexity of obesity management (Canadian Task Force on Preventive Health Care, 2015). In Canada and the United States, a similar staged approach of increased intensity of treatment (Barlow et al., 2007) is recommended to manage pediatric obesity in clinical settings (**Figure 1.1**). Ideally, patients start at the least intense stage of care for weight management and can be referred to the next stage based on response to treatment, age, health risks, severity of obesity, and motivation for further care. Additional considerations include whether healthcare providers have time and resources or feel prepared to address the weight issue. Patients could also start at a more intense stage if they are motivated and providers judge that the care offered at that level would be beneficial. Improvements in all stages are commonly measured at follow-up visits when it is decided whether to *(i)* continue with the recommended treatment plan, *(ii)* explore alternative courses of action at the same stage, or *(iii)* refer patients to a higher-intensity stage of treatment.

According to the staged approach (Barlow et al., 2007), the first stage includes brief counselling on healthy eating and activity behaviors (*e.g.*, eating fruits and vegetables, minimizing screen time, engaging in physical activity for at least one hour per day) provided by a primary care practitioner (*e.g.*, a family physician) upon recognition of a child's weight issue. Lifestyle habits, motivation for making lifestyle changes, and barriers to treatment are also assessed. Parents and

physicians work together to target specific behaviors and tailor treatment goals to families' values, preferences, and circumstances. Primary care providers are encouraged to use motivational interviewing (Miller, 2010) to enhance families' motivation to implement the target changes and a step-by step approach to foster parents' and children's confidence in meeting treatment goals. However, the limited impact of office-based counselling on weight outcomes suggests that novel approaches may need to be developed to enhance the effectiveness of interventions delivered at primary care settings or that primary care providers should be proactive in referring patients to more intense care for PWM (Sim et al., 2016).

Structured management is the second stage. Care at this stage also focuses on facilitating lifestyle changes, but it is delivered by a specialist in a particular area of weight management (*e.g.*, dietitians, exercise specialists, clinical psychologists) who provides additional support to families. Frequently, children must be referred by their primary care provider to access and enroll in this stage of care.

The third stage is MCC for obesity management, which is coordinated by a team of specialists and is characterized by an increase in intensity of behavioral changes, the frequency of clinical appointments, and the number of health professionals involved (*e.g.*, dietitian, exercise specialist, psychologist, nurse, social worker). Usually, this type of care is family-based and family-centered, offers one-on-one and/or group sessions, and includes nutrition, exercise, and behavioral components. To date, multidisciplinary care has demonstrated to be the most effective treatment option to manage childhood obesity (Canadian Task Force on Preventive Health Care, 2015). To enroll in this care, children with excess weight must be referred by a health professional after assessing whether they have responded appropriately to the previous stages of treatment. For example, in Alberta, primary care providers may refer patients to outpatient nutrition counselling

(stage 2, structured care) or to the Pediatric Centres for Weight and Health (PCWH) (stage 3, multidisciplinary care); some patients referred to outpatient nutrition counselling can be referred subsequently to a PCWH in Calgary and Edmonton.

Tertiary care for obesity management, considered the most intense treatment stage, includes pharmacological (*e.g.*, Orlistat) and surgical intervention (*e.g.*, bariatric surgery) to pediatric patients whose health is seriously compromised and have not responded properly to other interventions that take an exclusive focus on lifestyle and behavioral changes. Indeed, these strategies should be offered as adjuncts to lifestyle modifications and should be limited to exceptional cases (Lau et al., 2007) and to patients who can understand possible risks (Barlow et al., 2007).

A health care-centered approach, however, is not sufficient to address obesity in children due to *(i)* issues related to current availability of and accessibility to weight management services (He et al., 2010) and *(ii)* the challenges that the complexity of obesity has posed on traditional primary care practices structured to address acute and less complicated conditions (Frood et al., 2013). Holistic approaches that integrate responses from various sectors have been suggested (Gortmaker et al., 2011), including the chronic care model (Bodenheimer et al., 2002) that capitalizes on synergistic efforts between the health care system, self-management, and community resources. Holistic approaches increasingly see school and community programs as important complementary resources to clinic-based interventions in the promotion of healthy lifestyles (Grow et al., 2013). These resources are also useful to recruit hard-to-reach target populations and to alleviate logistic barriers to participation in obesity interventions including transportation to and distance from program venues (Perez et al., 2015a).

1.2.3. Patient Engagement in Obesity Management

Having a multi-level system in place is a necessary but insufficient condition to address obesity. The other important condition is the engagement of patients and health professionals in health services for weight management. Patient engagement is commonly understood from a research perspective in which patients are involved in all or some steps of the research process including the definition of the research question and data gathering and analysis (Domecq et al., 2014). Conversely, my doctoral research focused on engagement in obesity-related health services, which has been poorly conceptualized (Nobles et al., 2016). Thus, in the context of my dissertation, I operationally defined engagement in PWM as decisions and actions that may or may not benefit patients from treatment (Perez and Ball, 2017). This definition has three main features. First, it is not limited to patients' engagement and includes the engagement of health professionals, parents, and other family members. Second, engagement decisions can lead to actions or no actions including not enrolling in PWM. Third, unlike prescriptive concepts such as patient activation (Hibbard et al., 2004) and shared decision making (Weston, 2001) that suggest how patients should behave or how healthcare decisions should be made, engagement is a concept that defines a reality to be understood. Optimal engagement of patients in services has been encouraged for several reasons, including *(i)* being an important component of disease prevention and management, along with accessibility to and quality of services, *(ii)* maximizing health outcomes as a result of patients' participation in care, *(iii)* minimizing the demands placed on professionals, and *(iv)* meeting the demands that a less paternalistic health care approach places on patients and their families (Center for Advancing Health, 2010).

Engagement in services for managing pediatric obesity relates to a variety of issues including care-seeking, discussions about weight, delivery of a brief counselling at primary care

settings, referral making, enrollment in obesity services, delivery of structured, multidisciplinary, and tertiary care, and treatment completion and adherence. The level of engagement of patients and health professionals may vary across these issues. For example, it is expected that families of children with obesity are more actively involved in seeking care and deciding whether to enroll in treatment, while primary care providers are more involved in providing brief counselling and making referrals. These engagement issues can be also seen as steps that need to be completed to achieve positive lifestyle and weight management outcomes (Kuhle et al., 2015).

Overall, the engagement of health professionals, patients, and families in PWM is far from optimal. For example, many primary care providers do not or inappropriately assess (*e.g.*, visual recognition) children's weight status (He et al., 2010; Dilley et al., 2007). Physicians have indicated a lack of familiarity with BMI, disagreements with BMI and growth charts as screening tools, and lack of time as barriers to measuring children's weight status (Flower et al., 2007). Also, many primary care physicians (*i*) do not provide counselling to children with obesity (Kraschnewski et al., 2013), (*ii*) refer children to specialized care several years after obesity was initially diagnosed (Quattrin et al., 2005), or (*iii*) do not refer them at all due to several barriers including lack of knowledge about available services, lack of confidence in raising the weight issue, and lack of skills to counsel patients on lifestyle changes (Gerards et al., 2012).

Most research on engagement in PWM relates to treatment enrollment, program/treatment completion (or lack thereof), and adherence. Approximately 50% of patients referred to structured or multidisciplinary care do not enroll in treatment (Shaffer et al., 2016). According to the existing literature, children who are overweight, younger, and male are less likely to enroll in weight management interventions compared with their more overweight, older, and female peers. Reasons for non-enrollment include perceived absence of a weight problem, logistic factors (*e.g.*, time

constraints, distance), and children's lack of interest in the offered program (Finne et al., 2009; Alff et al., 2012). Attrition in PWM, either defined as not completing an initial phase of or not returning to the program, is also high. Approximately 50% of children who enroll in obesity interventions leave care prematurely (Skelton & Beech, 2011). Canadian studies have reported similar levels of attrition in relation to involvement in multidisciplinary obesity services (Avis et al., 2013; Ball et al., 2011). Children categorized as overweight (vs obese), younger (vs older), Caucasian (vs non-Caucasian), and with middle-to-high-income (vs low income) are less likely to discontinue care (Dhaliwal et al., 2014).

The fact that patients enroll in and continue care for obesity management does not necessarily mean that they adhere to treatment recommendations during and after interventions. Ultimately, patients benefit from obesity interventions if they follow health advice. Adherence has been also found to be sub-optimal among patients who completed obesity interventions, especially during the maintenance period (Smith et al., 2015; Straker et al., 2014). For example, Smith and colleagues (2015) found that during a twelve-month maintenance period *(i)* less than half of adolescents adhered to the recommendation of increasing vegetable intake, *(ii)* energy intake remained stable, and *(iii)* saturated fat gradually returned to baseline levels. In the same timeframe, these adolescents also made marginal changes in physical activity and sedentary time (Straker et al., 2014).

Based on the current literature on obesity identification (*e.g.*, having and seeing a primary care provider), diagnosis (*e.g.*, using a BMI growth chart), and management (*e.g.*, providing brief counselling, adhering to treatment) in primary care settings, Kuhle and colleagues (2015) estimated that only 0.6% of Canadian children who are classified as overweight or obese are likely to make lifestyle changes and achieve clinically significant weight loss per year. This estimate

could be even lower since the percentage of patients who do not enroll in treatment after being referred by primary care providers was not included in the analysis.

1.3. Ontological, Epistemological, and Theoretical Underpinnings

My doctoral research is informed by the constructivist-naturalistic paradigm (Guba & Lincoln, 1994), which is useful when applied to the study of social and behavioral phenomena. Ontologically, I believe that an external reality exists, which in the case of the social reality, is intangible, constructed, and multiple. In this regard, I think that the contradiction between an external reality and multiple constructed realities is apparent, since they refer to different epistemological issues, namely whether a reality exists beyond individuals' minds and whether that reality is tangible vs intangible, one vs multiple, and constructed vs given. In my view, there is an external social reality that is made up of multiple socially constructed realities (*e.g.*, parents' perspectives of enrollment in PWM). The external social reality and representations of that reality, both constructed, cannot be understood separately. According to symbolic interactionism, social structures exist, but individuals construct and reproduce them (Blumer, 1969). I also agree with the constructivist viewpoint that reality, whether physical or social, is not fragmented, but complex and interconnected, and is always dynamic and procedural (Charmaz, 2014), so that time cannot be excluded from its interpretation.

Epistemologically, the constructivist paradigm (Guba & Lincoln, 1982) states that research is constructed (*e.g.*, research problems, data, analysis, interpretations) according to researchers' values, preconceptions, and interactions, especially with research participants. Data, for example, are never value- or theory-free regardless of whether the research design was explicitly framed according to a certain theoretical framework. Value systems affecting the inquiry include those of researchers, participants, the chosen paradigm, the selected methodology, and the social, political,

and economic environments within which inquiries occur (Guba & Lincoln, 1982). For example, parents' responses during the interviews conducted in studies 2, 3, and 4 were influenced by the interactions between parents and interviewers, especially the skills, agendas, and experiences that each brought to the interview process. Consequently, these qualitative data, like any data, were never collected or gathered, but made and constructed.

The constructed nature of research suggests that researchers' perspectives need to be taken into consideration as an inherent part of the research reality and examined in a reflexive and critical manner (Charmaz, 2004). From a constructivist viewpoint, the use of strategies such as empirical triangulation, peer debriefing, and member checking (Guba 1981) to enhance credibility of study findings cannot be understood as an effort to be objective in investigating an externally constructed reality, but as attempts to improve a constructed interpretation of a constructed reality. In the strict sense, it is not possible to prove the validity of knowledge and theories because all the means at our disposal are also "sensorially" and cognitively constructed (Glaserfeld, 1995). Theories, however, can work, but that depends on how usefulness is defined and measured (Guba & Lincoln, 1982).

Consistent with constructivist paradigm, I also think that *(i)* realities need to be studied holistically because they are complex and this complexity can neither be reduced to the sum of its parts nor to a few variables in order to make parsimonious explanations of study phenomena, *(ii)* research on social phenomena should aim to produce an idiographic body of knowledge (vs. a nomothetic one) in terms of "working hypothesis" due to its historical, contextual, and situational determinations, *(iii)* data analysis iteratively influences data collection and vice versa; both influence and are influenced by the research design so that the research design can also emerge during the research process and not necessarily need to be fully defined prior to the onset of the

inquiry, (iv) researchers and participants always interact and affect one another; this interactivity is not only unavoidable, but potentially beneficial since it may provide researchers with new insights into the study design and phenomenon, and (v) causality in social phenomena (e.g., health decisions) may be better understood, not as regular associations between events, but as an interplay of influences that interact with one another simultaneously and reciprocally, linking events and outcomes.

None of the studies conducted in my doctoral research were formally framed within a specific theoretical framework due to (i) the constraints of the quantitative data collected through referral forms and clinic records (study 1) and (ii) the inductive qualitative analysis performed (studies 2, 3, and 4). For example, data available for study 1 did not include motivational factors known to influence enrollment such as perceived weight status, weight concern, and perceived participation barriers. However, findings from all four studies were discussed from the perspective of prominent health behavior theories including Social Cognitive Theory (Bandura, 1982), Theory of Planned Behavior (Ajzen, 1991), and the Integrative Behavioral Model (Fishbein et al., 2001). I also borrowed constructs from the behavioral literature to label factors underlying parents' decisions to enroll or not to enroll their children in PWM, especially when those constructs accurately captured my interpretation of parents' remarks.

1.4. Rationale for the Studies and the Chosen Perspective

1.4.1. Rationale for Conducting the Included Studies

At the onset of my PhD training, I was asked to develop my research dissertation based on a CIHR-funded operating grant (Ball et al., 2012). As mentioned at the beginning of the introduction, this multi-site research sought to shed light on factors underlying the decision to enroll, continue, and terminate care for managing pediatric obesity. After a preliminary

examination of the literature on patient engagement in PWM, I realized that (i) several quantitative, qualitative, and systematic review studies had been conducted on retention or the lack thereof (attrition), (ii) little was known about enrollment in weight management interventions, although clinical experiences suggested that many patients referred to these interventions did not enroll in treatment, and (iii) most studies on enrollment had explored this issue in relation to research (e.g., participation in clinical trials) rather than health services. Consequently, these issues led me to undertake my doctoral research to understand enrollment in multidisciplinary services for managing childhood obesity.

Later on in my doctoral research, I found additional reasons for examining enrollment in obesity services in a more comprehensive manner. For example, patient engagement in general and patient enrollment in particular, have been poorly conceptualized. Most studies either did not provide definitions or provided operational definitions only. Conceptual clarity was also needed since terms such as *recruitment*, *enrollment*, *participation*, *initiation*, *attendance*, and *engagement* were used interchangeably. Particularly, enrollment levels, and consequently, factors associated with enrollment, had been determined primarily in relation to obesity research, and in many cases, enrollment was defined as the intention to enroll as opposed to actual enrollment. To the best of my knowledge, only one study (Shaffer et al., 2016) has so far examined factors associated with actual enrollment in MCC for PWM, which suggests that replicability and data from other contexts are necessary. This study, however, did not examine enrollment-related factors (e.g., referring physician, length of the enrollment), which can also predict and influence enrollment.

Additionally, most studies on enrollment were quantitative and cross-sectional; of the few qualitative studies conducted, most tended to focus on reasons for (non)enrollment, so that little was known about enablers of enrollment beyond motivation for treatment of parents and children

to whom weight management interventions had been offered (Gillespie et al, 2015). Further research gaps in the qualitative literature on enrollment include insufficient knowledge on children's perspectives of the decision to enroll and families' perspectives on strategies to enhance enrollment in weight management interventions (Perez et al., 2017). This is an important gap since to date, most recommendations to improve enrollment have been suggested by researchers who have indirectly derived them from variables associated with and reasons for (non)enrollment.

1.4.2. Rationale for Exploring the Parental Perspective

A premise upon which my research dissertation is built is that the health and weight status of children with overweight or obesity can be improved if weight management interventions and patients' engagement are also improved. Patients' perspectives, which in my studies includes parents' and families' perspectives, are important sources of information that can be used to enhance both services and engagement. Initially, I was interested in exploring the perspectives of parents and children regarding enrollment reasons, facilitators, and recommendations. However, the qualitative data collected from children were not sufficient to provide insights into their views of enrollment, which was acknowledged as an important limitation in my three qualitative studies. Children's perspectives are important because their motivation for treatment (or the lack thereof) can facilitate or impede enrollment (Perez et al., 2016; Perez et al., 2015). Knowing children's motivation allows service providers to tailor interventions to children's expectations and interests, which has been suggested as a way to enhance enrollment and retention (Holt et al., 2015). Conversely, a substantial amount of qualitative data were collected about parents' perspectives of enrollment that allowed me to explore these perspectives deeply at the level of the meanings underlying parents' decisions to enroll or not enroll their children in MCC for PWM. Parents'

perspectives on enrollment are vitally important given that parents play a key role in seeking care and supporting initial and continued attendance (Golan & Crow, 2004).

In the context of PWM, qualitative research designs have been suggested to explore families' perspectives as a way to understand their decisions and actions (Oude Luttikhuis et al., 2009). Such designs have also been recommended when there is a scant literature on the study phenomenon (Maxwell & Loomis, 2003). Consequently, three of the four studies included in my dissertation are qualitative, a type of inquiry that is suitable to understand individuals' perspectives and behaviors in situated contexts; the nascent literature on enrollment and the importance of families' input to improve the engagement of pediatric patients are also valid justifications for my health services research in PWM. Thus, it is important to highlight that in studies 2 and 3, parents' perspectives were explored to understand enrollment from an ontological viewpoint, that is, as a phenomenon to be understood, while in study 4, parents' perspectives were explored as a source of insights into enhancing enrollment in MCC for PWM.

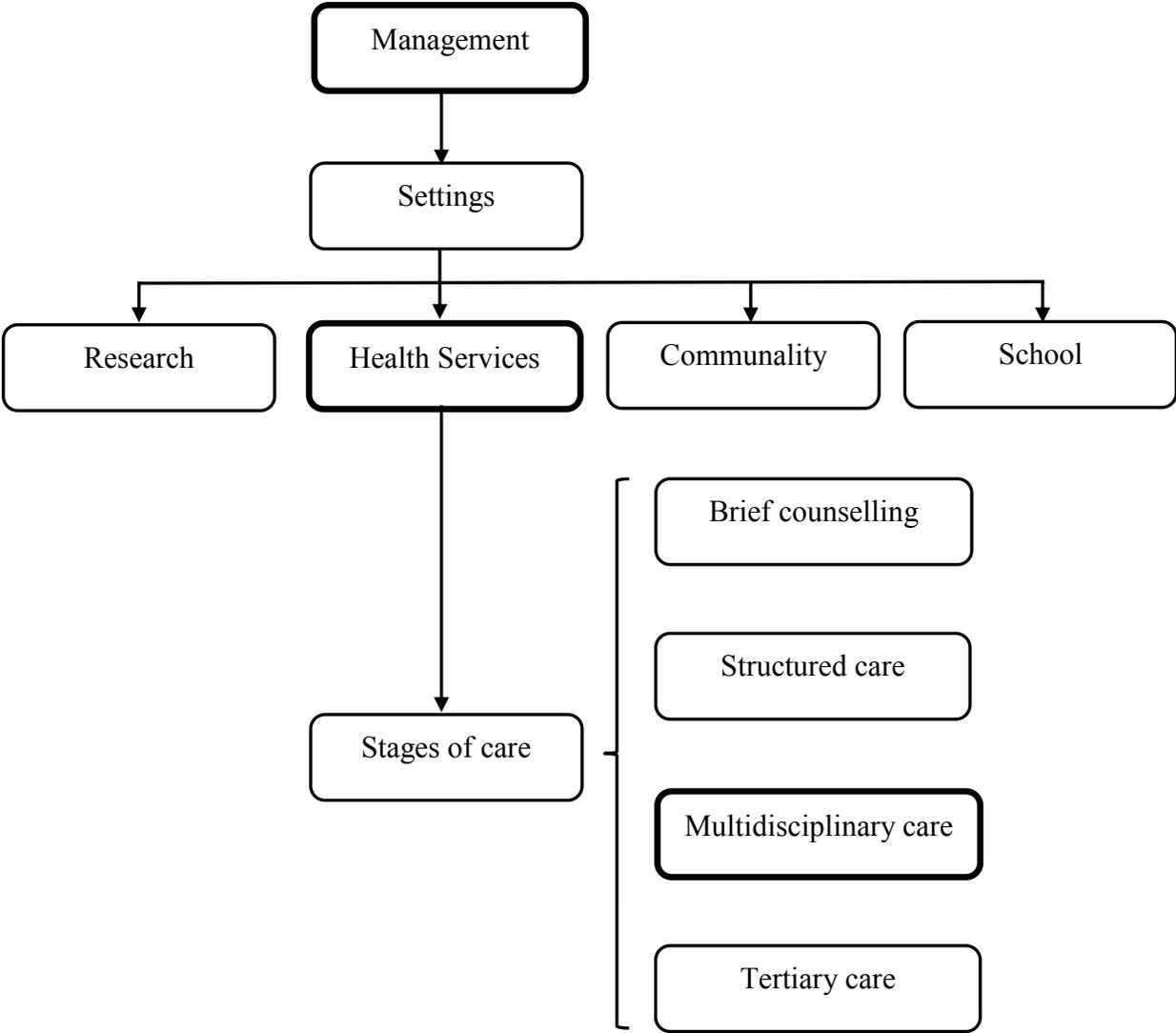
1.5. Overarching Objectives

- (i)* To determine enrollment and predictors of enrollment in patients referred to MCC for PWM in Alberta, Canada.
- (ii)* To understand parents' perspectives regarding reasons for (non)enrollment and facilitators of enrollment in MCC for PWM in Canada.
- (iii)* To explore parents' recommendations to enhance enrollment in MCC for PWM in Canada.

Table 1.1. Studies conducted.

Study	Focus	Design	Status
1	Predictors of enrollment	Quantitative	Ready for submission
2	Reasons for non-enrollment	Qualitative	Published
3	Reasons for and facilitators of enrollment	Qualitative	Published
3	Recommendations to enhance enrollment	Qualitative	Submitted

Figure 1.1. Stages of care for pediatric weight management within the health care system.



References

- Ajzen, I. The theory of planned behavior. *Organ Behav Hum* 1991;50:179–211.
- Alff F, Markert J, Zschaler S, Gausche R, Kiess W, Blüher S. Reasons for (non)participating in a telephone-based intervention program for families with overweight children. *PLoS One* 2012;7:e34580.
- August GP, Caprio S, Fennoy I, Freemark M, Kaufman FR, Lustig RH, Silverstein JH, Speiser PW, Styne DM, Montori VM. Prevention and treatment of pediatric obesity: an endocrine society clinical practice guideline based on expert opinion. *J Clin Endocrinol Metab* 2008;93:4576–4599.
- Avis JL, Ambler KA, Jetha MM, Boateng H, Ball GD. Modest treatment effects and high program attrition: the impact of interdisciplinary, individualized care for managing paediatric obesity. *Paediatr Child Health* 2013;18:e59–e63.
- Ball GDC, Perez Garcia A, Chanoine JP, Morrison KM, Legault L, Sharma AM, Gokiert R, Holt NL. Should I stay or should I go? Understanding families' decisions regarding initiating, continuing, and terminating health services for managing pediatric obesity: A qualitative study protocol. *BMC Health Serv Res* 2012;12:486.
- Ball GD, Mackenzie-Rife KA, Newton MS, Alloway CA, Slack JM, Plotnikoff RC, Goran MI. 2011. One-on-one lifestyle coaching for managing adolescent obesity: findings from a pilot, randomized controlled trial in a real-world, clinical setting. *Paediatr Child Health* 2011;16:345–350.
- Bandura, A. Self-efficacy mechanism in human agency. *Am Psychol* 1982;37:122–147.

- Barlow SE; Expert Committee. Expert committee recommendations regarding the prevention, assessment, and treatment of child and adolescent overweight and obesity: summary report. *Pediatrics* 2007;120 Suppl 4:S164–192.
- Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness. *JAMA* 2002;288:1775–1779.
- Blumer H. *Symbolic interactionism: perspective and method*. Englewood Cliffs, NJ: Prentice Hall; 1969.
- Canadian Task Force on Preventive Health Care. Recommendations for growth monitoring, and prevention and management of overweight and obesity in children and youth in primary care. *CMAJ* 2015;187:411–421.
- Center for Advancing Health. “A New Definition of Patient Engagement: What is Engagement and Why is it Important?” [accessed on January 16, 2011]. Available at http://www.cfah.org/pdfs/CFAH_Engagement_Behavior_Framework_current.pdf.
- Charmaz, K. *Constructing grounded theory: A practical guide through qualitative Analysis*. London: Sage; 2014.
- Dhaliwal J, Nosworthy NM, Holt NL, Zwaigenbaum L, Avis JL, Rasquinha A, Ball GD. Attrition and the management of pediatric obesity: an integrative review. *Child Obes* 2014;10:461–473.
- Dilley K, Martin L, Sullivan C, Seshadri R, Binns H. Identification of overweight status is associated with higher rates of screening for comorbidities of overweight in pediatric primary care practice. *Pediatrics* 2007;119:148–155.
- Domecq JP, Prutsky G, Elraiyah T, Wang Z, Nabhan M, Shippee N, Brito JP, Boehmer K, Hasan R, Firwana B, Erwin P, Eton D, Sloan J, Montori V, Asi N, Dabrh AM, Murad MH. Patient engagement in research: a systematic review. *BMC Health Serv Res* 2014;14:89.

Ebbeling CB, Pawlak DB, Ludwig DS. Childhood obesity: public-health crisis, common sense cure. *Lancet* 2002;360:473–82.

Finne E, Reinehr T, Schaefer A, Winkel K, Kolip P: Overweight children and adolescents—is there a subjective need for treatment? *Int J Public Health* 2009;54:112–116.

Fishbein M, von Haefen I, Appleyard J. The role of theory in developing effective interventions: Implications from Project SAFER. *Psychol Health Med* 2001;6:223–238.

Flower KB, Perrin EM, Viadro CI, Ammerman AS. Using body mass index to identify overweight children: barriers and facilitators in primary care. *Ambul Pediatr* 2007;7:38–44.

Frood S, Johnston LM, Matteson CL, Finegood DT. Obesity, complexity, and the role of the health system. *Curr Obes Rep* 2013;2:320–326.

Gerards SM, Dagnelie PC, Jansen MW, De Vries NK, Kremers SP. Barriers to successful recruitment of parents of overweight children for an obesity prevention intervention: a qualitative study among youth health care professionals. *BMC Fam Pract* 2012;13:37.

Gillespie J, Midmore C, Hoeflich J, Ness C, Ballard P, Stewart L. Parents as the start of the solution: a social marketing approach to understanding triggers and barriers to entering a childhood weight management service. *J Hum Nutr Diet* 2015 Suppl 1:83–92.

Glaserfeld, E. von. *Radical constructivism: A way of knowing and learning*. London: Falmer Press; 1995.

Golan M, Crow S. Parents are key players in the prevention and treatment of weight-related problems. *Nutr Rev* 2004;62:39–50.

Gortmaker SL, Swinburn BA, Levy D, Carter R, Mabry PL, Finegood DT, Huang T, Marsh T, Moodie ML. Changing the future of obesity: science, policy, and action. *Lancet* 2011;378:838–847.

- Greenway FL. Physiological adaptations to weight loss and factors favouring weight regain. *Int J Obes (Lond)* 2015;39:1188–96.
- Grow HM, Hsu C, Liu LL, Briner L, Jessen-Fiddick T, Lozano P, Saelens BE. Understanding family motivations and barriers to participation in community-based programs for overweight youth: one program model does not fit all. *J Public Health Manag Pract* 2013;19:E1–E10.
- Guba EG, Lincoln YS. Competing paradigms in qualitative research. In: Denzin NK, Lincoln YS, eds. *Handbook of Qualitative Research*. London: Sage Publications; 1994.
- Guba EG, Lincoln YS. Epistemological and methodological bases of naturalistic inquiry. *ECTJ* 1982;30:233–252.
- Guba EG. Criteria for assessing the trustworthiness of naturalistic inquiries. *ECTJ* 1981;29:75–92.
- He M, Piche L, Clarson CL, Callaghan C, Harris SB. Childhood overweight and obesity management: a national perspective of primary health care providers' views, practices, perceived barriers and needs. *Paediatr Child Health* 2010;15:419–426.
- Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Serv Res* 2004;39(4 Pt 1):1005–1026.
- Holt NL, Neely KC, Newton AS, Knight CJ, Rasquinha A, Ambler KA, Spence JC, Ball GD. Families' perceptions of and experiences related to a pediatric weight management intervention: A qualitative study. *J Nutr Educ Behav* 2015;47:427–431.
- Jeffery AN, Voss LD, Metcalf BS, Alba S, Wilkin TJ. Parents' awareness of overweight in themselves and their children: cross sectional study within a cohort (EarlyBird 21). *BMJ* 2005;330:23–24.

- Kraschnewski JL, Sciamanna CN, Stuckey HL, Chuang CH, Lehman EB, Hwang KO, Sherwood LL, Nembhard HB. A silent response to the obesity epidemic: decline in US physician weight counseling. *Med Care* 2013;51:186–192.
- Kuhle S, Doucette R, Piccinini-Vallis H, Kirk SF. Successful childhood obesity management in primary care in Canada: what are the odds? *Peer J* 2015;3:e1327.
- Latner JD, Stunkard AJ. Getting worse: the stigmatization of obese children. *Obes Res* 2003;11:452–456.
- Lau DC, Douketis JD, Morrison KM, Hramiak IM, Sharma AM, Ur E; Obesity Canada Clinical Practice Guidelines Expert Panel. 2006 Canadian clinical practice guidelines on the management and prevention of obesity in adults and children [summary]. *CMAJ*. 2007;176:S1–13.
- Lundahl A, Kidwell KM, Nelson TD. Parental underestimates of child weight: a meta-analysis. *Pediatrics* 2014;133:e689–e703.
- Lustig RH. The neuroendocrinology of childhood obesity. *Pediatr Clin North Am* 2001;48:909–930.
- Maxwell, J., & Loomis, D. Mixed methods design: An alternative approach. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social & behavioral research* (pp. 241–272). Thousand Oaks, CA: Sage; 2003.
- Miller NH. Motivational interviewing as a prelude to coaching in healthcare settings. *J Cardiovasc Nurs* 2010;25:247–251.
- Modi AC, Loux TJ, Bell SK, Harmon CM, Inge TH, Zeller MH. Weight-specific health-related quality of life in adolescents with extreme obesity. *Obesity (Silver Spring)* 2008;16:2266–2271.

- Nguyen B, McGregor KA, O'Connor J, Shrewsbury VA, Lee A, Steinbeck KS, Hill AJ, Shah S, Kohn MR, Baur LA. Recruitment challenges and recommendations for adolescent obesity trials. *J Paediatr Child Health* 2012;48:38–43.
- Nobles J, Griffiths C, Pringle A, Gately P. Design programmes to maximise participant engagement: a predictive study of programme and participant characteristics associated with engagement in paediatric weight management. *Int J Behav Nutr Phys Act* 2016;13:76.
- Ogden CL, Carroll MD, Lawman HG, Fryar CD, Kruszon-Moran D, Kit BK, Flegal KM. Trends in obesity prevalence among children and adolescents in the United States, 1988-1994 through 2013-2014. *JAMA* 2016;315:2292–9.
- Ogden CL, Carroll MD, Kit BK, Flegal KM. Prevalence of obesity and trends in body mass index among US children and adolescents, 1999-2010 *JAMA* 2012;307:483–490.
- Oude Luttikhuis H, Baur L, Jansen H, Shrewsbury VA, O'Malley C, Stolk RP, Summerbell CD. Interventions for treating obesity in children. *Cochrane Database Syst Rev* 2009;CD001872.
- Perez AJ, Ball GD. Paradoxically speaking about engagement in pediatric weight management. *Pediatr Obes*. 2017 Feb 16. doi: 10.1111/ijpo.12207. [Epub ahead of print].
- Perez A, Avis J, Holt N, Gokiert R, Chanoine JP, Legault L, Morrison K, Sharma A, Ball G. Why do families enroll in pediatric weight management? A parental perspective of reasons and facilitators. *Child Care Health Dev* 2016;42:278–87.
- Perez A, Holt N, Gokiert R, Chanoine JP, Legault L, Morrison K, Sharma A, Ball G. Why don't families initiate treatment? A qualitative multicentre study investigating parents' reasons for declining paediatric weight management. *Paediatr Child Health* 2015a;20:179–84.
- Perez A, Ball GDC. Beyond 'oblivobesity': Seven myths about parental misperceptions of children's weight. *Child Obes* 2015b;11:735–737.

- Puhl RM, Peterson JL, Luedicke J. Weight-based victimization: bullying experiences of weight loss treatment-seeking youth. *Pediatrics* 2013;131:e1–e9.
- Quattrin T, Liu E, Shaw N, Shine B, Chiang E. Obese children who are referred to the pediatric endocrinologist: characteristics and outcome. *Pediatrics* 2005;115:348–351.
- Reilly JJ, Methven E, McDowell ZC, Hacking B, Alexander D, Stewart L, Kelnar CJ. Health consequences of obesity. *Arch Dis Child* 2003;88:748–752.
- Reinehr T. Effectiveness of lifestyle intervention in overweight children. *Proc Nutr Soc* 2011;70:494–505.
- Roberts KC, Shields M, de Groh M, Aziz A, Gilbert JA. Overweight and obesity in children and adolescents: results from the 2009 to 2011 Canadian health measures survey. *Health Rep* 2012;23:37–41.
- Rodd C, Sharma AK. Recent trends in the prevalence of overweight and obesity among Canadian children. *CMAJ*. 2016;188:E313–20.
- Shaffer LA, Brothers KB, Burkhead TA, Yeager R, Myers JA, Sweeney B. Factors associated with attendance after referral to a pediatric weight management program. *J Pediatr* 2016;172:35–39.
- Sharma AM and Padwal R. Obesity is a sign – over-eating is a symptom: an aetiological framework for the assessment and management of obesity. *Obes Rev* 2010;11:362–370.
- Sim LA, Lebow J, Wang Z, Koball A, Murad MH. Brief primary care obesity interventions: A meta-analysis. *Pediatrics* 2016;138.pii:e20160149.
- Singh AS, Mulder C, Twisk JW, van MechelenW, ChinapawMJ. Tracking of childhood overweight into adulthood: a systematic review of the literature. *Obes Rev* 2008;9:474–488.

- Skelton JA, Beech BM. Attrition in paediatric weight management: a review of the literature and new directions. *Obes Rev* 2011;12:e273–281.
- Skinner AC, Perrin EM, Skelton JA. Prevalence of obesity and severe obesity in US children, 1999-2014. *Obesity (Silver Spring)* 2016;24:1116–1123.
- Smith KL, Kerr DA, Howie EK, Straker LM. Do overweight adolescents adhere to dietary intervention messages? Twelve-month detailed dietary outcomes from Curtin University's Activity, Food and Attitudes Program. *Nutrients* 2015;7:4363–4382.
- Straker LM, Howie EK, Smith KL, Fenner AA, Kerr DA, Olds TS, Abbott RA, Smith AJ. The impact of Curtin University's activity, food and attitudes program on physical activity, sedentary time and fruit, vegetable and junk food consumption among overweight and obese adolescents: a waitlist controlled trial. *PLoS One* 2014;9:e111954.
- The Team to Address Bariatric Care in Canadian Children (Team ABC³): Team Grant Study Protocol. *BMC Research Notes* (In Review).
- van't Riet J, Sijtsema SJ, Dagevos H, De Bruijn GJ. The importance of habits in eating behaviour. An overview and recommendations for future research. *Appetite* 2011; 57:585–596.
- Weston WW. Informed and shared decision-making: the crux of patient centred care. *CMAJ* 2001;165:438–440.
- Withrow D, Alter DA. The economic burden of obesity worldwide: a systematic review of the direct costs of obesity. *Obesity Rev* 2011;12:131–141.

Chapter 2

Perez A, Kebbe M, Yaskina M, Maximova K, Peng C, Patil T, Nielsen C, Holt N, Ho J, Luca P, Connors A, Bennett T, Brunet Wood K, Baron T, LaFrance R, Godziuk K, Ball G. Predicting enrollment in children referred to multidisciplinary clinical care for weight management in Alberta, Canada (Manuscript prepared for submission to *Pediatrics*).

2.1. Abstract

Objectives: Our objectives were to (i) determine the proportion of referred children who enrolled in multidisciplinary clinical care (MCC) for pediatric weight management (PWM), (ii) characterize the children who were referred and those who enrolled, and (iii) examine the predictors of enrollment.

Method: This cross-sectional study included 2–17 year olds who were referred to one of three multidisciplinary weight management clinics in Calgary and Edmonton (anonymized as clinics A, B, and C) in Alberta from April 2013 to April 2016. Demographic, anthropometric, and referral data were retrieved from standardized referral forms. Clinic enrollment data were obtained from administrative databases maintained by Alberta Health Services. Descriptive statistics were calculated to characterize referred and enrolled children. Generalized linear mixed models and binomial logistic regression were used to determine the independent effects of possible predictors of enrollment. Multivariate logistic regression analysis was used to examine the combined effect of the variables that independently predicted enrollment.

Results: Of the 2,014 unique patients (mean age: 11.4 years \pm 0.1; mean BMI z-score: 3.42 \pm 0.03) referred to MCC for PWM, 757 (37.6%) enrolled in treatment. Most children (both referred and enrolled) were referred by physicians, had severe obesity, and lived in urban areas. Children had higher odds of enrollment if they (i) were referred to clinic A compared to clinic B ($p=0.0001$; OR: 0.58; 95% CI: 0.451, 0.753) or C ($p=0.0001$; OR: 0.445; 95% CI: 0.335, 0.592), (ii) had a shorter time gap between their orientation session attended and the date of the initial appointment booked ($p=0.01$; OR: 0.93; 95% CI: 0.883, 0.986), and (iii) were less severely obese ($p=0.046$; OR: 0.928; 95% CI: 0.863, 0.999). Multivariate logistic regression revealed that treatment clinic ($p=0.02$) and time gap ($p=0.035$) predicted enrollment, while BMI z-score was no longer significant ($p=0.19$) in

the final model. Children's age and sex, distance, seasonality, and type of referral provider did not predict enrollment (all $p > 0.05$).

Conclusion: Most children referred for MCC for PWM in Alberta did not enroll in treatment, especially those with severe obesity. Referring a greater number of children without severe obesity, facilitating the enrollment of children with severe obesity, and optimizing enrollment processes at the clinic level, including reducing wait times, may enhance enrollment in PWM.

2.2. Introduction

Multi-component, family-based, lifestyle interventions delivered by multidisciplinary teams can be effective in managing pediatric obesity (Oude Luttikhuis et al., 2009); however, less than one-half of families referred to multidisciplinary care do not enroll in treatment (Shaffer et al., 2016). Enrollment in research and service interventions for weight management is important (Stockton et al., 2012), because it enhances the external and internal validity of studies and prevents additional costs associated with further actions to reach sample size targets (Cui et al., 2015). More importantly, enrollment may prevent further weight gain, promote healthy lifestyle changes, enhance the quality of life of children with obesity, and also decrease the burden of obesity on healthcare systems (Reinehr, 2011).

Efforts to understand enrollment in PWM have largely focused on research interventions, which differs from service interventions. For example, unlike enrollment in health services, participants in weight management clinical trials must meet defined eligibility criteria, be willing to be randomized into different treatment arms, adhere to study conditions, and complete (often extensive) data collection procedures (Story et al., 2003). Additionally, barriers such as distrust of researchers (Cruz et al., 2014) and the need to apply a range of recruitment methods to achieve sample size targets may be unique to research since enrollment in health services usually occurs through referrals from health professionals.

These differences suggest that enrollment in health services for weight management warrants special examination. For instance, studies on enrollment in research (Rieder et al., 2013; Nguyen et al., 2012; Dhingra et al., 2011) have commonly calculated the proportion of children enrolled based on the estimated number of children with overweight or obesity in the study area or the number of inquiries to participate. These methods may not be appropriate to determine

enrollment in health services since the population of interest (*e.g.*, referred patients) can be determined accurately and the number of patients interested in the recommended treatment may represent only a fraction of those who do not enroll in care (Perez et al., 2015). Additionally, enrollment in PWM has not been defined consistently across studies. Dhingra and colleagues (2011) defined enrollment as returning a consent form (*intended enrollment*) while Hartlieb and colleagues (2015) defined enrollment as involvement in a 6-month weight management intervention (*actual enrollment*).

Children's weight status has been associated with enrollment in weight management research (Alff et al., 2012). However, the evidence is inconsistent regarding whether sociodemographic factors and recruitment methods also predict enrollment. For example, child sex, parental education, and family income have been associated with enrollment in some (Shaffer et al., 2016; Alff et al., 2012), but not all (Ghai et al., 2014; Markert et al., 2013) studies. Particularly, the effectiveness of health professional referrals as a recruitment method has also varied across studies (Nguyen et al., 2012; O'Connor et al., 2008). Although both passive (*e.g.*, providing information) and active (*e.g.*, encouraging participation) referral strategies have been used in recruitment, active forms have seldom included additional components (*e.g.*, pre-clinical orientation sessions) to enhance enrollment in health services.

Because several factors may influence enrollment in interventions for managing pediatric obesity, proportions and predictors of enrollment need to be determined in relation to specific groups, types and levels of intervention, characteristics of the enrollment process, and settings (*e.g.*, communities, hospitals). To our knowledge, only one US-based study examined actual enrollment (attending an initial appointment) of children referred to a multidisciplinary clinic for managing pediatric obesity (Shaffer et al., 2016). This study, however, was based on data collected

from one clinic, did not examine procedural factors (*i.e.*, how the enrollment process is structured) related to enrollment, and did not include an intermediate step (*e.g.*, orientation session) before families attended an initial clinical appointment, which is common in Canada. Thus, there is a clear need for generating data from other jurisdictions and examining predictors of enrollment beyond sociodemographic and anthropometric variables. Our objectives were to (*i*) determine the proportion of referred children who enrolled in MCC for PWM in Alberta from April 2013 to April 2016, (*ii*) characterize the children who were referred to and those who enrolled in PWM, and (*iii*) examine demographic, anthropometric, procedural, and contextual variables as predictors of enrollment in PWM.

2.3. Methods

2.3.1. Participants and Settings

Participants in this cross-sectional study included children (2–17 years of age; body mass index [BMI] $\geq 85^{\text{th}}$ percentile [Kuczmarski et al., 2002]) who were referred by physicians and nurse practitioners to three clinics (two in Edmonton and one in Calgary which serves two sites) from April 2013 to April 2016. These three clinics (anonymized as clinics A, B, and C) and four sites (anonymized as sites 1, 2, 3, and 4) are part of a larger provincial strategy for preventing, treating, and managing adult and pediatric obesity, which operates under the auspices of Alberta Health Services (AHS). They offer free-of-charge multidisciplinary assessments and interventions for PWM by clinical teams that include pediatricians, dietitians, exercise specialists, psychologists, nurses, social workers, and administrative professionals.

2.3.2. Enrollment Process

Referred families enroll in clinics through a highly structured, multi-step process. After referrals are received (by fax) and processed (electronically) centrally by AHS Central Access, families are contacted by telephone to discuss availability and book an orientation session at families' preferred clinic site. Prior to their orientation session, families receive a reminder phone call to confirm their attendance. Orientation sessions were designed to inform families about the health services available to them and were offered in several formats, including group (in-person) or one-on-one (in-person or telephone) sessions, Telehealth (videoconference), and webinars. Families who participated in orientation sessions may or may not have booked an initial clinical appointment; similarly, those who booked an initial clinical appointment may or may not have attended that appointment. Families who booked, but did not attend their clinical appointment, were contacted by telephone in an effort to re-schedule their appointment. Regardless of whether families enrolled in one of the clinics, letters were mailed to update referring physicians and nurse practitioners on the status of all referred children.

2.3.3. Data Collection

Baseline data, including children's sex, date of birth, measured height (cm) and weight (kg), postal code, referral date, and type of referral provider (physician or nurse practitioner), were retrieved from standardized referral forms. Potential predictors of enrollment were grouped into demographic (children's sex and age), anthropometric (children's BMI z-score), and procedural (type of referral provider, treatment clinic, time gap between the orientation session attended and the initial clinical appointment booked, and duration of the entire enrollment process) and contextual (seasonality, distance between clinics and families' homes, and geographical area) variables. Data regarding families' sociodemographic characteristics (*e.g.*, parental education,

ethnicity) were not available since they were not required fields on the referral form. Enrollment data, including name and postal code of treatment clinics, booked and/or attended orientation session dates, and booked and/or attended initial appointment dates were obtained from electronic databases maintained by AHS. All booking and attendance data were collected up to October 2016, a 6-month period within which to track the enrollment of patients referred up to April 2016. Research ethics and operational approvals were obtained from the Human Research Ethics Board of the University of Alberta and AHS, respectively.

2.3.4. Data Analysis

The proportions of patients who booked and attended the orientation session as well as those who booked and attended their initial appointment were calculated in relation to the total number of patients referred. Measures of central tendency (means, medians) and proportions were calculated for continuous and categorical variables, respectively. BMI was calculated using height and weight data and subsequently converted to BMI z-scores (WHO, 2009). The following weight status categories were created: *overweight* ($1 \leq OW < 2$ BMI z-score units), *obese* ($2 \leq OB < 3$ BMI z-score units), and *severely obese* ($SO \geq 3$ BMI z-score units). Duration of the enrollment process was defined as the time (in months) between the referral date and the date of the initial appointment booked; this period included the intermediate time gap between the orientation session attended and the initial appointment booked, which was calculated as a separate variable. Residential postal codes were geocoded using CanMap (DMTI Spatial, 2016) in ArcGIS Desktop 10.5 software (Esri, 2015). Next, the Network Analyst extension was used to determine the network distance (Statistics Canada, 2016) between families' residences and the clinic site where the orientation session was booked. Based on the first three postal code digits, the geographical

areas in which referred children lived were classified as urban (population: $\geq 100,000$) or non-urban (population: $\leq 99,999$) (Statistics Canada, 2016).

Based on previous, local research (Carson et al., 2010), we classified seasons as spring (March to May), summer (June to August), fall (September to November), and winter (December to February) as surrogates of weather, which we identified previously as a perceived barrier to treatment enrollment (Perez et al., 2015). Seasonality was calculated in relation to the date of the orientation session for those who booked or attended this session, and in relation to the date of the initial clinical appointment for those who booked or attended this appointment.

Generalized linear mixed models (GLMs) with binary outcomes and maximum likelihood estimates and binomial logistic regressions were conducted to examine the independent effect of demographic, anthropometric, procedural, and contextual variables on enrollment. For all referred children, age, sex, BMI z-score, geographical area, and type of referral provider were included in the analysis. Additionally, treatment clinic, distance, and seasonality were included for those who booked an orientation session, while time gap between orientation session attended and initial appointment booked and duration of enrollment were included for those who booked an initial appointment. Multivariate logistic regression analysis was conducted to determine the combined effect of the variables that independently predicted enrollment ($p > 0.05$). Descriptive data were calculated using SPSS 24.0 (SPSS Inc., Chicago, IL) and regression models were generated using SAS v9.4 (SAS Institute Inc., Cary, NC). Statistical significance was set as $p < 0.05$.

2.4. Results

Figure 2.1 shows the enrollment of patients referred to the three clinics from April 2013 to April 2016. In total, 2,014 unique patients (mean age: 11.4 years ± 0.1 ; mean BMI z-score: 3.42 ± 0.03) were referred during the study period. Most children (**Table 2.1**) were referred by

physicians (n=1,922; 95.6%), met the criteria for SO (n=1,056; 52.4%), lived in urban areas (n=1,643; 81.6%), and were 2–12 years old (n=1,273, 63.2%); however, similar proportions of boys and girls were referred (p=0.1). Interestingly, the total number of referrals increased annually over the 3-year study period (p<0.0001).

Almost one-half (n=980; 44.2%) of referred patients did not book or attend an orientation session, which were delivered most often through in-person, group-based sessions (n=1,535; 76.2%). Of those who attended an orientation session (n=1124), approximately one-third (32.6%) did not book or attend an initial appointment; however, almost all (94.0%) of those who booked an initial appointment attended this appointment. Overall, of the 2,014 unique patients referred, 757 (37.6%) enrolled in treatment. Proportionally, most children (**Table 2.1**) who enrolled were classified as having SO (n=413; 54.6%), lived in urban areas (n=644; 85.1%), and were 2–12 years old (n=485; 64.1%). Similar proportions of boys and girls also enrolled in treatment (p=0.21). On average, the entire enrollment process lasted 5.0±0.1 months and one-half of families who booked an orientation session lived within ~18.0 km of treatment clinics. The absolute number of children that enrolled in treatment tended to increase annually over the study period, but year-to-year differences were not statistical significance (p=0.09).

GLMs were adjusted for treatment site (n=4) as a random effect, which was statistically significant for all the study variables (all p<0.05) in relation to initial attendance, except for treatment clinic (n=3), duration of enrollment, and the time gap between the orientation session attended and the initial appointment booked. In these cases, binomial logistic regression was modeled to estimate their effect on enrollment. As **Table 2.2** shows, enrollment varied by treatment clinic (p=0.0001). Specifically, patients who were referred to clinic A had 42% and 56% higher odds of enrollment than those who were referred to clinics B and C, respectively. Further,

those who were referred to clinic B had 31% higher odds of enrollment than patients referred to clinic C. Time gap was also associated with enrollment ($p=0.013$). Specifically, for every 1-month increase in this time gap, there were 6.7% lower odds of enrollment. Conversely, duration of the entire enrollment process approached significance ($p=0.06$) as a predictor of enrollment.

Children's BMI z-score was inversely associated with enrollment ($p=0.046$). That is, for every 1.0 BMI z-score unit increase, there was a 7.2% lower odds of enrollment. However, the relationship between BMI z-score and enrollment varied by weight status. Specifically, enrollment was negatively associated with weight status for the SO ($p=0.009$; OR: 0.873; 95% CI: 0.788, 0.9666) group, but not for the OW ($p=0.41$; OR: 1.853; 95% CI: 0.425, 8.078) or OB ($p=0.89$; OR: 0.964; 95% CI: 0.564, 1.649) groups. For every 1.0 BMI z-score unit increase in the SO group, there was a 12.7% lower odds of enrollment. Children's age and sex, seasonality, and distance between children's home and treatment venues (**Figure 2.2**) were not associated with enrollment (all $p>0.05$).

In the multivariate logistic regression analysis (**Table 2.3**), only treatment clinic ($p=0.02$) and time gap ($p=0.035$) predicted enrollment, while the interaction between these two variables was not statically significant ($p=0.80$).

2.5 Discussion

Approximately 2 out of every 5 children referred to MCC in Alberta from April 2013 to April 2016 enrolled in treatment. Most referred and enrolled children had SO, were 2–12 years old, and lived in urban areas. Treatment clinic, time gap between orientation session attended and initial clinical appointment booked, and BMI z-score independently predicted enrollment. Particularly, BMI z-score predicted enrollment in children with SO, but not in children without

SO. However, in the multivariate logistic regression analysis, only treatment clinic and time gap remained as predictors of enrollment.

Our data are consistent with a previous report from our team that found that most children referred to one of our clinics for PWM had SO (Ambler et al., 2010). This suggests that many children in Alberta who meet the clinical criteria for OW and OB may not benefit from MCC for weight management not only because they may not enroll, but also because they may not be referred. In Canada, only 1.3% of children with OB and SO are likely to be referred to obesity programs by their primary care providers (Kuhle et al., 2015). Physicians' choice to not refer children may be due to physician- (*e.g.*, lack of actual and perceived skills to discuss the weight issues) and family-related (*e.g.*, no recognition of child's weight as a concern) factors (Gerards et al., 2012) as well as the relatively small number of clinics in Canada, which are mostly based in urban centers (Ball et al., 2011). Additionally, many children are referred for weight management several years after having obesity (Quattrin et al., 2005), which presents a challenge since it is difficult to reverse excess weight once established (Oude Luttikhuis et al., 2009). Insufficient numbers of referrals and enrollment are key concerns given that family-based, multicomponent, multidisciplinary interventions can be effective for managing pediatric obesity (Whitlock et al., 2010).

Despite the enrollment process used by the clinics in our study was highly structured, only 37.6% percent of referred children enrolled in the recommended care; however, the vast majority of those who booked an initial appointment enrolled in treatment. Similar and higher enrollment levels (40–60%) have been found in PWM clinics that apply less structured enrollment processes (Shaffer et al., 2016; Cheng et al., 2014). Despite contextual and sociodemographic differences,

children in these two studies were referred to a single clinic, which limits the understanding of potential clinic-level factors (*e.g.*, geography, enrollment procedures) that may affect enrollment.

A possible explanation for the low enrollment found in our study is that the supporting structures provide the opportunity to enroll (*e.g.*, by re-booking orientation sessions and initial appointments); however, other conditions that behavior theorists have deemed necessary to perform behaviors including motivation, skills, and absence of barriers (Fishbein et al., 2001) may not be addressed. Additionally, the complexity and duration of the enrollment process may have increased the burden of attending an initial appointment and become a source of dissatisfaction.

Overall, findings concerning predictors of enrollment in PWM are inconsistent, which is likely due to differences between studies regarding context, type/level of care, and definitions of enrollment. Data on predictors of enrollment within the healthcare system may need to be contextualized in relation to previous studies that defined enrollment in a similar manner, examined predictors at the same level of care, and shared a similar focus on health services delivery. Similar to Cheng and colleagues (2014), we did not find that child sex predicted enrollment, which may be due to the fact that a large proportion of children in both studies were younger (<12 years), so it may be that sex-related differences in weight-related norms did not act as a motivational factor for treatment initiation. Consistent with Shaffer and colleagues (2016), our analyses showed that child age and distance between families' homes and treatment venues did not predict enrollment.

Research on the relationship between weight status on enrollment is mixed (Shaffer et al., 2016; Cheng et al., 2014). However, we found that enrollment varied by weight status. For example, weight status was associated with enrollment within the SO category, but not within the OW or OB categories. While perceived weight status may be a better predictor of enrollment than

actual weight status (Dhingra et al., 2011), the relationship between children's weight status and enrollment does not appear to be a linear process in which high weight status increases weight awareness, weight awareness increases weight concern, and weight concern increases the likelihood of taking action including seeking care for weight management. Previous studies have reported that parents who were more aware of their children's excess weight were *not* more likely than their less aware counterparts to be concerned about this issue (Jain et al., 2001) and to take actions (Neumark-Sztainer et al., 2008). Our findings support the notion that the relationship between weight status and enrollment is variable and complex.

The low enrollment of children with SO is an important contribution to the literature since little is currently known about the utilization of weight management services in this particular group. However, research has documented that children with SO are more likely to suffer from weight-related comorbidities compared to their leaner peers (Bass & Eneli, 2015; Salawi et al., 2014) and the presence of comorbidities is associated with a lower likelihood of treatment initiation (Dhingra et al., 2011) and retention (Cote et al., 2004). Parents may give priority to other health issues (*e.g.*, type 2 diabetes, respiratory problems) or they may regard those issues and the excess weight in itself as impediments to implementing lifestyle changes (Cote et al., 2004). In a qualitative study on treatment initiation, parents indicated not being able to meet program demands regarding attendance and behavioral change as a reason for not enrolling their children in MCC for weight management (Perez et al., 2015). SO is also more prevalent among children living in families of lower socio-economic status (Skinner et al., 2014), which has been directly (Alff et al., 2012) and indirectly associated with lower treatment initiation at individual (Alff et al., 2012) and neighborhood (Shaffer et al., 2016) levels. Consequently, the perceived and evaluated need (Andersen, 1995) for enrollment in MCC for weight management may not be enough for referred

children with SO to enroll in treatment since they may face other health (physical and mental) and/or financial barriers to care.

Despite the fact that participating clinics have similar enrollment processes and operate in similar environments, the differences found across clinics with respect to enrollment suggested that clinic-level factors (*e.g.*, location, nature of the orientation session, staffing levels) are relevant. We know from anecdotal, subjective experience that, for instance, clinician availability and frequency of orientation sessions varied within and between our clinics over the study period. While we were unable to quantify these data, they may have influenced our findings. Additionally, our data regarding the relationship between duration of enrollment and treatment initiation, particularly the time gap between orientation sessions and initial appointments, is consistent with a previous study that showed that a shorter waiting time (*e.g.*, <5 weeks) improved the enrollment of new patients in hospital-based clinics for managing pediatric obesity (Hampl et al., 2011). While descriptive in nature, identifying best practices related to patient engagement and enrollment would be an important undertaking to assist programs in quality improvement initiatives, especially since factors such as time gap may be responsive to enhancements in processes and procedures.

The lack of observed associations between enrollment and other contextual barriers including seasonality and distance suggests that the influence of these barriers on initial attendance might differ from their influence on continued attendance, which may be due to their cumulative effect. This may explain why logistical barriers have been reported consistently as reasons for attrition from PWM (Dhaliwal et al., 2014). Additionally, the influence of contextual barriers is ultimately mediated by individuals' perceived and actual capability to overcome them, while

barriers to initial attendance may be underestimated and, to some extent, tolerated, which may facilitate enrollment (Perez et al., 2016).

Our study has both strengths and limitations to acknowledge. First, all children referred to MCC for PWM in Alberta over the 3-year study period were included in our analysis, so we were able to report findings based on this provincial population. Second, measured height and weight data were used to calculate children's weight status, which is superior to using self-reported data due to potential recall bias and weight misperceptions. Third, enrollment procedures and contextual variables (*e.g.*, seasonality, distance) were examined, which are important additions to the literature since previous research focused on sociodemographic and anthropometric predictors of enrollment. However, we were constrained by the referral and clinic data that were collected, so other salient predictors of enrollment (*e.g.*, parent education, child and parent motivation for treatment) were not examined. Additionally, we did not examine the proportion of eligible children who were not referred to treatment, which would have offered a more complete picture of the recruitment and uptake stages of the enrollment process.

2.6. Conclusion

Children in Alberta who meet the eligibility criteria for weight management may not benefit from MCC because they are not referred in a timely manner or families decide not to enroll in treatment. Enrollment predictors such as treatment clinic, time gap between the orientation session and the first clinical appointment, and weight status highlighted the importance of considering both organizational- and individual-level factors when planning strategies to enhance treatment initiation. Further research is warranted to better define modifiable predictors that are theoretically and empirically related to enrollment. Our data suggested that a multi-step enrollment process may not enhance treatment initiation unless it is structured to provide further opportunities

to enroll, enhance treatment motivation, and address barriers to accessing care. Along with increasing referrals by allowing other health professionals to refer children and encouraging clinicians and nurse practitioners to refer children who meet the criteria for OW and OB, feasible, appropriate, and effective strategies are still needed to optimize enrollment, especially for children with SO.

Table 2.1. Characteristics of children referred to and enrolled in multidisciplinary care for pediatric weight management in Alberta.

Characteristics	Children Referred n=2,014 (100%)	Children Enrolled n=757 (37.6%)
Sex		
<i>Male</i>	1,035 (51.4)	373 (49.3)
<i>Female</i>	963 (47.8)	383 (50.6)
<i>Missing data</i>	16 (0.8)	1 (0.1)
Age (mean \pm SD)	11.37 \pm 0.1	11.5 \pm 3.5
≤ 12 years	1,273 (63.2)	485 (64.1)
> 12 years	741 (36.8)	272 (35.9)
BMI z-score (mean \pm SD)	3.43 \pm 0.03	3.39 \pm 1.35
<i>Overweight (≥ 1 and < 2)</i>	132 (6.6)	50 (6.6)
<i>Obesity (≥ 2 and < 3)</i>	791 (39.3)	281 (37.1)
<i>Severe obesity (≥ 3)</i>	1,056 (52.4)	413 (54.6)
<i>Missing data</i>	35 (1.7)	13 (1.7)
Referral providers		
<i>Physicians</i>	1,922 (95.4)	720 (95.1)
<i>Nurse practitioners</i>	88 (4.4)	33 (4.4)
<i>Missing data</i>	4 (0.2)	4 (0.5)
Geographical area		
<i>Urban ($\geq 100,000$)</i>	1,643 (81.6)	644 (85.1)
<i>Non-urban ($\leq 99,999$)</i>	371 (18.4)	113 (14.9)

Data presented as n (%) unless otherwise indicated.

Table 2.2. Independent predictors of enrollment using general linear models (adjusted for treatment site) and binomial logistic regression.

Predictors	OR	95% CI	P Value
<i>Demography</i>			
Sex (boys vs girls)	1.201	(0.779, 1.852)	0.21
Age (years)	1.013	(0.985, 1.041)	0.37
<i>Anthropometry</i>			
BMI z-score	0.928	(0.863, 0.999)	0.046
Overweight (≥ 1 and < 2)	1.853	(0.425, 8.078)	0.41
Obesity (≥ 2 and < 3)	0.964	(0.564, 1.649)	0.89
Severe obesity (≥ 3)	0.873	(0.788, 0.967)	0.009
<i>Procedural</i>			
Referral providers (physician vs nurse practitioner)	0.902	(0.311, 2.613)	0.72
Duration of enrollment: referral to IA booked	0.948	(0.896, 1.002)	0.06
Time gap: OS attended to IA booked	0.933	(0.883, 0.986)	0.013
Treatment clinic	–	–	<0.0001
A vs B	0.583	(0.451, 0.753)	<0.0001
A vs C	0.445	(0.335, 0.592)	<0.0001
B vs C	1.309	(1.038, 1.649)	0.023
<i>Contextual</i>			
Distance (km)	1.001	(0.9996, 1.002)	0.19
Geographical area (Urban vs Non-Urban)	0.750	(0.414, 1.360)	0.17
Seasonality	–	–	0.12
Summer vs Fall	1.087	(0.763, 1.548)	0.58
Summer vs Winter	1.043	(0.715, 1.523)	0.79
Summer vs Spring	1.434	(1.020, 2.016)	0.04

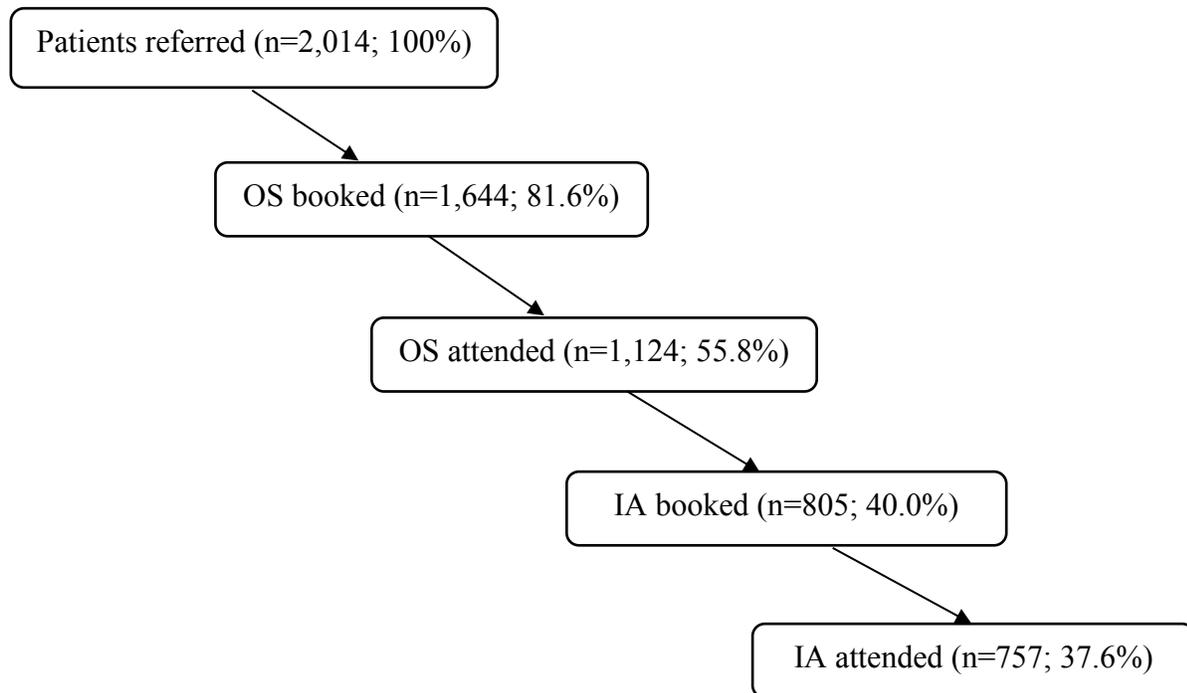
OS: orientation session; IA: initial appointment. In this table, categorical variables include sex, age, referral provider, treatment clinic, and seasonality. The remaining variables are continuous.

Table 2.3. Combined predictors of enrollment using multivariate logistic regression.

Predictors	OR	95% CI	P Value
BMI z-score	0.889	(0.744, 1.062)	0.19
Treatment clinic	–	–	0.02
A vs B	1.709	(0.723, 4.043)	0.22
A vs C	0.611	(0.269, 1.389)	0.24
B vs C	2.798	(1.346, 5.819)	0.006
Time gap: OS attended – IA booked	0.940	(0.884, 1.000)	0.035

OS: orientation session; IA: initial appointment. In this table, treatment clinic is a categorical variable and BMI z-score and time gap are continuous variables.

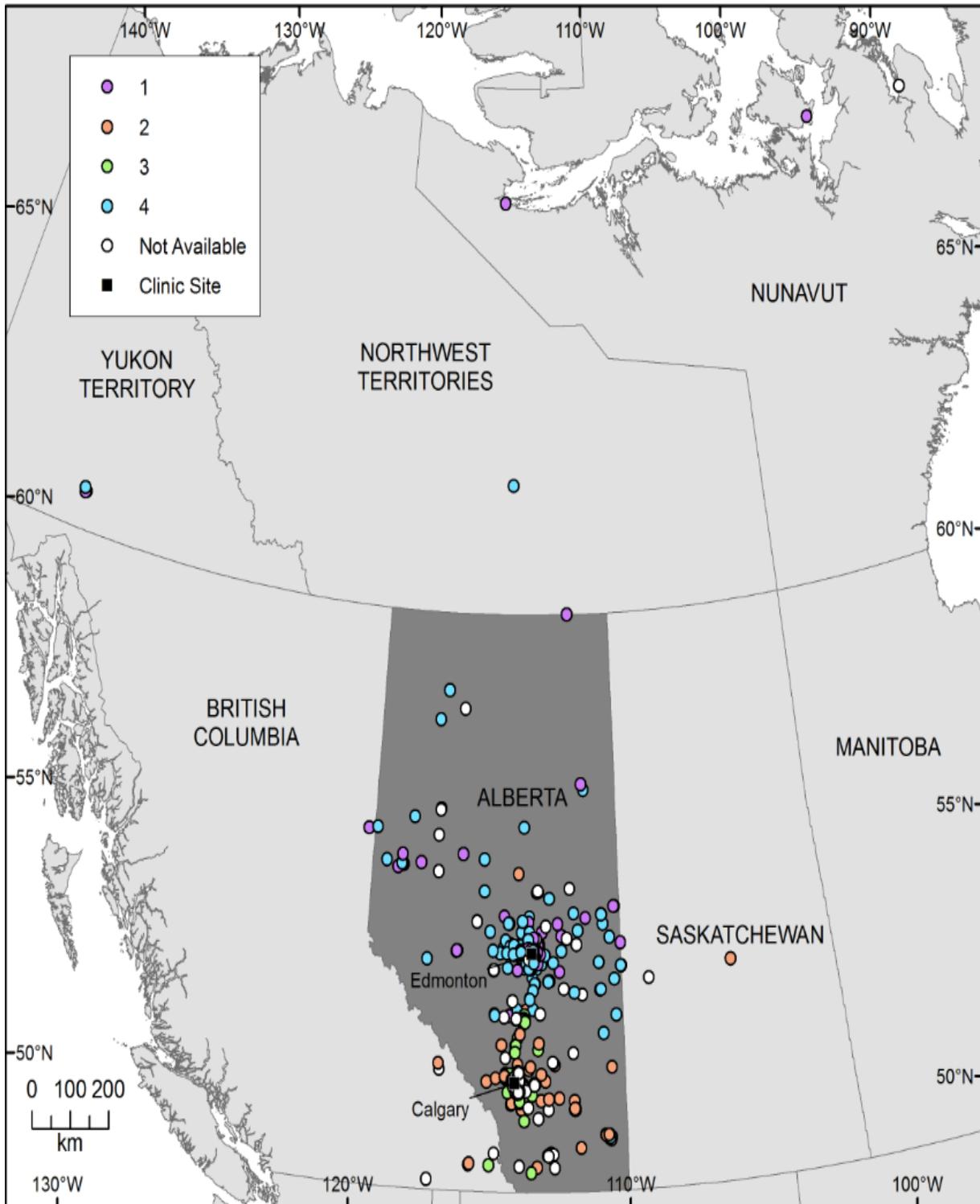
Figure 2.1. Enrollment of referred patients in multidisciplinary clinical care for pediatric weight management.



OS (Orientation Session); IA (Initial Appointment)

Note: For consistency, all proportions were calculated based on the total number of patients referred (n=2,014).

Figure 2.2. Geographical location of treatment sites and families' places of residences.



References

- Alff F, Markert J, Zschaler S, Gausche R, Kiess W, Blüher S. Reasons for (non)participating in a telephone-based intervention program for families with overweight children. *PLoS One* 2012;7:e34580.
- Ambler KA, Hagedorn DW, Ball GD. Referrals for pediatric weight management: the importance of proximity. *BMC Health Serv Res.* 2010;10:302.
- Andersen RM. Revisiting the behavioral model and access to medical care: does it matter? *J Health Soc Behav.* 1995;36:1–10.
- Ball GD, Ambler KA, Chanoine JP. Pediatric weight management programs in Canada: where, what and how? *Int J Pediatr Obes.* 2011;6:e58–e61.
- Bass R, Eneli I. Severe childhood obesity: an under-recognised and growing health problem. *Postgrad Med J.* 2015;91:639–45.
- Brook E, Cohen L, Hakendorf P, Wittert G, Thompson C. Predictors of attendance at an obesity clinic and subsequent weight change. *BMC Health Serv Res.* 2014 Feb 20;14:78.
- Carson V, Spence JC, Cutumisu N, Boule N, Edwards J. Seasonal variation in physical activity among preschool children in a northern Canadian city. *Res Q Exerc Sport.* 2010;81:392–9.
- Cheng JK, Wen X, Coletti KD, Cox JE, Taveras EM. 2-year BMI changes of children referred for multidisciplinary weight management. *Int J Pediatr.* 2014;2014:152586.
- Cote MP, Byczkowski T, Kotagal U, Kirk S, Zeller M, Daniels S. Service quality and attrition: an examination of a pediatric obesity program. *Int J Qual Health Care* 2004;16:165–173.
- Cruz TH, Davis SM, FitzGerald CA, Canaca GF, Keane PC. Engagement, recruitment, and retention in a trans-community, randomized controlled trial for the prevention of obesity in rural American Indian and Hispanic children. *J Prim Prev.* 2014;35:135–49.

Cui Z, Seburg EM, Sherwood NE, Faith MS, Ward DS. Recruitment and retention in obesity prevention and treatment trials targeting minority or low-income children: a review of the clinical trials registration database. *Trials* 2015;16:564.

Dhaliwal J, Nosworthy NM, Holt NL, Zwaigenbaum L, Avis JL, Rasquinha A, Ball GD. Attrition and the management of pediatric obesity: an integrative review. *Child Obes.* 2014;10:461–73.

Dhingra A, Brennan L, Walkley J. Predicting treatment initiation in a family-based adolescent overweight and obesity intervention. *Obesity (Silver Spring)* 2011;19:1307–10.

DMTI Spatial. CanMap Content Suite - Platinum Postal Code, 2001-2015 [digital data] <http://www.dmtispatial.com/canmap/> (2016).

Esri. ArcGIS Desktop, Release 10.5 [software] <http://www.esri.com> (2015)

Fishbein, M. Triandis, H. C., Kanfer, F. H., Becker M., Middlestadt, S. E. and Eichler, A. Factors influencing behavior and behavior change, in A. Baum, T. A. Revenson and J. E. Singer (eds) *Handbook of Health Psychology*. Mahwah, NJ: Lawrence Erlbaum Associates; 2001, 3–17.

Gerards SM, Dagnelie PC, Jansen MW, De Vries NK, Kremers SP. Barriers to successful recruitment of parents of overweight children for an obesity prevention intervention: a qualitative study among youth health care professionals. *BMC Fam Pract.* 2012;13:37.

Ghai NR, Reynolds KD, Xiang AH, Massie K, Rosetti S, Blanco L, Martinez MP, Quinn VP. Recruitment results among families contacted for an obesity prevention intervention: the Obesity Prevention Tailored for Health Study. *Trials.* 2014;15:463.

Hampl S, Paves H, Laubscher K, Eneli I. Patient engagement and attrition in pediatric obesity clinics and programs: results and recommendations. *Pediatrics.* 2011 Sep;128 Suppl 2:S59–64.

Hartlieb KB, Jacques-Tiura AJ, Naar-King S, Ellis DA, Jen KL, Marshall S. Recruitment strategies and the retention of obese urban racial/ethnic minority adolescents in clinical trials: the FIT families project, Michigan, 2010-2014. *Prev Chronic Dis* 2015;12:E22.

Heinberg LJ, Kutchman EM, Lawhun SA, Berger NA, Seabrook RC, Cuttler L, Horowitz SM. Parent involvement is associated with early success in obesity treatment. *Clinical Pediatrics* 2009; 49:457–465.

Jain A1, Sherman SN, Chamberlin LA, Carter Y, Powers SW, Whitaker RC. Why don't low-income mothers worry about their preschoolers being overweight? *Pediatrics* 2001;107:1138–1146.

Kuczumski RJ, Ogden CL, Guo SS, Grummer-Strawn LM, Flegal KM, Mei Z, Wei R, Curtin LR, Roche AF, Johnson CL. 2000 CDC growth charts for the United States: methods and development. *Vital Health Stat* 11 2002;246:1–190.

Kuhle S, Doucette R, Piccinini-Vallis H, Kirk SF. Successful childhood obesity management in primary care in Canada: what are the odds? *PeerJ* 2015;3:e1327.

Markert J, Alff F, Zschaler S, Gausche R, Kiess W, Blüher S. Prevention of childhood obesity: recruiting strategies via local paediatricians and study protocol for a telephone-based counselling programme. *Obes Res Clin Pract*. 2013;7:e476–86.

Neumark-Sztainer D, Wall M, Story M, van den Berg P. Accurate parental classification of overweight adolescents' weight status: does it matter? *Pediatrics* 2008;121:e1495–e1502.

Nguyen B, McGregor KA, O'Connor J, Shrewsbury VA, Lee A, Steinbeck KS, Hill AJ, Shah S, Kohn MR, Baur LA. Recruitment challenges and recommendations for adolescent obesity trials. *J Paediatr Child Health* 2012;48:38–43.

- O'Connor J, Steinbeck K, Hill A, Booth M, Kohn M, Shah S, Baur L. Evaluation of a community-based weight management program for overweight and obese adolescents: The Loozit study. *Nutrition & Dietetics* 2008;65:121–7.
- Oude Luttikhuis H, Baur L, Jansen H, Shrewsbury VA, O'Malley C, Stolk RP, Summerbell CD. Interventions for treating obesity in children. *Cochrane Db Syst Rev*. 2009;CD001872.
- Perez AJ, Avis JL, Holt NL, Gokiart R, Chanoine JP, Legault L, Morrison KM, Sharma AM, Ball GD. Why do families enrol in paediatric weight management? A parental perspective of reasons and facilitators. *Child Care Health Dev*. 2016;42:278–87.
- Quattrin T, Liu E, Shaw N, Shine B, Chiang E. Obese children who are referred to the pediatric endocrinologist: characteristics and outcome. *Pediatrics*. 2005;115:348–51.
- Reinehr T. Effectiveness of lifestyle intervention in overweight children. *Proc Nutr Soc*. 2011;70:494–505.
- Rieder J, Khan UI, Heo M, Mossavar-Rahmani Y, Blank AE, Strauss T, Viswanathan N, Wylie-Rosett J. Evaluation of a community-based weight management program for predominantly severely obese, difficult-to-reach, inner-city minority adolescents. *Child Obes*. 2013;9:292–304.
- Salawi HA, Ambler KA, Padwal RS, Mager DR, Chan CB, Ball GD. Characterizing severe obesity in children and youth referred for weight management. *BMC Pediatr*. 2014;14:154.
- Shaffer LA, Brothers KB, Burkhead TA, Yeager R, Myers JA, Sweeney B. Factors associated with attendance after referral to a pediatric weight management program. *J Pediatr*. 2016;172:35–9.
- Skinner AC, Skelton JA. Prevalence and trends in obesity and severe obesity among children in the United States, 1999–2012. *JAMA Pediatr* 2014;168:561–6.

Statistics Canada. Census and Intercensal Road Network. Statistics Canada Catalogue no. 92-500-X [digital data]. 92-500-X <http://www12.statcan.gc.ca/census-recensement/2011/geo/RNF-FRR/index-eng.cfm> (2016).

Statistics Canada. <http://www.statcan.gc.ca/eng/subjects/standard/pcrac/2016/introduction>. 2016.

Stockton MB, McClanahan BS, Lanctot JQ, Klesges RC, Beech BM. Identification of facilitators and barriers to participation in weight gain prevention research by African American girls. *Contemp Clin Trials* 2012;33:38–45.

Story M, Sherwood NE, Obarzanek E, Beech BM, Baranowski JC, Thompson NS, Owens AS, Mitchell M, Rochon J. Recruitment of African-American pre-adolescent girls into an obesity prevention trial: the GEMS pilot studies. *Ethnicity and Disease* 2003;13:78–87.

Whitlock EP, O'Connor EA, Williams SB, Beil TL, Lutz KW. Effectiveness of weight management interventions in children: a targeted systematic review for the USPSTF. *Pediatrics*. 2010;125:e396–418.

WHO, 2009 (<http://www.who.int/growthref/tools/en/>).

Chapter 3

Perez A, Holt N, Gokiart R, Chanoine JP, Legault L, Morrison K, Sharma A, Ball G. Why don't families initiate treatment? A qualitative multicenter study investigating parents' reasons for declining paediatric weight management. *Paediatr Child Health* 2015;20:179-84.

3.1. Abstract

Objective: Many families referred to specialized health services for managing pediatric obesity do not initiate treatment; however, reasons for non-initiation are poorly understood. Our study aimed at understanding parents' reasons for not initiating tertiary-level health services for pediatric weight management (PWM).

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

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

Conclusions: Physicians should not only discuss the need for and value of specialized care for managing pediatric obesity, but also explore parents' intention to initiate treatment and address reasons for non-initiation that are within their control.

3.2. Introduction

Family-based interventions that emphasize healthy nutrition and physical activity habits combined with behavioral change techniques are efficacious for managing pediatric obesity (Oude Luttikhuis et al., 2009). Families who initiate obesity management can benefit in several ways, including becoming aware of underlying medical issues, being better informed about available care, gaining knowledge about healthy lifestyles and enhancing their initial motivation for treatment. Despite these benefits, a minority of families referred for care choose to initiate PWM (Markert et al., 2013; Finne et al., 2009). Delay in treatment may lead to further unhealthy weight gain and missed opportunities to improve children's health and well-being. These issues are of concern given that younger children and children with a lower level of obesity are more likely to be successful in obesity management (Thomas, 2011).

Both active (*e.g.*, physician referral) and passive (*e.g.*, newspaper advertisement) methods have been used to recruit children for weight management interventions, but neither tends to yield substantial numbers (Raynor et al., 2009; Rice et al., 2008). Several anthropometric, sociodemographic and subjective factors have been associated with non-initiation of PWM. For example, compared with their peers, children who are younger, male, less overweight and from low-income families are less likely to initiate care (Alff et al., 2012, Finne et al., 2009). Parents' positive appraisals of their children's physical well-being and life-style habits have also been associated with non-initiation (Alff et al., 2012).

To date, few studies have examined reasons for non-initiation; of those that have, reasons identified by families include time constraints, distance, participation in other programs and perceived healthy lifestyle of the child (Grow et al., 2013; Alff et al., 2012). These reasons have been identified in the context of clinical trials and community-based programs. Given that

characteristics of treatment affect initiation (Drieschner et al., 2004), reasons for participating in research or community initiatives may differ from reasons for participating in weight management services, which are typically accessed via physician referral. Furthermore, reasons for non-initiation have often been grouped into categories that provide little insight into their underlying meanings.

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

3.3. Methods

3.3.1 Study Design

The present study was part of a larger project designed to understand initiation, continuation, and termination of PWM among families referred for multidisciplinary health services (Ball et al., 2012). Parents were sampled because they play a primary decision-making role. The study was approved by the Research Ethics Boards at all three study sites (University of British Columbia, Vancouver, British Columbia; University of Alberta, Edmonton, Alberta; and Hamilton Health Sciences/ McMaster University, Hamilton, Ontario).

3.3.2. Participants

Between 2011 and 2013, parents were recruited from three Canadian multidisciplinary weight management clinics (in Vancouver, Edmonton and Hamilton) to which their children were referred. Children had to be referred by a physician to receive treatment, which was free of charge.

Parents and children were invited to an orientation session (before ever attending the clinic) in which families learned about details of available health services. Although services across participating clinics varied somewhat according to type, length, mode of delivery and content, they shared a similar focus on family-centered care and combined behavioral and cognitive techniques offered by a multidisciplinary team of clinicians (*e.g.*, physicians, nurses, dietitians, exercise specialists, psychologists) to enhance lifestyle habits and improve psychosocial and physical outcomes. Parents were eligible to participate in the study if they: had a child (10 to 17 years of age; body mass index [BMI] $\geq 85^{\text{th}}$ percentile) (Kuczmarski et al., 2002) who was referred to one of the clinics; were present when the referral was made; and declined the referral by not attending any clinical appointment. Parents were ineligible if they did not speak English or French, or if the child had a serious health condition that precluded their participation in the recommended clinic. Contact information for potential participants was obtained via referral forms. On interview completion, participating families received a \$100 gift card as a token of appreciation.

3.3.3 Data Collection

Written informed consent was obtained from parents before data collection. Semi-structured, one-on-one interviews lasting approximately 60 min were conducted by trained research assistants. Open-ended and follow-up questions were asked to explore reasons for the referral, referral context, information received about the clinic, interaction with the referring physician, reasons for declining care, children's view of the referral and, if applicable, experience in pre-clinical orientation sessions. The interview guide (**Table 3.1**) was developed, piloted and reviewed by researchers with expertise in qualitative methods, pediatric obesity and health behavior. Interviews were digitally recorded and transcribed verbatim. Demographic (*e.g.*, age, sex) and measured anthropometric (*e.g.*, weight, BMI) data of children were obtained from referral

forms.

3.3.4. Data Analysis

Transcribed data were entered into NVivo 9 (QSR International, Australia) for data management. Data were analyzed thematically (Braun & Clarke, 2006). Transcripts were read and re-read for familiarization with the data. A preliminary coding scheme of reasons for non-initiation was developed and discussed with the research team. Data were then coded systematically using the developed coding scheme; when necessary, new codes were added. Related codes were grouped into potential themes. The appropriateness of these groupings was checked in relation to data coded under each theme and the entire dataset. An adequate level of data saturation was achieved at the theme level as each theme provided sufficient details and variety (Patton, 2002). As a final step, quotes that best represented identified reasons for non-initiation were chosen to illustrate the study results. Several techniques were used to ensure rigor of the analysis including triangulation of data from different settings, peer checking and comparison of alternative forms of interpretation of the data (Patton, 1999).

3.4. Results

Eighteen parents (mean age 44.1 years; range 34 to 55 years) were interviewed approximately one year (11.1 ± 7.0 months) after children were referred for care in Vancouver (n=5), Edmonton (n=3), and Hamilton (n=10). Most participants were female (n=16 [89%]), Caucasian (n=15 [83%]), had objectively measured obesity ($BMI \geq 30.0 \text{ kg/m}^2$; n=12 [66%]), held a university degree (n=13 [71%]) and had an annual household income $> \$50,000$ (n=10 [56%]). All children of interviewed parents met the criteria for obesity ($BMI \geq 95$ th percentile; mean BMI percentile 98.9). On average, children were 13.9 years of age (range 10 to 17 years) and most (n=10 [56%]) were girls.

3.4.1. Reasons for not Initiating PWM

Parents provided several reasons for not initiating PWM, which were grouped into five themes: no perceived need for weight management; no perceived need for further actions; no intention to initiate recommended care; participation barriers; and situational factors. The themes, subthemes (reasons) and corresponding quotes are presented in **Table 3.2**.

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

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

No intention to undertake the recommended care. Parents who perceived the need for taking further action did not necessarily intend to enroll their child in the recommended clinic. In fact, most of the reasons parents provided showed that they had not formed the intention to initiate the recommended care. Some parents (n=11) were hesitant to participate because of the psychological (*e.g.*, reinforcing the weight problem), educational (*e.g.*, children taking time away

from school) and financial costs (*e.g.*, transportation, parents taking time off from work) associated with initiation. Perceived low effectiveness of the weight management program also undermined parents' intention to initiate treatment (n=5). Those who regarded the referred program as ineffective stated that: a focus on lifestyle habits would not address the root cause (*e.g.*, metabolic problems) of the children's unhealthy weight; it would rely too heavily on families to manage children's obesity rather than address the issue with children directly; care would be delivered primarily through group-based sessions whereas one-on-one sessions were preferred; it would focus too much on children rather than on the family as a whole; and care would be provided by specialists who appeared to ignore the complexity of obesity by offering limited advice (*e.g.*, eat less, exercise more). Furthermore, the intention to initiate treatment was weakened by the perceived lack of control (n=5) over expected program demands including helping children to make lifestyle changes and limiting their access to unhealthy foods in different settings (*e.g.*, school, community) as well as families' preference (n=4) for an alternative option (*e.g.*, self-management).

Initiation barriers. Some parents appeared to have formed the intention to initiate the recommended care, but did not engage in treatment due to external and internal barriers. External barriers included lack of time/conflicting schedule (n=11), child's lack of motivation (n=7), distance from home or transportation problems (n=5). Parents did not refer to specific strategies to address participation barriers. Instead, they highlighted some difficulties to overcoming them. For example, parents' accounts for not addressing their children's lack of motivation included: lack of knowledge and confidence regarding how to encourage children to participate; belief that motivation must come from within; intention to avoid an additional source of stress in their children's lives; and belief that pushing children to participate may undermine their willingness to

initiate treatment in the future. Internal barriers included misperceptions of the referred care (n=3), self-identified personal characteristics (*e.g.*, procrastination) (n=2) and personal illnesses (n=1). Misperceptions arose during interviews when parents realized that some of their perceptions that deterred them from engaging in care (*e.g.*, program length, appointment frequency and hours of operation) were inaccurate.

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

3.5. Discussion

In examining the reasons that led parents to decline PWM, we identified several themes, including: no perceived need for weight management; no perceived need for further actions; no intention to initiate the recommended care; initiation barriers; and situational factors. These themes can also be regarded as necessary conditions for parents to initiate treatment given their similarities with key constructs (*e.g.*, perceived risk, behavioral motivation and barriers) of prominent health behavior theories, including the Health Belief Model (Becker, 1974), Social Cognitive Theories (Bandura, 1982) and Major Theorists' Model of Behavior (Fishbein, 2000), used to explain behavioral intention and actual behavior. It appears to be unlikely that parents will engage in PWM if they do not perceive the need for care, believe that further actions are unnecessary, have no intention to initiate the recommended care or face major/unexpected barriers to initiating treatment.

In terms of treatment motivation, the difference between parents' perceived need for weight management and their intention to engage in the recommended care is consistent with that of goal

intention and behavior intention. According to Gollwitzer (1993), the former refers to the intention to pursue a goal while the latter refers to the intention to perform a particular behavior to achieve that goal. Thus, individuals may not have even formed the intention to accomplish a goal (*e.g.*, manage children's weight status) or they may have this intention, but not the intention to perform the recommended behavior to achieve the goal (*e.g.*, engage in tertiary level weight management). The assumption that parents did not engage in pediatric weight management because they were not interested in the recommended treatment should be interpreted with caution. More fundamental reasons related to goal intention and intentions to perform further actions and overcome existing barriers may also explain parents' refusal of care.

Referring physicians may be able to enhance initiation by tailoring their interventions to each family's situation and level of readiness for initiation. For example, providing families with more information about the clinic may be of little benefit if parents believe that their child does not have a weight problem, or that their current lifestyle behaviors are adequate to address obesity.

Similarly, encouraging families to engage in the recommended care by discussing children's weight status and the health-related consequences of obesity may not be sufficient to enhance treatment initiation among those who prefer self-management strategies or face major barriers to treatment initiation. These interventions may need to vary depending on whether families have formed the intentions or are impeded to act upon formed intentions (Fishbein & Yzer, 2003). Several clinical tools and techniques (Ball et al., 2013; Makoul & Clayman, 2006; Glasgow & Miller, 2006; Gollwitzer et al., 2005; Miller & Rollnick, 2002) are available and can assist clinicians to help families form and act on health care intentions.

Empirically, our results are consistent with findings of previous studies that identified practical, motivational and perceptual factors related to nonparticipation (Grow et al., 2013; Taylor

et al., 2013; Alff et al., 2012). However, we identified several novel reasons that led parents to decline care, including costs associated with participation, perceived low control over expected program demands, perceived low effectiveness of the intervention and internal barriers (e.g., program misperceptions), all of which broaden our view of issues that preclude treatment initiation. Identified reasons for non-initiation suggest that informing families about the need for weight management and recommending a weight management program are insufficient to ensure treatment initiation. Parents of children with obesity are known to distrust physicians' assessments, may not perceive excess weight as a health condition that needs immediate attention and tend to underestimate their children's weight status (Hudson et al., 2012; Eckstein et al., 2006; Jain et al., 2001). Particularly, the perceived need for weight management appears to be influenced by perceptions such as perceived versus actual weight status, weight gain attributions, perceived susceptibility to obesity and perceived severity of obesity. Consequently, along with determining whether the unwillingness to initiate care is driven by the lack of perceived need for weight management, it is important to know which underlying perceptions lead families to misperceive this need.

Our data also suggest that the decision to decline treatment is made in the context of other behavioral options and pressing needs. Families' competing commitments appeared to affect initiation by constraining their time to engage in care. Whether treatment was initiated appeared to depend on the extent to which competing behaviors were regarded as easier and more desirable (Bagozzi, 1992) and other issues were regarded as more important. Thus, a more thorough explanation of treatment initiation needs to consider alternative behaviors and other issues demanding equal or greater attention and resources from families.

It is noteworthy that the parents in our study did not take action to address initiation barriers

due to a perceived lack of knowledge and skills, as well as the costs associated with taking action. This suggests that the presence of barriers was not what ultimately led parents to decline care, but their perceived inability to overcome them. On the other hand, parents can also overestimate their control over barriers, which may prevent them from implementing planned actions, especially in circumstances in which perceived control over barriers exceeded actual control (Ajzen, 1991).

Parents were also very sensitive to barriers and program shortcomings, which may have been influenced by their lack of motivation to enroll in the recommended care. Less motivated parents are more likely to perceive more barriers than motivated parents (Nock & Photos, 2006). Thus, reported barriers may have indicated real impediments to participate or a coping mechanism (*e.g.*, rationalization, denial) to avoid uncomfortable thoughts and feelings for not taking action. The extent to which parents' reported barriers or other types of reasons for declining care reflect real struggles, coping mechanisms or a combination of both remains to be explored.

We also identified situational factors that appeared to affect families' attendance, but not the decision to initiate treatment. In fact, parents who referred to these factors provided reasons that were nested within other categories when a new appointment was scheduled. It is worth noting, however, that unexpected, transient circumstances (*e.g.*, family emergencies) may hinder the translation of intentions into behavior (Sheeran et al., 2005). **Figure 3.1** presents a preliminary framework developed to account for parents' decision to initiate PWM based on study findings.

Our study had some limitations that need to be acknowledged, including: a small sample size that reduces generalization of study results; reliance on retrospective recall; use of parents' stated reasons as proxies for actual determinants of the decision to decline care; and absence of children's perspectives regarding not initiating care. As part of our larger study (Ball et al., 2012), additional analyses are underway to explore families' reasons and decisions regarding initiating

care following a referral, continuing care for an extended period and discontinuing care prematurely, all of which will enable us to optimize health services for managing pediatric obesity.

3.6. Conclusion

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

Table 3.1. Interview guide to explore parents' reasons for non-enrollment in PWM.

- Why was your child referred to the program?
 - What did the physician tell you about the program?
 - What did you and your child think about coming to the program?
 - To what extent did your child need the recommended program?
 - Who was involved in the decision to not come to the program?
 - What were the reasons for not coming to the program?
 - What were your thoughts and feelings after the orientation session?
 - How confident were you in meeting the requirements of the program including attendance?
-

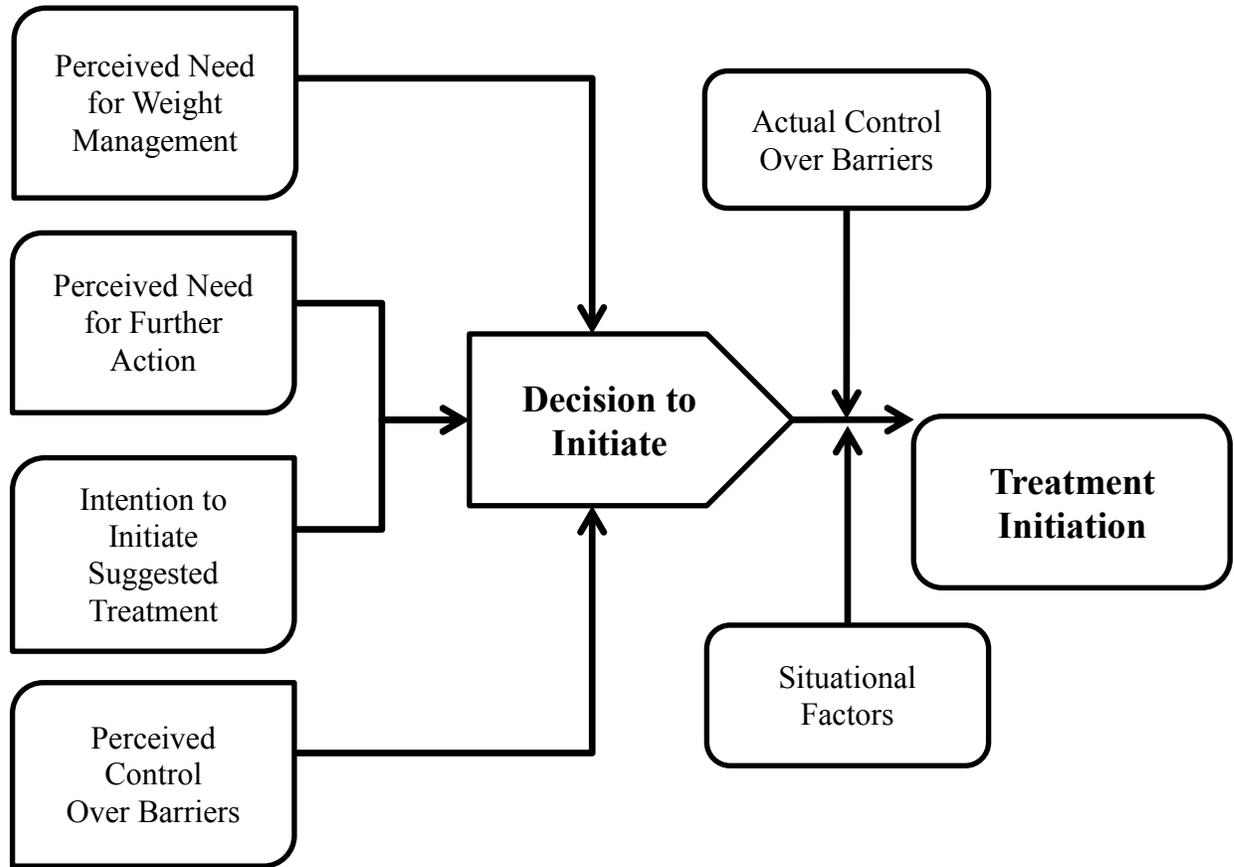
Table 3.2. Parental perspectives of reasons for declining PWM.

Themes	Reasons	Selected Quotes	Freq.
No perceived need for care	No perceived weight problem	“Another reason was that when we finally did get the referral, she [the child] had lost a fair amount of weight already.”	4
	No perceived health problem	“We don’t see it [child’s weight] now as a health scare. If there is something else you know health wise and you can see it instantly, we would jump in to say OK, we gotta do something, right?”	2
No perceived need for further actions	Current involvement in weight management	“My daughter is currently in a program in which she’s lost 25 pounds already.”	4
	Perceived healthy lifestyle	“The doctor knows she [the child] is active. She is not like some kids who are eating all day. She is out doing things, so I don’t think there’s anything else she could have done.”	2
No intention to initiate the recommended care	Associated costs	“If one person’s struggling, you don’t really want to sort of highlight that. She [the child] is very private. And there is still the stigma you don’t want to be one of the fat girls, you know what I mean. Well, I mean it’s horrible to say that’s her.”	11
	Perceived lack of effectiveness	“The program was less calories, more exercise and that had already been well-tried and was providing absolutely no results.”	5
	Perceived lack of control	“He doesn’t exercise enough and eats too much of the bad things. When he comes from the school, I am not there to watch him. I can’t do anything.”	5
	Preference for an alternative	“In her case, she [the child] took the problem [excess weight] under her own control and she dealt with it.”	4

source of
management

Initiation barriers	Lack of time or conflicting schedule	“Another issue is to find a night where I’ve got a couple of hours to get down here. Time is definitely one of the major issues. And my husband works many evenings.”	11
	Child’s lack of motivation	“She doesn’t say too much, she just says I don’t want to participate, I don’t want to, I don’t want to.”	7
	Parents’ accounts for not addressing child’s lack of motivation	“I don’t know how you make somebody ready. You can’t make them [children] ready. You can give them tools and information when they are ready.” (motivational belief) “She was so upset with coming to the program. I didn’t want to make things worse.” (cost attributed)	
	Distance or transportation problems	“I would definitely be, you know, enrolling her in that program. Um, it was just the distance that I wasn’t able to travel every week for.”	5
	Misperception	“I thought it was gonna be more like every other Wednesday evening which was kind of my hesitancy to commit to doing something like that right. So it wouldn’t be an issue at all if it’s in the daytime or once a month. I can make that work. So that’s good to know.”	3
	Personality trait	“So that’s why I never really ever did rebook that appointment because it’s laziness, I know it.”	2
	Personal illness	“I’ve been dealing with an illness myself that has also not helped them [children] on being motivated. Now, I’m getting better and I wanna, you know, start exploring different options.”	1
Situational factors	Weather, tiredness, forgetfulness	“But I remember that day in March. The weather was bad and we could not make it.”	3

Figure 3.1. Conceptual model of parents' decision to initiate treatment for PWM.



References

- Ajzen I. The theory of planned behavior. *Organ Behav Hum* 1991;50:179–211.
- Alff F, Markert J, Zschaler S, Gausche R, Kiess W, Blüher S. Reasons for (non)participating in a telephone-based intervention program for families with overweight children. *PLoS One* 2012;7:34580.
- Bagozzi RP. The self-regulation of attitudes, intentions, and behavior. *Soc Psychol Quart* 1992;55:178–204.
- Ball GDC, Farnesi BC, Newton AS, Holt NL, Gellar J, Johnson ST, Matteson C, Sharma AM, Finegood DT. Join the conversation! The development and preliminary application of Conversation Cards© in pediatric weight management. *J Nutr Educ Behav* 2013;45:476–478.
- Ball GD, Perez Garcia A, Chanoine JP, Morrison KM, Legault L, Sharma AM, Gokiart R, Holt NL. Should I stay or should I go? Understanding families' decisions regarding initiating, continuing, and terminating health services for managing pediatric obesity: The protocol for a multi-center, qualitative study. *BMC Health Serv Res* 2012;12:486.
- Bandura A. Self-efficacy mechanism in human agency. *Am Psychol* 1982;37:122–147.
- Becker MH. The health belief model and sick role behavior. *Health Educ Monogr* 1974;2:409–419.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–

101.

Drieschner KH, Lammers SM, Van Der Staak CP. Treatment motivation: An attempt for clarification of an ambiguous concept. *Clin Psychol Rev* 2004;23:1115–1137.

Eckstein KC, Mikhail LM, Ariza AJ, Thomson JS, Millard SC, Binns HJ; Pediatric Practice Research Group. Parents' perceptions of their child's weight and health. *Pediatrics* 2006;117:681–90.

Finne E, Reinehr T, Schaefer A, Winkel K, Kolip P. Overweight children and adolescents – is there a subjective need for treatment? *Int J Public Health* 2009;54:112–6.

Fishbein M, Yzer M. Using theory to design effective health interventions. *Commun Theor* 2003;13:164–83.

Fishbein M. The role of theory in HIV prevention. *AIDS Care* 2000;12:273–8.

Glasgow RE, Miller DC. Assessing delivery of the five “As” for patient-centered counseling. *Health Promotion Int* 2006;21:245–255.

Gollwitzer PM, Bayer UC, McCulluch KC. The control of the unwanted. In: RR Hassin, JS Uleman, JA Bargh, eds. *The New Unconscious*. New York: Oxford University Press; 2005:485–515.

Gollwitzer PM. Goal achievement: The role of intentions. *Euro Rev Social Psychol* 1993;4:141–185.

- Grow HM, Hsu C, Liu LL, Briner L, Jessen-Fiddick T, Lozano P, Saelens BE. Understanding family motivations and barriers to participation in community-based programs for overweight youth: One program model does not fit all. *J Public Health Manag Pract* 2013;19:E1–E10.
- Hudson E, McGloin A, McConnon A. Parental weight (mis) perceptions: Factors influencing parents' ability to correctly categorise their child's weight status. *Matern Child Health J* 2012;16:1801–1809.
- Jain A, Sherman SN, Chamberlin LA, Carter Y, Powers SW, Whitaker RC. Why don't low-income mothers worry about their preschoolers being overweight? *Pediatrics* 2001;107:1138–1846.
- Kuczmarski RJ, Ogden CL, Guo SS, Grummer-Strawn LM, Flegal KM, Mei Z, Wei R, Curtin LR, Roche AF, Johnson CL. 2000 CDC growth charts for the United States: methods and development. *Vital Health Stat* 11 2002;246:1–190.
- Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. *Patient Educ Counsel* 2006;60:301–12.
- Markert J, Alff F, Zschaler S, Gausche R, Kiess W, Blüher S. Prevention of childhood obesity: Recruiting strategies via local paediatricians and study protocol for a telephone-based counselling programme. *Obes Res Clin Pract* 2013;7:e476–e486.
- Miller WR, Rollnick S. *Motivational Interviewing: Preparing People for Change*, 2nd edn.

New York: The Guilford Press; 2002.

Nock MK, Photos V. Parent motivation to participate in treatment: Assessment and prediction of subsequent participation. *J Child Fam Stud* 2006;15:345–58.

Oude Luttikhuis H, Baur L, Jansen H, Shrewsbury VA, O'Malley C, Stolk RP, Summerbell CD. Interventions for treating obesity in children. *Cochrane Database Syst Rev* 2009;CD001872.

Patton M. *Qualitative research & evaluation methods*. Thousand Oaks: Sage Publications; 2002.

Patton M. Enhancing the qualitative and credibility of qualitative analysis. *Health Serv Res* 1999;34(5 Pt 2):1189–1208.

Raynor HA, Osterholt KM, Hart CN, Jelalian E, Vivier P, Wing RR. Evaluation of active and passive recruitment methods used in randomized controlled trials targeting pediatric obesity. *Int J Pediatr Obes* 2009;4:224–232.

Rice J, Thombs D, Leach R, Rehm R. Successes and barriers for a youth weight-management program. *Clin Pediatr* 2008;47:143–147.

Sheeran P, Sarah M, Webb TL, Gollwitzer PM. Implementation intentions and health behaviors. In: Coner M, Norman P, eds. *Predicting health behavior: research and practice with social cognitive models*. Buckingham: Open University Press; 2005:276–323.

Taylor RW, Williams SM, Dawson AM, Taylor BJ, Meredith-Jones K, Brown D. What factors influence uptake into family-based obesity treatment after weight screening? *J*

Pediatr 2013;163:1657–62.

Thomas R. Symposium III: Metabolic health, weight management and obesity prevention in childhood and adolescence. Effectiveness of lifestyle intervention in overweight children. Proc Nutr Soc 2011;70:494–505.

Chapter 4

Perez AJ, Avis JL, Holt NL, Gokiart R, Chanoine JP, Legault L, Morrison KM, Sharma AM, Ball GD. Why do families enroll in paediatric weight management? A parental perspective of reasons and facilitators. *Child Care Health Dev* 2016;42:278–87.

4.1. Abstract

Objectives: Few children with obesity who are referred for weight management enroll in treatment. Factors enabling enrollment are poorly understood. Our purpose was to explore reasons for and facilitators of enrollment in pediatric weight management (PWM) from the parental perspective.

Methods: Semi-structured interviews were conducted with parents of children (10 to 17 years of age; body mass index $\geq 85^{\text{th}}$ percentile) who were referred to one of four Canadian weight management clinics and enrolled in treatment. Interviews were audio-recorded and transcribed verbatim. Manifest/inductive content analysis was used to analyze the data, which included the frequency with which parents referred to reasons for and facilitators of enrollment.

Results: In total, 65 parents were interviewed. Most had a child with a BMI $\geq 95^{\text{th}}$ percentile (n=59; 91%), were mothers (n=55; 85%) and had completed some post-secondary education (n=43; 66%). Reasons for enrollment were related to concerns about the child, recommended care and expected benefits. Most common reasons included weight concern, weight loss expectation, lifestyle improvement, health concern and need for external support. Facilitators concerned the referral initiator, treatment motivation and barrier control. Most common facilitators included the absence of major barriers, parental control over the decision to enroll, referring physicians stressing the need for specialized care and parents' ability to overcome enrollment challenges.

Conclusions: Healthcare providers might optimize enrollment in PWM by being proactive in referring families, discussing the advantages of the recommended care to meet treatment expectations, and providing support to overcome enrollment barriers.

4.2. Introduction

Childhood obesity is a serious problem given its high prevalence and health-related consequences. One-third of children in Canada and the USA are either overweight or obese (Ogden et al., 2014; Roberts et al., 2012), which is related to adverse outcomes including obesity in adulthood, type 2 diabetes, hypertension, respiratory problems, depression and lower quality of life (Reilly et al., 2003). Multidisciplinary, tertiary-level care is recommended to address excess weight when primary care efforts are constrained or have failed to achieve optimal results (Barlow et al., 2007). Although such care has the potential to manage excess weight effectively, many children who are overweight [body mass index (BMI) $\leq 85^{\text{th}}$ and $< 95^{\text{th}}$ percentile] or with obesity ($\geq 95^{\text{th}}$ percentile) (Kuczmarski et al., 2000) do not enroll in treatment (Finne et al., 2009). Early enrollment in care is important because younger age and a lower level of obesity are both associated with an increased likelihood of successful weight management (Thomas, 2011).

Non-enrollment in care appears to be the result of three main factors. First, parents often misperceive their children's excess weight (Lundahl et al., 2014; Rietmeijer-Mentink et al., 2013), which can lessen the perceived need for health services and motivation to make healthy lifestyle changes (Mareno, 2014). Second, the proportion of referrals for PWM services is low, which has been attributed to factors at the healthcare provider (*e.g.*, low self-efficacy) and parent (*e.g.*, resistance to discuss weight-related issues) levels (Gerards et al., 2012). Lastly, it is not uncommon for parents to decide to not follow through with the referral and engage in health services for PWM (Markert et al., 2013). For instance, our clinical

experience suggests that up to 50% of families referred to tertiary care do not enroll in treatment (Ball et al., 2012).

Research on enrollment in PWM has generally focused on why families choose to decline care. Factors related to non-enrollment have included children's lower BMI, younger age, non-recognition of a weight issue, schedule conflict and children's lack of motivation for treatment (Perez et al., 2015; Alff et al., 2012; Finne et al., 2009). Factors leading to enrollment have been less documented (Gillespie et al., 2015) and are frequently limited to reasons for seeking care, including managing excess weight and improving children's well-being and quality of life (Stewart et al., 2008). Consistent with a strengths-based approach, research in this area *(i)* can help to capitalize on issues that enhance treatment initiation, especially in areas that are modifiable for families or clinicians; *(ii)* has the potential to inform recruitment strategies, service development and participation in PWM interventions (Grow et al., 2013); and *(iii)* can lead to a broader understanding of enrollment by identifying both promoters and inhibitors. Given that enablers of enrollment have been insufficiently explored, the purpose of our multi-center, qualitative study was to explore the reasons and facilitators that led parents to enroll their children in multidisciplinary clinics for weight management.

4.3. Methods

4.3.1. Design

As part of a larger research project to understand factors underlying families' decisions to initiate, continue and terminate PWM (Ball et al., 2012), this qualitative

descriptive study (Sandelowski, 2000) was designed to produce a descriptive summary of enablers of enrollment in care, which we operationalized as attending at least one clinic appointment. The parental perspective was chosen given parents' prominent role in seeking, initiating and completing care for their children (Golan and Crow, 2004). In our study, reasons for enrollment referred to parents' motivation for enrolling their children in care; facilitators referred to factors that allowed enrollment to happen by either enhancing the decision to enroll or translating this decision into actual enrollment. The study was approved by human research ethics boards at four Canadian study sites in Edmonton, Hamilton, Montreal and Vancouver.

4.3.2. Participants and Settings

Participants were purposely chosen (Patton, 1990) from four multidisciplinary PWM management clinics. All clinics offered family-centered lifestyle and behavioral interventions and informed families about available services in orientation sessions prior to treatment initiation. Only children who are overweight or with obesity referred by healthcare providers (*e.g.*, family doctors and pediatricians) were allowed to enroll in these specialty clinics. Parents were eligible to participate in the study if *(i)* they had a child with a BMI $\geq 85^{\text{th}}$ percentile who was referred to one of the four clinics and initiated treatment regardless of the length of their involvement; *(ii)* they were present when the referral was made; and *(iii)* they played a role in the decision to enroll in care. Parents were not eligible if they did not participate in the decision to enroll in care and did not speak English fluently. A \$100

(CDN) gift card to a local business (*e.g.*, grocery store) was offered as a token of appreciation for parents' participation in the study.

4.3.3. Data Collection

Informed, written consent was obtained from all participants before data collection. Individual interviews conducted by trained research staff took place in the clinics and ranged from 45 to 60 min in duration. Open-ended questions (**Table 4.1**) were followed by probing questions to explore a variety of topics, including reasons for the referral, information provided by healthcare providers during the referral, experiences in an orientation session, reasons for enrollment and facilitators and challenges of enrollment. Interviews were audio-recorded and transcribed verbatim. Demographic (*e.g.*, age and sex) and anthropometric (*e.g.*, BMI) data were collected from medical records.

4.3.4. Data Analysis

We used NVivo 9 (QSR International Pty Ltd, Doncaster, Victoria, Australia) to manage our data. Inductive/manifest content analysis was used to analyze the data, a strategy that is suitable to recognize and categorize patterns of responses from participants (Elo and Kyngäs, 2008). Transcripts were read and re-read for familiarization with the data, after which a preliminary coding scheme for reasons and facilitators was developed. Two rounds of discussion were held by research team members (A. J. Perez, N. L. Holt, and G. DC Ball) to enhance the coding scheme and generate the categories within which codes corresponding to reasons and facilitators could be grouped. Subsequently, the modified coding scheme was

used to code the entire data set. New codes were developed when necessary. Two researchers (A. J. Perez, N. L. Holt, and G. DC Ball) discussed the adequacy of assigned codes and selected the quotes that best illustrated identified reasons and facilitators. Any disagreements were resolved by consensus. The frequency with which participants indicated reasons and facilitators was calculated for illustrative purposes. Saturation of main reasons and facilitators was reached after approximately one-half of the transcripts were analyzed, but data analysis continued to better establish response patterns and expand on topics of empirical and theoretical relevance.

4.4. Results

In total, 65 parents were included in our study. Most participants were mothers (n = 55; 85%), Caucasian (n = 44; 68%), completed some post-secondary education (n = 43; 66%) and had a household income >\$50,000 CDN (n = 34; 52%). Most children (14.4±2.0 years) of interviewed parents were male (n = 34; 52%) and had a BMI ≥95th percentile (n = 59; 91%).

4.4.1. Reasons for Enrolling in PWM

According to parents, weight and health concerns were the most common reasons for physicians to refer their children to tertiary care. Parents' reasons for this enrollment were related to concerns, recommended care and expected benefits. **Table 4.2** presents parents' reasons, including selected quotes and frequency data.

Concern. The three primary concerns for parents were related to their children's weight, health and well-being. Most parents stated that they enrolled their children because of their weight status. Concerns about weight were based on children's rapid weight gain and presence of obesity among family members. Half of parents were concerned about their children's health. This concern emerged when children were experiencing or parents expected a weight-related health problem (*e.g.*, diabetes, high cholesterol and heart problems). Almost all parents who were concerned about well-being referred to psychosocial issues (*e.g.*, low self-esteem, teasing, isolation and stigma) that children experienced or could experience as a result of their excess weight and interaction with peers in potentially stigmatizing settings such as school.

Recommended care. Almost half of parents enrolled their children in care because they perceived the need for a reliable external source of support for weight management. Multidisciplinary, tertiary-level care was regarded as more effective than alternative options (*e.g.*, self-management) because of the perceived competence of care providers, level of program structure and the expectation that children would be more inclined to adhere to recommendations from physicians versus advice from parents. Support was also sought by parents to help avoid or manage conflict between them and their children in trying to implement lifestyle changes at home. Further, some parents initiated the recommended care simply because they wanted to comply with the advice from the physicians who made the referral.

Expected benefits. Most parents expected their children to lose weight by enrolling in health services for pediatric weight management. They also participated to enhance their

children's lifestyle habits and personal responsibility for their weight, as well as receive a comprehensive assessment of their children's health and well-being. Almost half of those who expected lifestyle improvements were interested in diet exclusively. Parents expected the recommended care would foster children's motivation to make healthy lifestyle choices and enhance self-management by developing a sense of responsibility and healthy lifestyle habits. They also expected a comprehensive assessment of their children's weight status, physical and mental co-morbidities, causes of obesity and reasons for the lack of motivation to undertake behavioral changes.

4.4.2. Facilitators of Enrollment in PWM

Parents described several factors that facilitated their enrollment in PWM, including referral initiation, motivation for treatment and barrier control. **Table 4.3** presents facilitators, including selected quotes and frequency data.

Referral initiation. Most referrals were initiated by physicians. However, some parents were proactive by requesting a referral or shared concern about their children's weight, which prompted physicians to make a referral. Some referrals were somewhat initiated by other healthcare providers (*e.g.*, nurse) who were concerned about children's weight and encouraged parents to ask their physician for a referral. Some parents recommended that physicians should be proactive in referring families for PWM rather than waiting for families to request further care for obesity.

Treatment motivation. Both external and internal factors had a positive influence on parents' and children's motivation for treatment. External factors included (*i*) physicians

showing concern about children's weight and stressing the need for specialized care; *(ii)* parents valuing information provided in orientation sessions that preceded clinic appointments; *(iii)* parents valuing clinic information available online or via brochure; and *(iv)* physicians involving children in the conversation about weight. Despite the positive influence of these external factors, many parents were not satisfied with the information received indicating that their referring physicians provided them with limited information about their children's weight issue, the recommended care and the potential benefits of enrollment. Some parents reported that the orientation session was 'too long' and 'boring', and left them feeling like they were being 'lectured'. In particular, three parents highlighted the need to enhance advertising of pediatric weight management programs as well as increase physicians' awareness of the health services available for families. With respect to internal factors, setting treatment enrollment as a priority and awareness of obesity consequences and chronicity were both motivators to initiate treatment.

Barrier control. Facilitators concerning barrier control were related to the perceived absence of major barriers, ability to address barriers and acceptance of enrollment costs. Several parents reported *(i)* having no difficulty with their children's lack of motivation or resistance to engage in treatment; *(ii)* facing no major logistical issues (*e.g.*, clinic location, parking, transportation, scheduling conflicts and financial constraints); and *(iii)* enrolling in the recommended care quickly. Two parents indicated that a longer time period between referral and enrollment might have undermined their spouses' and children's initial intention to engage. Perceived absence of barriers was also due to parents' control over the decision to enroll and underestimation of enrollment costs (*e.g.*, parking and time). Factors that

enabled parents to overcome barriers included having support from family, school and/or work to attend clinical appointments and implementing effective strategies. Specifically, parents applied several strategies to address children's lack of motivation including trying (giving the program a try), persuading (describing the potential benefits for the child and family), framing (describing engagement as attending medical appointments), normalizing (neither overemphasizing enrollment nor the need for specialized care) and punishing (threatening to remove some privileges if attendance was refused). In addition, some parents were not discouraged by their inability to address existing challenges and accepted enrollment costs in order to benefit from treatment.

4.5. Discussion

In this multi-center, qualitative study, we characterized reasons for and facilitators of enrollment in PWM from the parental perspective. Reasons included weight, health, and well-being concerns, perceived need for external support, complying with the referral and expected benefits of the intervention including weight, lifestyle and assessment outcomes. Identified facilitators were related to referral initiation, motivation for treatment and control over enrollment barriers.

Weight management, health concerns, lifestyle education and improved well-being have been reported as parental reasons for engaging in PWM (Grow et al., 2013; Stockton et al., 2012). However, the importance parents have given to these reasons is inconsistent across studies. For example, Stewart et al. (2008) found that perceived benefits to children's self-esteem and quality of life were more important for parents to enroll their children in

care than weight-related and health-related concerns. Similar to previous studies (Grow et al., 2013; Pescud et al., 2010), we found that these two concerns played a key role in parents' decision to enroll. Inconsistencies across studies are likely the result of variable sample characteristics, type of intervention, recruitment mode (*e.g.*, clinician-referred versus self-referred) and reasons for the referral. Most children of the parents in our study met the criteria for obesity and were referred to a multidisciplinary weight management clinic primarily because of a weight-related or health-related issue that parents were aware of, which likely influenced parents' treatment motivation.

Determining the relative importance of parents' reasons for initiating treatment was challenging for two reasons: they are linked (*e.g.*, making healthy lifestyle changes to lose weight to prevent obesity comorbidities) and it is not always apparent whether they are the desired goal (*e.g.*, being healthy) or a means to achieve the goal (*e.g.*, improving lifestyle). These different meanings suggest that the frequency with which reasons were described may not necessarily reflect their importance as motivational factors.

Similar to previous reports (Stewart et al., 2008), seeking an external source of care was a common reason for enrollment. Parents who sought external support reported that they failed to successfully address their children's excess weight on their own, children did not want to listen to them and health professionals were in a better position to motivate their children and other family members to change. Our study also revealed additional reasons for enrollment including complying with the referral and receiving a comprehensive assessment of the child's health status. Families with a tendency to comply with medical advice may not require additional motivation to enroll in care, but it may be necessary to help them remain

engaged in treatment. According to the Health Belief Model (Janz and Becker, 1984), symptoms and medical instructions including referrals may act as cues to action, especially when individuals are motivated enough to perform those actions and perceive that the benefits outweigh the costs. Given that parents tend to assess the efficacy and suitability of recommended care in relation to other sources of weight management (Perez et al. 2015), highlighting the benefits of receiving a comprehensive assessment for their children is a comparative advantage that multidisciplinary clinics have over alternative treatment options including self-management. Collectively, our data showed that parents' motivation for PWM was problem-driven regardless of whether the problem was experienced or expected.

To date, little research has explored factors facilitating enrollment in PWM. In our study, facilitators were not limited to control over initiation barriers but included factors that had a positive influence on referral making and motivation for treatment. Our data confirmed that clinicians are the main referrers (Stewart et al., 2008); however, several families sought a referral from physicians or expressed concern about their children's excess weight, which led physicians to make a referral. This suggests that clinicians and parents should both be encouraged to take a proactive approach to discussing and (potentially) completing a referral for PWM. Although the excess weight of the child may be a sensitive issue, clinicians should not assume that families will not be interested in discussing this problem and its adverse long-term consequences. In fact, many families may expect physicians to discuss excess weight as part of a comprehensive, well-child check-up.

We also found that discussing the weight issue with parents and including children in this conversation had the potential to enhance motivation for PWM (Banks et al., 2014).

Similar to previous reports (Laws et al., 2015; Edvardsson et al., 2009), many parents indicated that their clinicians did not raise this issue and when raised they focused on risks (*e.g.*, consequences of excess weight) and services (*e.g.*, potential efficacy of the suggested care). Despite the positive effect of these two forms of communication, clinicians should also help families to enroll in care and enhance their confidence in taking required actions, especially when internal or external barriers may deter them from enrollment. Along with these external facilitators, internal facilitators of motivation for treatment also played a role. For instance, prioritizing enrollment in PWM appeared to have a positive influence on actual enrollment in several ways, including *(i)* lowering the importance of competing demands; *(ii)* enhancing willingness and allocation of personal resources (*e.g.*, time and energy) to overcome barriers to enrollment; and *(iii)* accepting and redefining the costs of initiation (*e.g.*, viewing costs as challenges to overcome rather than barriers that cannot be mitigated). It is possible that once parents set enrollment as a priority, reallocating time from other lower priority activities may not be perceived as a cost. Because busy schedules with many competing interests and demands have been described as major barriers for treatment initiation and continuation (Alff et al., 2012; Skelton and Beech, 2011), additional research is warranted to better understand the process parents follow when they choose to prioritize the initiation of pediatric weight management.

The absence of major motivational (*e.g.*, lack of children's motivation), logistical (*e.g.* distance from residence to clinic) or registration (*e.g.*, lengthy period between referral and enrollment) barriers facilitated families' enrollment in our study. We found that parental control over the decision to enroll contributed to treatment initiation because it reduced the

impact of child-related barriers, especially lack of motivation, which is a common impediment to enroll in PWM (Perez et al., 2015). Our observation that some parents misperceived costs related to initiation suggested that perceived barriers may be more important than actual barriers for treatment to be initiated. However, the latter may be more important with respect to whether behaviors (*e.g.*, attending clinic appointments) are maintained over time (Ajzen, 1991). It was also noteworthy that some unmanageable costs (*e.g.*, cost of parking and transportation) were simply accepted, which may have been a consequence of perceived benefits outweighing costs.

Some research has explored strategies used by families to maintain participation in PWM (Grow et al., 2013), which can reduce the risk of attrition. Our data illuminated specific strategies that parents applied to address discordant levels of motivation when they were more ready, willing and able to initiate treatment than their children. These strategies (*e.g.*, trying and convincing) facilitated enrollment but not necessarily the commitment required to achieve long-term outcomes such as sustained lifestyle changes. Many parents will likely benefit from clinical support to help them address, manage or reconcile their children's lack of motivation. Further, once families are successful in initiating care, clinicians and program administrators have the opportunity (and arguably, the responsibility) to optimize their health services to help families continue program participation. This is desirable because a greater intervention dose, which is usually offered over an extended period, is linked with weight management success (Whitlock et al., 2010) and aligned with a family-centered model of care that incorporates families' needs and interests (American Academy of Pediatrics, 2003).

Our study has some limitations that need to be acknowledged, including parents' recall bias, interpretation constraints imposed by the research design (*e.g.*, sequential instead of simultaneous data collection and data analysis) and the absence of children's perspectives in the decision to enroll in PWM. Further, the fact that most interviewed parents were Caucasian and relatively well-educated with fair family incomes limits the generalizability of our findings to other sociodemographic groups. However, the study has important strengths such as conducting numerous in-depth interviews, allowing us to reach data saturation and identify patterns in the reasons and facilitators reported by parents. Our ability to interview parents from four geographically diverse clinics that had different levels of engagement in the recommended care highlights the diversity of experiences we were able to explore.

4.6. Conclusion

The enrollment in PWM resulted from a combination of reasons and facilitators. In our sample, parents were the primary decision makers with others (*e.g.*, children, health professionals and family members) acting as sources of information, encouragement, and support but also as barriers. Treatment was initiated when parents were motivated to prioritize care and either did not face or overcame motivational, logistic and registration barriers. Despite their success in addressing enrollment barriers, parental support is needed to overcome other barriers that may exert a negative impact on their long-term commitment to obesity management. Along with discussing weight-related issues with families in a sensitive and objective manner, referring physicians and other clinicians have valuable roles

to play by highlighting the comparative advantages of structured weight management over alternative options, enhancing families' resources to enroll in treatment including self-confidence and leveraging modifiable factors that can enable enrollment. The process of prioritizing treatment enrollment warrants further examination because it seems to be a critical precursor for actual enrollment to occur.

4.7. Key Messages

- Enrollment in PWM is suboptimal and understudied
- Clinicians and parents should take a proactive approach when discussing the need for specialized care
- Motivation for and facilitators of treatment should be explored and optimized to enhance enrollment in PWM
- The comparative advantages of recommended care over alternative options should be discussed with families.

Table 4.1. Interview guide to explore reasons for and facilitators of enrollment in PWM.

- How did you get involved in this program?
 - Who referred you and why?
 - How did you feel when you got referred?
 - What did [referral provider] tell you about coming to this program?
 - What did you think of the orientation session?
 - Who made the decision to come and what were the main reasons?
 - Was your child motivated to come?
 - What were the most challenging things about coming to this program?
 - What helped you to come to this program?
-

Table 4.2. Parents’ reasons for enrollment in PWM.

Category	Reason	Selected Quote	Freq.
<i>Concern</i>	Weight concern	“I was just really concerned about the fact that she had gained a lot of weight very quickly.”	56
	Health concern	“We just want to know how to control the blood pressure and cholesterol because of my husband’s family side. His mother got a stroke. So that is one thing that we worry about.”	32
	Well-being concern	“She’s going into a very difficult time of her life. She is just going into high school, right? You don’t know how people are going to react with kids that are overweight. So, one [reason] was her health and that’s my first, you know concern and secondly, her self-esteem.”	13
<i>Recommended Care</i>	Perceived need for external support	“I look forward because they will teach him what to eat. Some kids don’t listen to their parents while they listen to other people. So that’s why I felt kind of positive about it.”	29
	Compliance with the referral	“Because the doctor told me to come. So I did it.”	8
<i>Expected Benefits</i>	Weight loss expectations	“I decided to come because he was overweight and he needed to lose weight. And um that’s basically it.”	42
	Lifestyle improvement	“It’s never a bad thing for kids to learn about proper nutrition with specialists in nutrition and diet who will be able to provide more information than parents can do. We thought, we’d give it a try.”	37
	Comprehensive assessment	“We said, we should go just to make sure that it was just the weight and it wasn’t like diabetes, or something we weren’t seeing, you know? Something like cholesterol or anything like that. I wanted to get all those things ruled out.”	10
	Improvement of self-management	“I wanted them to have little bit their own responsibility so when they go on their own they kind of know do it themselves. I don’t want to check on him, I want him to understand.”	8

Table 4.3. Parents’ perspective of facilitators of enrollment in PWM.

Category	Facilitator	Selected Quote	Freq.
<i>Referral Initiator</i>	Family referred by a physician	“He was very overweight before he hit puberty. And so we went to the doctor and his blood pressure was sky high. The doctor was really worried and so she did some blood work and his cholesterol was really high. And so she sent us to this clinic.”	40
	Parent asking for referral	“I saw it [the clinic] advertised on the Alberta Health Services website and it said you need a referral. So I was able to print off the form, I took it into my family doctor, I said I want a referral for my child and she had no problem referring him.”	19
	Another health care provider suggesting the referral	“She [a dietitian] said to me um actually there’s a pediatric weight loss program. Would you be interested? And she said, I can’t refer you but your doctor can. So what she did is she just wrote a note to our doctor to ask her to refer us. So I just took it back to my family doctor and she said absolutely and put our name in for a referral.”	4
<i>Treatment Motivation</i>	<i>External factors</i> Physician stressing the need for specialized care	“I was quite happy. The talked quite highly of it [need for taking actions], that the child gained weight so rapid and that something drastic had to be done. Also that if we didn’t do something, we would be looking at bad case scenarios, right?”	20
	Parents valuing information provided in the orientation session	“I thought it [orientation session] was good. It was pretty useful. Kinda described the process and how things were gonna go through. I had gotten to the point where I felt like we probably needed something like that to kind of keep us on track or guide us better because at that time I didn’t feel like I was heading down the right path.”	18
	Parents valuing online and	“The way they described in the newsletter was good, ‘cause it wasn’t like a weight-loss type of program. It was changing your lifestyle, it was eating healthier, it was	9

	brochure information	exercising, it was recognizing what's important for you to keep your body healthy and happy. And that's the way we described it to the kids, not that we're gonna go lose weight, but we're gonna go eat better, we're gonna, you know exercise more. And I think that's what you have to emphasize, not that, you know you're gonna go lose 100 pounds or 50 pounds. It's more a lifestyle change."	
	Physician involving children in the discussion	"After the doctor described all the stuff that you know was wrong and what could happen, he [the doctor] said to him [the child] like, do you understand what I'm telling you. He's not a stupid kid, he knew that there's gotta do something."	5
	<i>Internal factors</i>		
	Setting treatment enrollment as a priority	"It was one more thing to add into our lives. At first it was a bit like oh my God, how we gonna do this. So we had to make the commitment to do it, so we did it and I got quite involved in it. It became a priority 'cause I was doing it for my child. And it kind of drew us together a bit more, I think."	15
	Awareness of obesity consequences and chronicity	"He gained a lot of weight, so I wanted to come. It's important because even if you are in good health condition, but if you have much weight, it will little by little harm your heart and some organs. Overweight is not good. So I want to try. It's very important. Even though at that time maybe he was not sick, but you never know in the future if he will have even diabetes."	10
<i>Barrier Control</i>	Absence of major motivational barriers	"The doctor, of course, asked myself and my child if we were interested in joining because I'd have to bring her. My child luckily agreed and she was pretty, pretty good in the beginning."	38
	Parental control over decision to enroll	"It was my decision that she would come. She could say no, but she still would be coming."	29
	Effective strategies	"He did not like it [the program]. I think lots children do not like to see the doctor. So we explained to him this program is not only about controlling the weight, we	17

	also have to learn how to control the cholesterol and the blood pressure. Yeah and that is for his long term and for his whole life. And then yeah, he felt much better yeah.”	
Absence of major logistical barriers	“I really like the location because it’s easy to get here and there is parking. I don’t have to park on the street.”	16
Absence of major registration process	“All happened so quickly so you didn’t have a lot of time to think. It’s better if it’s quicker because they [daughter and husband] think too much. It’s good to have some discussion but there are some negative thoughts that come out too, obviously because of the unknown factors, right? Like what’s coming up, what have you got me into, what are you doing, why do you think there’s a problem? I know these are the types of questions I’m getting from them. So you can skip a lot of that if you’re going through quicker and then it’s like all of a sudden you’re in the program.”	11
Support for attendance	“I’m grateful at my place of employment for having 35 hours of family responsibility time that I can use to take my child to appointments. It makes it easier to come to appointments during business hours.”	8
Acceptance of costs	“The parking lot is quite expensive, but it’s just something extra I have to deal with.”	8
Misperception of costs	“And I didn’t expect the parking to be that much. I thought maybe hospital prices are about 4 dollars for the day, 24 or 12 hours. But here it’s like 15. I couldn’t believe it. And then the drive is an hour and a half or hour 15 minutes. I didn’t mind it at first but I think collaboratively with the parking cost and the gas, that was probably a huge factor in why we stopped coming.”	3

References

- Ajzen I. (1991) The theory of planned behavior. *Organ Behav Hum* 1991;50:179–211.
- Alff F, Markert J, Zschaler S, Gausche R, Kiess W, Blüher S. Reasons for (non)participating in a telephone-based intervention program for families with overweight children. *PLoS One* 2012;7:34580.
- Ball GDC, Perez A, Chanoine JP, Morrison KM, Legault L, Sharma AM, Gokiert R, Holt NL. Should I stay or should I go? Understanding families' decisions regarding initiating, continuing, and terminating health services for managing pediatric obesity: the protocol for a multi-center, qualitative study. *BMC Health Serv Res* 2012;12:486.
- Banks J, Cramer H, Sharp DJ, Shield JP, Turner KM. Identifying families' reasons for engaging or not engaging with childhood obesity services: a qualitative study. *J Child Health Care* 2014;18:101–110.
- Barlow SE, Expert Committee. Expert committee recommendations regarding the prevention, assessment, and treatment of child and adolescent overweight and obesity: summary report. *Pediatrics* 2007;120 Suppl 4:S164–192.
- American Academy of Pediatrics. Family-centered care and the pediatrician's role. *Pediatrics* 2003;112:691–697.
- Edvardsson K, Edvardsson D, Hörnsten A. (2009) Raising issues about children's overweight—maternal and child health nurses' experiences. *J Adv Nurs* 2009;65:2542–2551.

- Elo S, Kyngäs H. (2008) The qualitative content analysis process. *J Adv Nurs* 2008;62:107–115.
- Finne E, Reinehr T, Schaefer A, Winkel K, Kolip P. Overweight children and adolescents—is there a subjective need for treatment? *Int J Public Health* 2009;54:112–116.
- Gerards SM, Dagnelie PC, Jansen MW, De Vries NK, Kremers SP. Barriers to successful recruitment of parents of overweight children for an obesity prevention intervention: a qualitative study among youth health care professionals. *BMC Fam Pract* 2012;13:37.
- Gillespie J, Midmore C, Hoeflich J, Ness C, Ballard P, Stewart L. Parents as the start of the solution: a social marketing approach to understanding triggers and barriers to entering a childhood weight management service. *J Hum Nutr Diet* 2015;28 Suppl 1:83–92.
- Golan M, Crow S. Parents are key players in the prevention and treatment of weight-related problems. *Nutr Rev* 2004;62:39–50.
- Grow HM, Hsu C, Liu LL, Briner L, Jessen-Fiddick T, Lozano P, Saelens BE. Understanding family motivations and barriers to participation in community-based programs for overweight youth: one program model does not fit all. *J Public Health Manag Pract* 2013;19:E1–E10.
- Janz NK, Becker MH. The Health Belief Model: a decade later. *Health Educ Q* 1984;11:1–47.
- Kuczumarski RJ, Ogden CL, Grummer-Strawn LM, Flegal KM, Guo SS, Wei R, Mei Z, Curtin LR, Roche AF, Johnson CL. CDC growth charts: United States. *Adv Data* 2000;(314):1–27.

- Laws R, Campbell KJ, van der Pligt P, Ball K, Lynch J, Russell G, Taylor R, Denney-Wilson E. Obesity prevention in early life: an opportunity to better support the role of maternal and child health nurses in Australia. *BMC Nurs* 2015;14:26.
- Lundahl A, Kidwell KM, Nelson TD. Parental underestimates of child weight: a meta-analysis. *Pediatrics* 2014;133:e689–703.
- Mareno N. Parental perception of child weight: a concept analysis. *J Adv Nurs* 2014;70:34–45.
- Markert J, Alff F, Zschaler S, Gausche R, Kiess W, Blüher S. Prevention of childhood obesity: recruiting strategies via local pediatricians and study protocol for a telephone-based counselling program. *Obes Res Clin Pract* 2013;7:e476–86.
- Ogden CL, Carroll MD, Kit BK, Flegal KM. Prevalence of childhood and adult obesity in the United States, 2011–2012. *JAMA* 2014;311:806–814.
- Patton MQ. *Qualitative Evaluation and Research Methods*, 2nd edn. Sage, Newbury Park, CA, US; 1990.
- Perez A, Holt N, Gokiart R, Chanoine JP, Legault L, Morrison K, Sharma A, Ball G. Why don't families initiate treatment? A qualitative multicentre study investigating parents' reasons for declining pediatric weight management. *Paediatr Child Health* 2015;20:179–184.
- Pescud M, Pettigrew S, McGuigan MR, Newton RU. Factors influencing overweight children's commencement of and continuation in a resistance training program. *BMC Public Health* 2010;10:709.
- Reilly JJ, Methven E, McDowell ZC, Hacking B, Alexander D, Stewart L, Kelnar CJ. Health consequences of obesity. *Arch Dis Child* 2003;88:748–52.

- Rietmeijer-Mentink M1, Paulis WD, van Middelkoop M, Bindels PJ, van der Wouden JC. Difference between parental perception and actual weight status of children: a systematic review. *Matern Child Nutr* 2013;9:3–22.
- Roberts KC, Shields M, de Groh M, Aziz A, Gilbert J. Overweight and obesity in children and adolescents: results from the 2009 to 2011 Canadian health measures survey. *Health Rep* 2012;23:37–41.
- Sandelowski M. Focus on research methods: whatever happened to qualitative description? *Res Nurs Health* 2000;23:334–40.
- Skelton JA, Beech BM. Attrition in pediatric weight management: a review of the literature and new directions. *Obes Rev* 2011;12:e273–81.
- Stewart L, Chapple J, Hughes AR, Poustie V, Reilly JJ. Parents' journey through treatment for their child's obesity: a qualitative study. *Arch Dis Child* 2008;93:35–39.
- Stockton MB, McClanahan BS, Lanctot JQ, Klesges RC, Beech BM. Identification of facilitators and barriers to participation in weight gain prevention research by African American girls. *Contemp Clin Trials* 2012;33:38–45.
- Thomas R. Symposium III. Metabolic health, weight management and obesity prevention in childhood and adolescent. Effectiveness of lifestyle intervention in overweight children. *Proc Nutr Soc* 2011;70:494–505.
- Whitlock EP, O'Connor EA, Williams SB, Beil TL, Lutz KW. Effectiveness of weight management interventions in children: a targeted systematic review for the USPSTF. *Pediatrics* 2010;125:e396–e418.

Chapter 5

Perez A, Kebbe M, Holt NL, Gokiart R, Chanoine JP, Legault L, Morrison KM, Sharma AM, Ball GDC. Parent recommendations to enhance enrollment in multidisciplinary clinical care for pediatric weight management (Manuscript prepared for submission to the *Journal of Pediatrics*).

5.1. Abstract

Objectives: Many families referred to pediatric weight management (PWM) interventions do not enroll in treatment. Strategies to enhance enrollment have been understudied. The objective of our study was to explore parents' recommendations to enhance enrollment in multidisciplinary clinical care (MCC) for managing pediatric obesity.

Methods: Parents were eligible to participate if their children (10–17 years old) had overweight or obesity (BMI $\geq 85^{\text{th}}$ percentile) and were referred to one of four multidisciplinary weight management clinics in Canada. In addition, parents needed to be present at the time of referral and/or at the orientation session. Data were collected through individual, semi-structured interviews that were audio-recorded, transcribed verbatim, and analyzed thematically.

Results: In total, 79 parents were interviewed (87.3% were female, 75.9% were Caucasian, 69.6% had post-secondary education, and 84.2% had children who met the criteria for obesity [BMI $\geq 95^{\text{th}}$ percentile] or severe obesity [BMI $\geq 99^{\text{th}}$ percentile]). Parents' recommendations referred to enrollment opportunities, information about obesity services, motivation for treatment, and accessibility to obesity services. Specifically, parents recommended to increase referral options and follow-up contacts with families during the enrollment process, inform referring physicians and families about the availability and characteristics of obesity services, enhance families' motivation for treatment, prevent families from getting discouraged, make services more appealing to families, and address accessibility issues including appointment times and transportation.

Conclusions: Many recommendations to enhance enrollment were aligned with current guidelines regarding engagement of patients in PWM and principles of family-centered care. The impact of individual or combined strategies designed to enhance referral making and enrollment in general remains to be examined empirically.

5.2. Introduction

To address the high prevalence of childhood obesity, numerous recommendations have been published over the years related to assessing, preventing, and managing excess weight (Canadian Task Force on Preventive Health Care, 2015; Barlow et al., 2007). For instance, experts and organizations have endorsed assessing children's weight status, health risks, and lifestyle habits; encouraging specific healthy eating and physical activity behaviors; and tailoring interventions to patients' responses to treatment, degree of obesity, and readiness to change (Barlow et al., 2007).

In contrast, few reports have been published regarding recommendations to address patients' engagement in PWM interventions. This represents a substantial shortcoming since approximately one-half of physician-referred children do not enroll in treatment (Shaffer et al., 2016), up to 70% of children discontinue care prematurely (Dhaliwal et al., 2014), and less than one-half of children adhere to treatment recommendations following the completion of an intervention (Smith et al., 2015). Treatment initiation, continuation, and adherence are key elements to successfully managing obesity in children (Gillespie et al., 2015; Ball et al., 2012). Indeed, length of clinic involvement (Avis et al., 2013) and adherence to treatment (Germann et al., 2007) have been associated with better weight outcomes. Poor patient engagement may lead to further weight gain, increase costs of health services, lower patients' confidence in managing obesity in the future, and hamper the actual effectiveness of interventions (Newson et al., 2013; Skelton et al., 2012; Lengacher et al., 2001).

Research on engagement has focused primarily on families who withdraw from interventions (Banks et al., 2014). Consequently, most recommendations to improve engagement relate to enhancing retention in weight management interventions by increasing treatment motivation and improving accessibility, content, and delivery of care. Unlike studies of retention, few reports have documented issues related to enrollment in PWM and ways with which to facilitate actual enrollment (Shaffer et al., 2016; Newson et al., 2013), which has been operationalized as attending at least one clinical appointment (Perez et al., 2015). Particularly, enrollment in multidisciplinary care is critical since children with greater need for weight management due to their degree of obesity are most likely to be referred to this level of care (Shaffer et al., 2016), which has demonstrated to be the most effective treatment option to manage childhood obesity (Canadian Task Force on Preventive Health Care, 2015).

Recommendations to enhance enrollment have been derived mainly from research on methods of recruitment (Stockton et al., 2012), factors associated with and reasons for (non)enrollment (Grow et al., 2013), barriers to and facilitators of enrollment (Perez et al., 2015), and strategies that clinics have used to enhance enrollment and retention (Hampl et al., 2011). Little is currently known about families' perspectives on improving enrollment, even though strategies to enhance enrollment have the potential to be successful if they reflect families' needs, preferences, and circumstances (Grow et al., 2013). Given that parents play a key role in seeking care for PWM and supporting initial and continued attendance to obesity

interventions, the purpose of our study was to explore parents' recommendations to enhance enrollment of children referred to multidisciplinary clinics for managing pediatric obesity.

5.3. Methods

5.3.1. Design

This report is part of a larger study that was designed to understand families' reasons for initiating, continuing, and terminating health services for managing pediatric obesity (Ball et al., 2012). Interpretative description guided the current report, a method suitable to describe themes and patterns of contextually constructed patient experiences to inform clinical understandings and decisions (Thorne et al., 2004). Ethics approval was obtained from the Human Research Ethics Boards of four Canadian universities (University of Alberta [Edmonton, AB]; Hamilton Health Sciences / McMaster University [Hamilton, ON]; McGill University [Montreal, QC]; and University of British Columbia [Vancouver, BC]) prior to recruitment and data collection.

5.3.2. Recruitment and Sample

Participants were parents of children (10–17 years of age) referred by local physicians and nurse practitioners to multidisciplinary clinics for PWM from 2011 to 2013. Children could be referred to and receive treatment from participating clinics if they had overweight or obesity (body mass index BMI $\geq 85^{\text{th}}$ percentile) (Kuczmarski et al., 2002). Prior to treatment, referred families were invited to an orientation session about services offered at each clinic. Some referred children did not attend the orientation session while others attended but did not

initiate treatment (*non-initiators*). Children who initiated treatment either discontinued care prematurely (*initiators*) or completed care (*continuers*). Parents received reminder phone calls in relation to orientation sessions and first clinical appointments and these two scheduled visits were rebooked when necessary. Our sample was chosen purposely (Patton, 2002) whereby families had to: (i) have first-hand experience of (at least) being referred, which included parents of children who declined, initiated, or continued care and (ii) be able to provide insight on how to improve the enrollment process from the time of referral to attendance of the first clinical appointment. Parents with first-hand experience but little insight on improving enrollment were excluded. The number of families was estimated based on previous studies in which an adequate level of saturation was reached after interviewing at least 15 families per site and level of engagement category (non-initiators, initiators, and continuers) (Perez et al., 2015; Holt et al., 2008). However, recruiting parents from four clinics and with different levels of engagement was not performed to examine associations between recommendations and these variables, but to increase the variability of our sample, a sampling strategy that can capture the diversity of perspectives and experiences regarding recommendations and allows the identification of themes across participant and organizational differences (Patton, 2002).

Contact information of parents was obtained from referral forms. Parents were contacted by phone or approached in-person by a research assistant who invited them to take part in the study. As a token of appreciation, parents who participated in the study were

eligible to receive a \$100 (CDN) gift card to a local business (*e.g.*, grocery store) after interviews were conducted.

5.3.3. Settings

Children were referred to four multidisciplinary clinics including the Pediatric Centre for Weight and Health (PCWH; Edmonton, AB), Centre for Healthy Weights: Shapedown BC (Vancouver, BC), Growing Healthy Weight Management Program (Hamilton, ON), and Healthy Weight Clinic (Montreal, QC). These four clinics are located at children's hospitals in urban areas in Canada and include multidisciplinary teams composed of physicians, nutritionists, exercise specialists, nurses, and social workers. Interventions tend to be long-term, patient-centred, family-based, and multicomponent including dietary, physical activity, and behavioral modifications. Clinics offer care through different modes of contact including in-person (one-on-one or group sessions) and distance-supported (*e.g.*, videoconference, email, telephone), especially if families face barriers to attendance. Additionally, some clinics have established partnerships with community-based lifestyle programs to support families during and after treatment. Details of each clinic have been reported elsewhere (Tremblay et al., 2016).

5.3.4. Data Collection

Data were collected through individual, semi-structured interviews conducted by trained research assistants in a private office located at the referred clinic. Interviews lasted 30–45 minutes in duration and were audio-recorded. The interview guide (**Table 5.1**) was informed by team members' expertise in qualitative research, pediatric obesity, and health

services for weight management. Open-ended questions followed by probing questions were used to elicit parents' experiences about the referral and the orientation session, including potential challenges associated with session attendance (*e.g.*, transportation, parking, distance). In exploring these experiences, questions focused on areas for improvements in relation to enrollment (*e.g.*, what needs to be changed) and recommendations to address identified issues (*e.g.*, what may help to address each issue). Demographic (*e.g.*, age, sex, ethnicity) and anthropometric (*e.g.*, BMI) characteristics of parents and children were obtained from medical records (including referral forms) and objectively determined prior to interviews, respectively. Written and informed consent was obtained from parents prior to data collection.

5.3.5. *Data Analysis*

Audio-recorded interviews were submitted to *The Comma Police* (www.commapolice.com) for verbatim transcription. Data were managed with *NVivo 10* (QSR, Melbourne, Australia) and analyzed thematically. Thematic analysis (Braun & Clarke, 2006) is a flexible and useful method to identify inductively patterns of responses within the data and group them into themes or categories that are not necessarily theoretically or methodologically driven as in other qualitative methods including grounded theory and phenomenology. AP and MK read all of the transcripts for familiarization and located the data related to recommendations to enhance enrollment. Based on these preliminary readings, a coding scheme was developed and applied by AP to the entire data set. New codes for recommendations were developed when necessary. MK and another team member reviewed the adequacy of the

assigned codes and their groupings into themes. Inter-rater reliability regarding the coding of recommendations was high (Cronbach's $\alpha=0.89$). Disagreements regarding coding and theming were discussed and resolved by consensus. The proportion of parents who made recommendations related to each theme was calculated and quotes were chosen to illustrate themes. Along with data triangulation (*e.g.*, different sites) and the involvement of more than one researcher in data analysis, saturation of themes was sought to enhance the credibility of our findings.

5.4. Results

In total, 79 parents (17 *non-initiators*, 27 *initiators*, and 35 *continuers*) were interviewed from Edmonton (n=19), Hamilton (n=29), Montreal (n=6), and Vancouver (n=25). Approximately one-fifth (21%) of families we approached agreed to participate in the study. Most families refused due to lack of time, lack of interest in the study, and self-reported poor insight on how enrollment could be improved. On average, parents were 45.2 years old, predominantly female (87.3%), and Caucasian (75.9%). Approximately two-thirds (69.6%) had a post-secondary education, slightly more than one-half (53.1%) had household incomes \geq \$50,000 CDN (**Table 5.2**), most (84.2%) had a child who met the criteria for obesity or severe obesity, and only 15.8% had children who were overweight. The length of time (mean \pm standard deviation) between the referral date and the date of the first clinic appointment was 3.3 ± 2.2 months for families who either discontinued or continued PWM. No appreciable differences between respondent categories (*non-initiators*, *initiators*, and *continuers*) were observed (p-value = 0.90) regarding the types of recommendation, so data were combined

across groups. Recommendations on the issues discussed with parents were organized into the following four themes: enrollment opportunities, information about obesity services, motivation for treatment, and accessibility to obesity services (**Table 5.3**).

Enrollment opportunities. Parents made several recommendations intended to increase opportunities to enroll in the recommended care (n=35; 44.3%). Specifically, parents recommended that physicians should proactively refer eligible children to weight management interventions rather than wait for families to express interest or request a referral. Parents based this recommendation on personal experiences during their interactions with physicians in which they felt that requesting a referral was what triggered the physician's decision to refer them to a specialized care for obesity management. Parents also suggested that families be given the option to enroll in care by self-referral, arguing that some self-referred families may be more ready for treatment than their referred counterparts. Regarding families who had already shown some interest in treatment (*e.g.*, those who attended the orientation session), parents highlighted the value of reminder phone calls, rescheduling initial clinical appointments, and having referring physicians follow up with referred families to confirm and support their enrollment.

Information about services. Overall, parents valued being adequately informed about services to decide whether or not to enroll and to form proper expectations about available services (n=54; 68.4%). Families wanted to be informed by *(i)* referring physicians who they regarded as reliable sources and *(ii)* obesity service providers who they perceived as responsible for ensuring that information about their services was made more available to the general public. Parents also stressed the need to inform referring physicians about obesity services due

to their limited knowledge about the availability and characteristics of these services. Even though parents preferred physicians as the main informants, other sources of information were also acceptable including brochures and websites, followed by word-of-mouth, newspapers, newsletters, mails, and e-mails. Settings in which families preferred to receive information included health clinics, hospitals, community centers, and schools. Few families were satisfied with being informed of names and locations of clinics only; most desired further details including treatment goals, intervention content, types of services, duration of care, times and frequency of appointments, and aspects of care that may be flexible or negotiable (e.g., frequency, mode of delivery). Parents suggested brief and simple educational resources about services considering families' limited time, communication preferences, and variable literacy levels.

Motivation for treatment. Parents (n=49; 62.0%) recommended that referring physicians and obesity service providers should motivate families for treatment at the time of referral and during orientation sessions by undertaking specific actions to either enhance motivation or minimize discouragement. Specific recommendations to enhance motivation included highlighting the benefits and suitability of obesity services, sharing successful stories (either online or in-person) of past participants, stressing the comparative advantages of engaging in obesity services (e.g., specialists providing care, structured environment) over alternative options (e.g., self-management), stressing the importance of acting sooner than later to prevent adverse health consequences, and having specific activities for children during the orientation session, which some parents regarded as informative, but adult-oriented.

Recommendations to prevent families from getting discouraged included shortening the enrollment process to maintain momentum, keeping in contact with families while they waited to initiate treatment, ensuring the privacy of children who do not want to be seen participating in a weight management program, raising weight- and health-related issues in a sensitive manner, avoiding judging parents based on their children's weight status and lifestyle choices, and not scaring children by alluding to extreme negative health consequences as a means to increase their motivation for treatment.

Parents also made specific recommendations to make obesity services more appealing to families. For example, parents suggested that services should be advertised as lifestyle interventions as opposed to weight interventions, offer additional programs such as summer camps and cooking classes, address multiple issues (*e.g.*, lifestyle behaviors, readiness to change, physical and mental health), and place more emphasis on the physical activity component of interventions. Parents also preferred services that involve the entire family, focus on facilitation of lifestyle changes as opposed to education exclusively, and more child-based as opposed to parent-based interventions for older children. Additional appealing features regarding service delivery included services tailored to families' needs and financial status as well as to children's special needs, offering one-on-one and group sessions, ensuring that activities for children were fun, hands-on, and age-appropriate, and subsidizing access to community facilities to provide children with more opportunities for being physically active.

Accessibility to obesity services. Most recommendations regarding accessibility sought to address logistical challenges including time demands and participation burden.

Overall, parents (n=61; 77.2%) recommended having obesity services closer to their homes, in their homes, or available online. Specifically, parents recommended having more program options across their communities (e.g., satellite clinics), offering home visits, providing services in areas with the highest prevalence of obesity, and telehealth/video-conferencing for service delivery. To avoid competing with other commitments (e.g., work, school, recreational activities), many families recommended offering multiple options for appointment times (e.g., evenings, weekends). Free parking and support for transportation (e.g., providing bus tickets) were suggested to ameliorate participation costs. Further, to enhance accessibility, some parents recommended shorter programs and the involvement of fewer family members, including allowing adolescents to attend on their own or accepting the presence of only one parent. Lastly, parents suggested that childcare services should be available for siblings of participating children during their appointments.

5.5. Discussion

Interview data from parents regarding recommendations to enhance enrollment were related to opportunities, information, motivation, and accessibility. Specifically, parents recommended to (i) increase referral options and follow-up contacts throughout the enrollment process, (ii) inform families and referring physicians about the availability and characteristics of obesity services, (iii) motivate families to enroll, avoid discouragement of families, and make services appealing to families, and (iv) address enrollment barriers including distance, schedule conflicts, and financial costs.

Our findings are in line with previous reports suggesting that increasing recruitment and referral options may help to enhance participation in weight management interventions. For example, the demonstrated effectiveness of passive methods of recruitment whereby individuals self-refer into services (Nguyen et al., 2012), and the fact that some families in our study were referred to the participating clinics after they requested a referral from their physician, suggest that giving families the opportunity to self-refer into weight management has the potential to increase enrollment. By definition, self-referred patients have a desire for and value external support, which may not be the case of patients referred by physicians.

Further, the recommendation that physicians should be proactive in referring eligible children to obesity services is consistent with reports showing that some physicians may not raise the issue of obesity or refer eligible children to specialized care due to physician- (*e.g.*, lack of confidence in counselling families) (Gerards et al., 2012) and family-level (*e.g.*, low readiness for treatment) (Robson et al., 2016) barriers. In general, theoretically-driven and strategically-planned methods of enrollment, active and passive methods of recruitment, tailored strategies for target populations, partnerships with other stakeholders (*e.g.*, schools), and physicians talking with other physicians about available services for obesity management have all been suggested as strategies to enhance enrollment in weight management interventions (Gillespie et al., 2015; Stockton et al., 2012; Smith et al., 2014). The recommendation of following up with families who showed interest in the recommended care is important since new barriers and situational factors (*e.g.*, forgetting the scheduled appointment) may hamper the translation of the *intention* to enroll into *actual* enrollment (Perez et al., 2015). In this regard,

having a designated person to (re)schedule clinic appointments and make reminder phone calls to families has the potential to enhance initial and continued attendance (Hampl et al., 2011).

Previous research has highlighted the value of providing families with detailed information about services, especially at the time of referral, to help them form accurate expectations about the recommended care (Banks et al., 2014). Also, informing families about the benefits of weight management interventions can facilitate enrollment (Perez et al., 2016). Although parents preferred (primarily) to be informed by their referring physician, they acknowledged that many physicians were ill-informed about the available services. Specifically, partnerships between PWM clinics and referring physicians has been suggested as a means to inform physicians about existing services and enhance their knowledge, skill, and competence to motivate families to enroll in obesity interventions (Smith et al., 2014; Twiddy et al., 2012).

Our data confirmed existing recommendations regarding the importance of assessing and enhancing motivation for weight management of parents and children from initial contacts to improve enrollment in obesity services (Banks et al., 2014; Stockton et al., 2012; Dhingra et al., 2011). Exploring the factors that drive families to enroll in weight management interventions is an important step to enhance motivation, especially since motivation can vary between parents (Grow et al., 2013), parents and children (Stockton et al., 2012), and families and obesity service providers (Dhingra et al., 2011). These observations highlighted the need to gain a more comprehensive, family-centric view of the motivation-related drivers of enrollment in obesity services.

Additionally, parents stressed the importance of preventing families from getting discouraged from enrolling in treatment. This is a novel and interesting recommendation – that is, help families to avoid discouraging situations since treatment motivation can change over time and individuals who are less motivated may get discouraged easily. Similar to recommendations drawn from previous research (Gillespie et al., 2015), parents suggested to avoid situations in which children and parents feel judged by health professionals or peers. Consistent with parents’ recommendation of shortening the enrollment process, Hampl and colleagues (2011) found higher enrollment in hospital-based clinics that had shorter waiting times (*e.g.*, <5 weeks) to enroll new patients. Additionally, researchers have reported the importance of minimizing the assessment burden on families (*e.g.*, assessing weight status, comorbidities, lifestyle habits), measurements that can span a number of separate appointments, to help keep them engaged by the time an intervention begins (Smith et al., 2014).

Parents’ expectations also included supporting families in accessing care. Most parents’ recommendations regarding accessibility related to enrollment (initial attendance) were similar to those related to optimizing ongoing attendance (*e.g.*, providing flexible and variable clinic appointment options) (Tremblay et al., 2016). Parents also recommended at-home and videoconferencing as practical approaches to enhance enrollment, strategies that have shown to be useful, feasible, and well-received, especially among families with lower household incomes and who live far from clinics (Davis et al., 2016; Appelhans et al., 2016). Interestingly, involving fewer family members in interventions and offering shorter programs were suggested to help mitigate scheduling conflicts and the logistic burden of continued attendance,

respectively. Offering interventions of varying length has been suggested to accommodate families who cannot commit to longer intervals (Holt et al., 2015); however, this directive is at odds with data showing that higher-intensity, longer interventions tend to be most effective in PWM (Whitlock et al., 2010). Additionally, in lieu of clinical programs offered in medical settings, community-based programs have been recommended to reduce participation burden for some families (Kumanyika et al., 2006). These recommendations highlight the importance of a proactive approach in which accessibility issues are considered as part of a commitment to develop and continually improve obesity services in pediatrics (Hampl et al., 2011).

Overall, parents' recommendations were aligned with Canadian guidelines (Canadian Task Force on Preventive Health Care, 2015) regarding managing pediatric obesity, including the referral of children in need for multidisciplinary care and the assessment and improvement of families' readiness for treatment. They were also aligned with patient- and family-centered approaches that stress the need for customizing health advice including referrals to families' needs, preferences, resources, and circumstances. Some parents' recommendations were (at least in part) implemented by study clinics, including offering flexible appointment times, making reminder phone calls for upcoming clinic appointments, providing orientation sessions via distance (*e.g.*, webinar, telephone), and providing support for transportation (*e.g.*, passes for public transit). Others strategies, such as allowing families to self-refer, is reasonable since emerging evidence supports effectiveness and feasibility (Smith et al., 2014), but remains less common when accessing care within children's hospitals, which typically require a physician referral. Further, some recommendations such as extending appointment times into the evenings

and reducing the waiting list for first-time clinic appointments may be more difficult to implement due to clinician preference and administrative processes at the health system level.

Our study has limitations that need to be acknowledged. For example, recall bias may have influenced parents' reports since our interviews did not occur immediately after the referral or orientation session. Since most parents in our study were Caucasian and had completed post-secondary education, our findings may not be applicable to parents and families with other sociodemographic characteristics. Also, we were unable to include children's perspectives in our study since our data were insufficiently rich, especially regarding recommendations to improve enrollment in obesity clinics.

5.6. Conclusion

In conclusion, parents offered a range of recommendations to increase enrollment opportunities, enhance the decision to enroll by improving information about services and motivation for treatment, and ameliorate the effect of accessibility barriers. The feasibility and effectiveness of these recommendations remain to be empirically demonstrated. In this regard, stakeholders could implement recommendations that they consider appropriate and feasible as part of quality improvement initiatives, which can help to generate both data and experience to inform research that is needed to demonstrate effectiveness. Additionally, families' varying treatment needs, expectations, preferences, and living circumstances suggest that a one-size-fits-all approach is unsuitable to address low enrollment in PWM interventions and strategies to enhance enrollment should be developed and tested for families at both group (targeted) and individual (tailored) levels.

5.7. Key messages

Parents' recommendations included increasing opportunities for enrollment, informing families and clinicians who refer families for care about available services, motivating families to initiate treatment and avoid discouragement, and facilitating accessibility to PWM interventions.

Table 5.1. Interview guide to explore parents' recommendations about enrollment.

1. Who referred you?
 2. Can you describe what they said and did?
 3. Did you know about the clinic beforehand? Where did you learn about it?
 4. Did your physician know about the clinic?
 5. What information did you receive about the program? How was it shared with you?
 6. What information did you receive about the referral process and next steps?
 7. What kind of information from the physician would be most helpful for you and your family?
 8. Was there anything positive or negative about the referral process that stood out to you?
 9. Was there anything that your physician could have done better?
 10. Did you come to the orientation session? Did you find it helpful?
 11. What were your feelings after the orientation session?
 12. Did your child come to the orientation session? What did he/she think?
 13. Did what you hear and see during the orientation session influence your decision to initiate the suggested care? How?
 14. What are the things that health care professionals could do to make it easier to initiate care?
 15. In your opinion, what do you think would help other families attend the program?
-

Table 5.2. Demographic and anthropometric characteristics of children and parents (n=79).

	Children	Parent
Age (y)	14.3±2.0	45.2±10.1
Sex (n; %)		
Female	38; 48.1	69; 87.3
Male	41; 51.9	10; 12.7
Ethnicity, (n; %)		
Caucasian	57; 72.2	60; 75.9
Non-Caucasian	22; 27.8	19; 24.1
Education (at least college or university) (n; %)	-	55; 69.6
Family income (>\$50,000/y CDN) (n; %)	-	43; 53.1
Height (cm)	163.6±11.9 ^a	163.5±8.1 ^b
Weight (kg)	87.6±24.9 ^a	88.6±23.6 ^b
Weight Status (n; %)		
Normal weight	-	13; 17.3 ^b
Overweight	12; 15.8 ^a	24; 32.0 ^b
Obese	32; 42.1 ^a	17; 22.7 ^b
Severely obese	32; 42.1 ^a	21; 28.0 ^b
Body Mass Index (BMI; kg/m ²)	32.2±6.2 ^a	32.5±7.8 ^b
BMI percentile	98.8±2.0 ^a	-
BMI z-score	2.8±0.8 ^a	-

^an=76, ^bn=75; the sample size is limited due to unreported data.

Table 5.3. Quotes on recommendations to enhance enrollment in PWM.

Theme 1: Enrollment opportunities	
<i>Increasing referral options</i>	<p>“The clinic only takes people by referral, see that’s also another barrier I guess. Maybe they can look into more open yeah.”</p> <p>“Family doctor should tell families there’s a program out there, and I think you should attend it. For like myself, I had to ask my doctor.”</p>
<i>Increase follow-up contacts</i>	<p>“It could have been a complete 180 if we got a call to say hey, we missed you at the information meeting, um you know, do you need some time to think about it, do you wanna come in for a one-on-one consultation just to you know explain the program.”</p> <p>“I think would be good if the person, a physician or somebody, who refers them [patients] to the clinic follow-up on them. The people are referred, they come to the orientation meeting, and then they go on anonymous.”</p>
Theme 2: Information about obesity services	
<i>Informing families and physicians</i>	<p>“Well it’s really hard to know what’s available. If the family doctor doesn’t know about the program, there doesn’t seem to be much else out there. I guess you just have to maybe advertise more, get the information out to parents.”</p> <p>“I think they [doctors] need to have a little more information of what is actually out there”</p>
<i>Sources of information</i>	<p>“Whatever doctor said is most likely correct. That’s very credential, right? It will be good if the information [about services] is shared by the internet. So we all could see it, right? After the doctor’s recommendation.”</p> <p>“Word of mouth and maybe advertise more with the schools. Like even posters that you know where they have the bulletin boards because parents always read those and there’s lots of overweight kids.”</p>
<i>Content and delivery of information</i>	<p>“The doctor just told me the name [of the program] and that somebody would be contacting me. I didn’t get any literature. She should’ve maybe given me a little bit more information about the program, how it was run, the hours, and what the program actually involved.”</p>
Theme 3: Motivation for treatment	
<i>Enhancing motivation</i>	<p>“I think that might be very motivational to see what happens after you go to the program, right? If families could see some positive results or some statistical information about that you know what happens like 6 months, a year. I think that’s powerful, very motivational.”</p> <p>“Stress the importance of children’s health, tell families that if you help children now, then later on they wouldn’t have as a severe problem. Doctors should stress that if you don’t start now it will get worse later on, but not in a scary way. Maybe that would urge them to go.”</p>

<i>Avoiding discouragement</i>	“If you have to wait a few months [to get enrolled], you could sort of lose your excitement. To keep people excited, they [services providers] could still meet with them, like once a month, just to make sure that they’re still interested, so they don’t lose that excitement about it.”
<i>Making services more appealing</i>	“I would try and put in more fitness and maybe a little more in depth the counselling part of it, kinda get to the root of the problem. For some people maybe it’s something going on, other people might just be like not knowing.”
Theme 4: Accessibility to obesity services	
<i>Addressing scheduling issues</i>	<p>“It is really tough for us to have a good schedule to attend the program. We prefer weekends but they only have the night time. And for us it is quite tough.”</p> <p>“If the clinic would allow children at this age to come on his own, he would take more ownership of what he has to do. He still has to go to school, but still if he’s come on his own, I don’t have to juggle two schedules.”</p>
<i>Reducing participation burden</i>	<p>“I just have a really hard time with night driving. I’d be concerned about getting in an accident or something and so the distance. If there was maybe something closer to where people live.”</p> <p>“Um perhaps it [the program] could be condensed and shorter. Shorter time frame but more intense. Um maybe that would help families not having to face such a long commitment.”</p>

References

- Canadian Task Force on Preventive Health Care. Recommendations for growth monitoring, and prevention and management of overweight and obesity in children and youth in primary care. *CMAJ* 2015;187:411–421.
- Barlow SE; Expert Committee. Expert committee recommendations regarding the prevention, assessment, and treatment of child and adolescent overweight and obesity: summary report. *Pediatrics* 2007;120 Suppl 4:S164–92.
- Shaffer LA, Brothers KB, Burkhead TA, Yeager R, Myers JA, Sweeney B. Factors associated with attendance after referral to a pediatric weight management program. *J Pediatr.* 2016;172:35–39.
- Dhaliwal J, Nosworthy NM, Holt NL, Zwaigenbaum L, Avis JL, Rasquinha A, Ball GD. Attrition and the management of pediatric obesity: an integrative review. *Child Obes.* 2014;10:461–473.
- Smith KL, Kerr DA, Howie EK, Straker LM. Do overweight adolescents adhere to dietary intervention messages? Twelve-month detailed dietary outcomes from Curtin University's activity, food and attitudes program. *Nutrients* 2015;7:4363–4382.
- Gillespie J1, Midmore C, Hoeflich J, Ness C, Ballard P, Stewart L. Parents as the start of the solution: a social marketing approach to understanding triggers and barriers to entering a childhood weight management service. *J Hum Nutr Diet.* 2015;28 Suppl 1:83–92.
- Ball GD1, Perez Garcia A, Chanoine JP, Morrison KM, Legault L, Sharma AM, Gokiart R, Holt NL. Should I stay or should I go? Understanding families' decisions regarding

- initiating, continuing, and terminating health services for managing pediatric obesity: the protocol for a multi-center, qualitative study. *BMC Health Serv Res.* 2012;12:486.
- Avis JL, Ambler KA, Jetha MM, Boateng H, Ball GD. Modest treatment effects and high program attrition: The impact of interdisciplinary, individualized care for managing paediatric obesity. *Paediatr Child Health* 2013;18:e59–e63.
- Germann JN, Kirschenbaum DS, Rich BH. Child and parental self-monitoring as determinants of success in the treatment of morbid obesity in low-income minority children. *J Pediatr Psychol.* 2007;32:111–121.
- Newson L, Povey R, Casson A, Grogan S. The experiences and understandings of obesity: families' decisions to attend a childhood obesity intervention. *Psychol Health* 2013;28:1287–1305.
- Skelton JA, Irby MB, Beech BM, Rhodes SD. Attrition and family participation in obesity treatment programs: clinicians' perceptions. *Acad Pediatr.* 2012;12:420–428.
- Lengacher CA¹, Gonzalez LL, Giuliano R, Bennett MP, Cox CE, Reintgen DS. The process of clinical trials: a model for successful clinical trial participation. *Oncol Nurs Forum* 2001;28:1115–1120.
- Banks J, Cramer H, Sharp DJ, Shield JP, Turner KM. Identifying families' reasons for engaging or not engaging with childhood obesity services: A qualitative study. *J Child Health Care* 2014;18:101–110.
- Perez A, Holt N, Gokiart R, Chanoine JP, Legault L, Morrison K, Sharma A, Ball G. Why don't families initiate treatment? A qualitative multicentre study investigating parents'

- reasons for declining paediatric weight management. *Paediatr Child Health* 2015;20:179–184.
- Stockton MB, McClanahan BS, Lanctot JQ, Klesges RC, Beech BM. Identification of facilitators and barriers to participation in weight gain prevention research by African American girls. *Contemp Clin Trials* 2012;33:38–45.
- Grow HM, Hsu C, Liu LL, Briner L, Jessen-Fiddick T, Lozano P, Saelens BE. Understanding family motivations and barriers to participation in community-based programs for overweight youth: one program model does not fit all. *J Public Health Manag Pract*. 2013;19:E1–E10.
- Hampl S, Paves H, Laubscher K, Eneli I. Patient engagement and attrition in pediatric obesity clinics and programs: results and recommendations. *Pediatrics* 2011;128 Suppl 2:S59–S64.
- Thorne S, Reimer-Kirkham S, O’Flynn-Magee K. The Analytic Challenge in Interpretive Description. *Int J Qual Methods* 2004;3:1–11.
- Kuczmariski RJ, Ogden CL, Guo SS, Grummer-Strawn LM, Flegal KM, Mei Z, Wei R, Curtin LR, Roche AF, Johnson CL. 2000 CDC growth charts for the United States: methods and development. *National Center for Health Statistics. Vital Health Stat* 11. 2002;(246):1–190.
- Patton MQ: *Qualitative evaluation and research methods*. 3rd edition. Newbury Park, CA: Sage; 2002.

- Holt NL, Moylan BA, Spence JC, Lenk JM, Sehn ZL, Ball GD: Treatment preferences of overweight youth and their parents in Western Canada. *Qual Health Res.* 2008;18:1206–1219.
- Tremblay M, Perez AJ, Rasquinha AM, Avis JL, Morrison KM, Chanoine JP, Legault L, Holt NL, Gokiert R, Sharma AM, Ball GD. Recommendations from parents to improve health services for managing pediatric obesity in Canada. *Acad Pediatr.* 2016;16:587–593.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* 2006;3:77–101.
- Nguyen B, McGregor KA, O'Connor J, Shrewsbury VA, Lee A, Steinbeck KS, Hill AJ, Shah S, Kohn MR, Baur LA. Recruitment challenges and recommendations for adolescent obesity trials. *J Paediatr Child Health* 2012;48:38–43.
- Gerards SM, Dagnelie PC, Jansen MW, De Vries NK, Kremers SP. Barriers to successful recruitment of parents of overweight children for an obesity prevention intervention: a qualitative study among youth health care professionals. *BMC Fam Pract.* 2012;16:13:37.
- Robson SM, Bolling C, McCullough MB, Stough CO, Stark LJ. A preschool obesity treatment clinical trial: reasons primary care providers declined referrals. *J Pediatr.* 2016;177:262–266.
- Smith KL, Straker LM1, McManus A, Fenner AA. Barriers and enablers for participation in healthy lifestyle programs by adolescents who are overweight: a qualitative study of the opinions of adolescents, their parents and community stakeholders. *BMC Pediatr.* 2014;14:53.

- Perez AJ, Avis JL, Holt NL, Gokiert R, Chanoine JP, Legault L, Morrison KM, Sharma AM, Ball GD. Why do families enroll in pediatric weight management? A parental perspective of reasons and facilitators. *Child Care Health Dev.* 2016;42:278–287.
- Twiddy M, Wilson I, Bryant M, Rudolf M. Lessons learned from a family-focused weight management intervention for obese and overweight children. *Public Health Nutr.* 2012;15:1310–17.
- Dhingra A, Brennan L, Walkley J. Predicting treatment initiation in a family-based adolescent overweight and obesity intervention. *Obesity (Silver Spring)* 2011;19:1307–1310.
- Davis AM, Sampilo M, Gallagher KS, Dean K, Saroja MB, Yu Q, He J, Sporn N. Treating rural paediatric obesity through telemedicine vs. telephone: outcomes from a cluster randomized controlled trial. *J Telemed Telecare.* 2016;22:86–95.
- Appelhans BM, Moss OA, Cerwinske LA. Systematic review of paediatric weight management interventions delivered in the home setting. *Obes Rev.* 2016;17:977–988.
- Holt NL, Neely KC, Newton AS, Knight CJ, Rasquinha A, Ambler KA, Spence JC, Ball GD. Families' perceptions of and experiences related to a pediatric weight management intervention: a qualitative study. *J Nutr Educ Behav.* 2015;47:427–431.
- Whitlock EP1, O'Connor EA, Williams SB, Beil TL, Lutz KW. Effectiveness of weight management interventions in children: a targeted systematic review for the USPSTF. *Pediatrics* 2010;125:e396–418.
- Kumanyika S, Grier S. Targeting interventions for ethnic minority and low-income populations. *Future Child.* 2006;16:187–207.

Chapter 6

Lessons Learned & Future Directions

6.1. Overview of Results

Overall, my research dissertation includes several important findings. Study 1 showed that only about two out of five children referred by their primary care provider to multidisciplinary clinical care (MCC) for weight management enrolled in treatment. Most referred and enrolled children had severe obesity, were aged 2.0–12.0 years old, and lived in urban areas. Treatment clinic and time period between information session and initial appointment booked predicted enrollment. Children's BMI z-score also predicted enrollment, but only in children with severe obesity. Higher BMI z-score within this weight category was associated with lower odds of enrollment. Parents' reasons for not enrolling their referred children in MCC in study 2 were related to *(i)* not perceiving the need for weight management (*e.g.*, not recognizing a weight problem), not perceiving the need for further actions (*e.g.*, believing that the child already had a healthy lifestyle), *(iii)* considering that the recommended care was not suitable or was not the most suitable option (*e.g.*, preference for self-management in addressing the weight issue), and *(iv)* facing internal and external enrollment barriers (*e.g.*, misperceptions about services, scheduling issues). Conversely, parents' reasons for enrolling their referred children in MCC in study 3 were related to *(i)* weight, health, and well-being concerns, *(ii)* perceived need for external support, *(iii)* compliance with a referral made by a physician, and *(iv)* expected benefits of the recommended care (*e.g.*, weight loss, lifestyle improvements, comprehensive assessment of the child's physical and mental health).

Study 3 also showed that facilitators of enrollment were related to *(i)* referral initiator (*e.g.*, parents asking physicians to refer their children to weight management interventions), *(ii)* motivation for treatment (*e.g.*, referring physicians emphasizing the need for and comparative advantages of the recommended care), and *(iii)* barrier control (*e.g.*, absence of major logistic, motivational, and registration barriers, capability to address existing participation barriers).

Based on personal experiences, in study 4 parents made several recommendations to enhance the enrollment of referred children in MCC for obesity management. These recommendations aimed to *(i)* increase the opportunity to enroll (*e.g.*, allowing families to self-refer, making reminder phone calls), *(ii)* inform families and referring physicians about the availability and characteristics of weight management services (*e.g.*, using websites and brochures, providing information on interventions' goals, content, duration, and frequency of appointments), *(iii)* motivate families to enroll (*e.g.*, sharing successful stories), avoiding discouragement (*e.g.*, shortening the enrollment process), and making services more attractive (*e.g.*, having a physical activity component), and *(iv)* facilitate accessibility to services (*e.g.*, having services closer to families' homes, offering multiple options for appointment times). Overall, parents' recommendations were aligned with current guidelines regarding weight management and principles of family-centered care.

6.2. Lessons Learned

In this section, I highlight key lessons learned throughout my doctoral research program from conceptual, methodological, and practical viewpoints.

6.2.1. Conceptual Lessons Learned

6.2.1.1. *Engagement in services is a category that has the potential to integrate the decisions and actions of patients and care providers in relation to pediatric weight management (PWM).*

My doctoral research focused on actual enrollment in MCC care for PWM; however, in most interviews I analyzed, parents talked about their experiences and perceptions in relation to several issues including referral making, orientation sessions, enrollment, dropout, completion of care, quality of services, interactions with healthcare providers, and recommendations to enhance enrollment and retention in weight management services. Gradually, I became aware of the need for a category that had the potential to integrate all of these experiences, perceptions, and interactions, which have been examined separately in the literature. *Engagement in services* may serve to this purpose, although it has been poorly conceptualized (Nobles et al., 2016).

Considering that engagement in services is multi-dimensional and can refer to families and healthcare providers, I understand engagement as *a category of behavior that includes decisions and actions that may or may not benefit patients from available health services* (Perez and Ball, 2017). My doctoral research suggests some dimensions of engagement that may be important to further understand this category, including *issue* (e.g., referral making, enrollment, retention, adherence), *subject* (e.g., children, parents, healthcare professionals), *goal/motivation* (e.g., weight loss, lifestyle improvement, well-being improvement), *performance* (e.g., how much, how well patients' engaged), *barriers and facilitators* (e.g., distance, ability to overcome

existing challenges), and *time* (e.g., when subjects engage and how long). For example, in my studies, I learned that regarding enrollment (issue), parents, children, and health care professionals, including referring physicians and service providers, were the main players (subjects). These players had both similar and different expectations about enrollment (goals). Referring physicians tended to focus on health and weight outcomes, while parents were also interested in their children's emotional well-being, which has been previously reported in the literature (Stewart et al., 2008). I found substantial variability regarding performance in terms of what subjects actually did. For example, some parents did not enroll their children in the recommended care while others initiated treatment, but dropped out of care prematurely. Also, some physicians referred families (proactive) and others made a referral only when families requested it (reactive). Scheduling issues and children's lack of interest in the recommended care were common barriers to enrollment, while absence of barriers and ability to overcome participation challenges enhanced enrollment. Time of enrollment in MCC also varied since some children enrolled when they had overweight and others when they had severe obesity. These dimensions can also guide the analysis of other engagement issues and the strategies to enhance engagement. For example, to enhance some engagement issues (e.g., adherence), some dimensions (e.g., subject, performance) may be more important than others.

6.2.1.2. Enrollment in care for managing pediatric obesity needs to be better defined.

Conceptually, it is important to differentiate between *intended* enrollment and *actual* enrollment. Intended enrollment refers to the intention to enroll, which can be expressed by signing a consent form or simply accepting the recommended care. Actual enrollment, on the

other hand, refers to attending at least one clinical appointment. The importance of differentiating these two concepts resides in the fact that many families seemingly interested in weight management interventions do not actually initiate treatment (Nguyen et al., 2012), which questions the common use of intended enrollment as a proxy indicator of actual enrollment in the engagement literature.

There may be at least three explanations for intenders not to enroll in treatment. First, the reported intention to enroll may differ from the actual intention. This distinction has not been suggested before, but I believe it may have conceptual value since social norms may lead parents to not openly reject an invitation to participate in an intervention to address their children's excess weight. Second, the intention to enroll may be better understood in terms of levels of motivation for obesity treatment, not as an all-or-nothing factor. Consequently, families with lower intention to enroll (*e.g.*, just having a desire to participate) may be less likely to enroll compared with those who are committed to initiating and continuing care for weight management. Third, several factors can negatively influence the translation of the intention to act into actual behavior (Ajzen, 1991). For example, I found that situational factors (*e.g.*, weather, forgetfulness) as well as misperceptions of barriers (*e.g.*, underestimation or unawareness of existing actual barriers) can hamper the actual enrollment of families interested in treatment.

Additionally, enrollment (intended or actual) differs from terms such as *recruitment*, *initiation*, and *participation*, which have all been used interchangeably in the literature. For example, recruitment commonly refers to ways whereby individuals are reached to invite them

to participate in weight management interventions, while initiation refers to the outcome of the decision to enroll. Participation has been commonly used in relation to obesity research (*e.g.*, participation rate in a randomized controlled trial) or to signify the length of patients' engagement in care. Conversely, enrollment provides a sense of process and encompasses recruitment, the decision to enroll, and the outcome of this decision. Thus, better definitions of engagement, enrollment, and related concepts are needed to enhance clarity and specificity.

6.2.1.3. The understanding of enrollment in MCC for managing pediatric obesity cannot be limited to individual-level factors.

In the research protocol (Ball et al., 2012) that provided the methodological framework for two of the studies (studies 2 and 3) included in my dissertation, enrollment was defined as a family decision in which, especially parents, played an important role. However, studies conducted as part of my doctoral research as well as the health literature confirm that although individuals can make a substantial contribution to their health and well-being (Norman & Paul, 2005), factors beyond their control can substantially influence these two outcomes. For example, families' enrollment in MCC for PWM depends on whether children are referred to MCC; however, many eligible children are not referred to care (Gerards et al., 2012). Also, enrollment depends on whether families can act upon their decision to enroll, which may be influenced by contextual factors including distance from treatment venues and appointment time availability. Thus, enrollment can be better understood as a situated process influenced by individual, family, community, organizational (clinic), and systemic factors.

6.2.1.4. Two main pathways seem to lead to the decision to enroll in MCC for PWM: the assessment and the adherence pathway.

Our data suggested that the intention to enroll is dynamic and fluctuates throughout the enrollment process depending on new information and experiences (sources of influence), which in turn, depend on how the enrollment process is structured. Further, I found that there were two main pathways leading to the intention to enroll, namely the assessment and the adherence pathways. These pathways suggest that the intention to enroll can be either deliberated or assimilated. Deliberated intentions were based on several subjective assessments including the assessment of the need for weight management (status level), the need for further actions (action level), the relative suitability of the recommended care compared with alternative options (option level), and the perceived personal capability to manage internal and external barriers (implementation level). A positive assessment of all these issues appeared to be necessary for making the decision to enroll. In fact, I found that many parents did not enroll their children in MCC because, despite recognizing the need for weight management and further actions, and the suitability of the recommended care, they did not perceive themselves as capable of overcoming either internal (*e.g.*, personal health problems) or external (*e.g.*, distance) enrollment barriers. Conversely, assimilated intentions were not deliberately formed, but passively taken from an external and credible source. For example, some families started treatment simply because their physicians asked them to enroll in a weight management program. Factors underlying this pathway warrant further examination. Relationship with and trust in referring physicians, personal health approach (*e.g.* physicians seen as authority figures

whose advice must be followed), and cultural values may also play important roles. Additionally, referrals may act as cues to actions (Becker, 1974) for parents who were already concerned about their children's excess weight. Overall, these two pathways suggest that providing referrals exclusively may work for families prone to the adherence pathway; for others, it may be necessary to alter their views of the weight issue and the effectiveness of the recommended care. **Figure 6.1** shows a comprehensive framework of factors influencing the decision to enroll and actual enrollment.

6.2.2. Methodological Lessons Learned

6.2.2.1. More qualitative interpretative and quantitative explanatory inquiries are needed to better understand the decision to enroll in weight management services.

The qualitative literature on enrollment in PWM interventions is limited and descriptive in nature. This is understandable considering that, as a topic of research, enrollment is in its infancy. Most qualitative studies conducted to date (Perez et al., 2016; Grow et al., 2013) have been limited to characterize reasons for and facilitators of (non)enrollment. Some of these studies have not progressed beyond a descriptive summary of the manifest content of participants' remarks. Consequently, underlying assumptions, motivations, perceptions, values, and contextual influences concerning enrollment warrant further exploration and higher levels of integration through more interpretative inquiries like phenomenology (Husserl, 1982) and grounded theory (Glaser & Strauss, 1967). In fact, grounded theory is a suitable method to understand the complexity of the decision to enroll, which by no means can be reduced to reported enrollment reasons and facilitators. On the other hand, most quantitative studies on

enrollment have been cross-sectional. This design allows researchers to identify predictors of enrollment and delineate the profile of those most and least likely to enroll in treatment; however, it provides insufficient evidence on the determinants of enrollment for which randomized controlled studies may be more suitable.

6.2.2.2. Several methods of data collection must be used to understand engagement-related decisions including the decision to enroll in weight management services.

To date, qualitative inquiries on enrollment have relied on interview data, which help to understand individuals' perspectives, but it has limited ability to understand health decisions. For example, it cannot be assumed that interviewees are fully aware of the determinants of their decisions or that they would be capable of articulating them in the context of a semi-structured interview process. In fact, individuals may not be able to report key details, things taken for granted, sensitive issues, or contextual factors (Gee, 1999; Patton, 1990). For instance, the documented influence of portion size, variability of food, and easy access over quantity and quality of food intake (Hardman et al., 2015; Hanks et al., 2012) may be overlooked by individuals asked to describe their food choices. Ultimately, individuals share their interpretations of the decisions they made (their stories), not necessarily an accurate account of the internal and external factors that shaped those decisions. Consequently, data from other sources including observations, analysis of documents, field notes, and questionnaires should be integrated to enhance the credibility of researchers' interpretations of health decisions of patients and care providers.

6.2.2.3. Face validity is not sufficient to demonstrate the effectiveness and feasibility of patients' recommendations to enhance weight management services and engagement issues including enrollment.

In the health literature, many recommendations to improve the quality of services are based on patients' recommendations. Although strategies to improve these services are likely to be effective if they reflect patients' views, values, and circumstances (Grow et al., 2013), patients' perspectives on how to improve engagement and services are not sufficient to prove the effectiveness and feasibility of their recommendations, which need to be tested empirically. In this regard, stakeholders could implement recommendations that they consider appropriate and generate the necessary data to demonstrate their effectiveness. Additionally, three lines of research may contribute to this end, including: *(i)* careful examination of successful programs in terms of recruitment and enrollment (best practices), *(ii)* systematic reviews to synthesize patients', care providers', and researchers' recommendations to enhance enrollment at family, organizational, community, and societal levels that also evaluate the amount and quality of the evidence supporting those recommendations, and *(iii)* effectiveness (vs efficacy) clinical trials to determine whether real-life circumstances impact the feasibility of families' recommendations to enhance service delivery and engagement in care.

6.2.3. Practical Lessons Learned

This section focuses on recruitment, especially physicians' referrals, information sessions as a key component of the enrollment process, and strategies to facilitate the enrollment of families in weight management services. Level of care, type of intervention, target

population, and context must be taken into consideration to generalize the practical lessons derived from my dissertation.

6.2.3.1. Several recruitment methods tailored to target groups should be used to enhance enrollment in MCC for obesity management.

For the most part, patients are recruited into MCC for PWM through physicians' referrals. While this recruitment method helps to ensure their eligibility for this level of care, many eligible children are not referred or do not initiate treatment. Given that not only family-related (*e.g.*, no recognition of the weight problem, resistance to discuss the weight issue), but also physician-related factors (*e.g.*, perceived and actual lack of counselling skills and fear of upsetting families) negatively affect enrollment (Gerards et al., 2012), additional modes of recruitment may need to be implemented considering their respective strengths and limitations. For example, passive methods of recruitment including newspaper advertisements, newsletters, brochures, and radio can reach more potential participants (Nguyen et al., 2012) and better inform them about obesity services; as we found (chapter 5), referring physicians may be unaware or ill-informed about available services. Targeted mailing, which is also an active method of recruitment, may have similar advantages to referrals. Besides capitalizing on their respective advantages, employing several methods of recruitment can produce positive synergies so that some methods may support others. In this regard, we found that some parents who learned about multidisciplinary clinics through friends and brochures asked their family doctors to be referred, which triggered the referral and facilitated enrollment.

6.2.3.2. *Enhancing treatment motivation as the primary goal of orientation sessions*

The rationale behind pre-clinic orientation sessions is not always clear; however, they seem to serve two main purposes. One purpose is to inform families about services to help them assess whether they are ready for treatment and committed to meeting treatment demands. Although a practical approach, this argument can be challenged from an ethical standpoint since enhancing readiness for treatment, especially among those who need it, should be part of the scope of practice of both referring physicians and weight management service providers. The second purpose is to inform participants as a way of enhancing their motivation for treatment. Information about services *per se* may have a limited impact on treatment motivation. Indeed, prominent theories of behavior (*e.g.*, Theory of Planned Behavior, Social Cognitive), which have largely focused on the motivational stage (*vs.* volitional stage) of behavioral performance (Norman & Paul, 2005), do not support the notion that informing individuals about certain courses of actions increases their likelihood of undertaking those actions. According to the Protection Motivation Theory (Rogers, 1975), more than describing services in itself, what may influence motivation is whether the information provided enhances individuals' perceived effectiveness of recommended protective actions (*e.g.*, enrolling in obesity programs) to address a serious health threat they experience or perceive they could develop if protective actions are not taken. Further, behavioral theorists agree that perceived personal capability to perform protective actions is even a better predictor of behavioral performance compared with the effectiveness attributed to certain actions (Norman & Paul, 2005). Consequently, the primary goal of pre-clinic orientation sessions should be to enhance families' readiness for treatment.

The development of orientation sessions should be theoretically guided, since theories of behaviors, including those previously mentioned, highlight the main constructs (*e.g.*, perceived severity of and susceptibility to a health problem, self-efficacy) that need to be targeted to enhance the intention to enroll and actual enrollment in obesity interventions.

Additionally, besides redefining their primary goal, information sessions should avoid discouraging families to enroll in treatment. We found that children, in particular, may get discouraged due to the amount and type of information provided. Thus, instead of *adult-oriented* orientation sessions, as some parents described them, these sessions should appeal to both parents and children. Overall, sessions should enhance families' motivation to enroll in treatment, commit to regular attendance, and implement lifestyle changes.

6.2.3.3. Referral making and enrollment need to be optimized

Studies conducted as part of PhD suggested that *(i)* referral providers should be encouraged to refer children who do not have severe obesity, *(ii)* nurse practitioners should refer more children in need for specialized care for weight management, *(iii)* physicians should be more proactive in referring families instead of waiting for families to request the referral, and *(iv)* the current criteria regarding who are allowed to refer (*e.g.*, physicians and nurse practitioners only) and enroll (*e.g.*, professionally referred children only) may need to be reconsidered. For example, allowing self-referred families to enroll may increase treatment initiation since these families may be more ready for treatment than professionally referred families. However, this type of strategy should be considered with caution since, for example, many motivated families may benefit from less structured and expensive stages of care for

PWM (Barlow et al. 2007) including office-based brief counselling and structured care provide by primary care providers and weight management specialists (e.g., a dietitian), respectively.

Regarding enrollment, conducted studies suggested that (i) the enrollment process should be structured in a way that provides further enrollment opportunities, motivates families to initiate treatment, and ameliorates the impact of enrollment barriers, (ii) clinics should strive to reduce the duration of the enrollment process so that families do not lose their initial motivation for treatment, (iii) organizational factors should be examined and addressed given observed differences between clinics regarding enrollment levels, and (iv) special consideration should be given to the enrollment of children with severe obesity who may face additional health and logistic challenges to initiate treatment.

6.2.3.4. Referring physicians and obesity services providers can use the “enrollment staging system” as a guiding framework to help families enroll in MCC for obesity management.

My doctoral research suggested that families are at different stages of readiness for treatment. Some families may not perceive the need for weight management or may not recognize that a condition exists that needs to be addressed. Others may not perceive the need for further actions assuming that the actions already undertaken are protective enough to prevent further weight gain. Still others may regard that some actions need to be taken, but do not believe that the recommended care is the most suitable option at hand. Further, there are families who may think that the recommended care is appropriate, but perceived barriers prevent them from making the decision to enroll. Lastly, some families may form the decision

to enroll, but after attending the orientation session, realize that they were unaware of additional barriers or that they underestimated the impact of previously considered barriers.

The use of an enrollment staging system suggests that strategies to enhance enrollment should be taken in accordance with families' stage of readiness. Some strategies that may be useful in each stage are presented below.

Stage 1: Not perceiving the need for weight management

- Raising the weight issue in a sensitive manner, using objective data, and focusing on health as the primary outcome of the need for taking actions.
- Using growth charts to accurately assess and communicate children' weight status.
 - Discussing with families the advantages of this method over visual assessment.
 - Assessing the trajectory/history of children's weight status.
- Assessing other risk factors including family obesity, lifestyle habits, and presence of weight-related comorbidities.
- Discussing children's risk for further weight gain and health problems based on the risk assessment performed.

Stage 2: Not perceiving the need for further actions

- Exploring the actions that families have undertaken to prevent further weight gain.
- Determining how long families have been undertaking those actions and their outcomes.
- Setting a follow-up appointment to assess the effectiveness of implemented actions.
- In the follow-up appointment, assessing whether further actions are necessary, including structured or multidisciplinary care for managing pediatric obesity.

Stage 3: Not perceiving the recommended care as the most suitable option

- Exploring all the options that families may have considered to address the weight issue.
- Discussing with families the pros and cons of each option, especially self-management.
- Providing families with adequate and accurate information about the recommended care.
- Highlighting the relative benefits of the recommended care in terms of assessment of physical and mental health, effectiveness of services, level of support and structure, and experience of care providers.
- Using reliable data and experiences of success from other families to support the effectiveness of MCC.

Stage 4: Perceiving internal and external barriers to enrolling in the recommended care

- Exploring internal and external enrollment barriers.
- Identifying misperceived barriers that could be addressed by providing accurate information about services.
- Informing families of the support that may be available to address some participation barriers.
- Exploring alternative modes of treatment delivery (e.g., home visit, tele-conferencing) that could ameliorate the impact of accessibility barriers.

Stage 5: Experiencing enrollment barriers

- Identifying barriers that families encountered when enrolling in treatment.
- Providing support to address these barriers accordingly.

- Re-scheduling initial appointments, especially if barriers were related to situational factors.
- Using the intention implementation model (Gollwitzer, 1993), which helps to define how, when, and where enrollment-related actions will be performed.

6.3. Concluding Remarks

In PWM to date, the primary focus has included the structure, delivery, and content of interventions whereas the engagement of patients and healthcare providers in obesity interventions has been a secondary issue. This is of concern for two main reasons. First, positive weight and health outcomes of weight management interventions depend on both the quality of services and optimal engagement of patients and healthcare professionals. Second, many eligible children for weight management interventions are not referred, many referred children do not enroll, and many enrolled children leave care prematurely or do not adhere to treatment recommendations.

The suboptimal engagement of patients and healthcare professionals in all level of care has been widely documented (Barlow et al., 2007). Particularly, the poor enrollment of referred children in MCC is worrying given that to date, this stage of care has demonstrated to be the most effective treatment option for PWM (Whitlock et al., 2010).

My doctoral research suggested that primary care providers should be more proactive in referring eligible children, especially those who were in the overweight and obese categories, who are also those more likely to benefit from lifestyle interventions compared with children with severe obesity (Reinehr et al., 2011). Special attention should also be given to the

enrollment of children with severe obesity who seem to face additional challenges to enroll in treatment. Further, service providers should partner with primary care physicians to inform them about available services and help them to motivate families to enroll in specialized care for obesity management. Service providers should also inform the public about available services using different means (*e.g.*, websites, brochures). Informed families may request a referral if they are concerned about their children's weight status and believe that specialized care is the most effective option to address their children's excess weight.

Of the sufficient conditions to perform behaviors including possessing the required skills and knowledge, being motivated, and not facing major barriers (*e.g.*, lack of services) (Fishbein et al., 2001), the last two played a major role in enrollment in MCC. Thus, a lack of enrollment was mainly due to lack of families' motivation and perceived/faced barriers to enrolling in treatment. Given that referred families were at different stages of readiness for enrollment primarily based on these two conditions, referral providers and weight management service providers are encouraged to explore families' readiness for treatment and act accordingly. Although still in a preliminary stage of development, the proposed enrollment staging system may serve as a guiding framework for this purpose, especially if supported by other behavioral tools including motivational interviewing (Miller, 2010) and the intention implementation model (Gollwitzer, 1993). In this regard, along with enhancing families' readiness for enrollment and making obesity services more appealing to parents and children, avoiding families from getting discouraged (*e.g.*, using sensitive language, shortening the enrollment process) may also help to improve enrollment.

In my study on recommendations to improve enrollment (chapter 5), parents made several recommendations to enhance the motivation to enroll (*e.g.*, sharing successful stories, highlighting the relative advantages of the recommended care over alternative options) and the opportunity to enroll (*e.g.*, allowing families to self-refer, and ameliorating the effect of logistical barriers including transportation and parking). Also, the study on reasons for and facilitators of enrollment suggested the need for *(i)* tailoring motivational strategies to families' weight and health concerns and expected benefits from interventions and *(ii)* capitalizing on family and contextual facilitators of enrollment. Additionally, the study on predictors of enrollment (chapter 2) suggested that addressing organizational level factors including shortening the duration of the enrollment process may enhance treatment initiation, which is aligned with parents' recommendation to enhance enrollment (chapter 5). Unfortunately, little has been documented about strategies to enhance enrollment, while parents' recommendations, although promising, remain to be evaluated empirically. Overall, findings of my doctoral research suggest that a one-size-fits-all approach is unsuitable to address the low enrollment of referred children in MCC for obesity management. Instead, evidence-based strategies that are tailored to families' treatment expectations, address participation barriers, and optimize facilitators of enrollment need to be developed.

6.4. Future Directions

1. Barriers to and facilitators of the engagement of patients and healthcare providers in each stage of care for managing pediatric obesity in Canada (brief counselling, structured care, multidisciplinary care, and tertiary care) need to be further examined.

Interactions between stages of care also require additional examination. For example, it is unknown whether primary care physicians referred patients to structured or multidisciplinary care because of the low response to brief counselling interventions or because they lacked training and confidence to counsel their patients. This evaluation will suggest areas for improvement in order to optimize engagement at each stage.

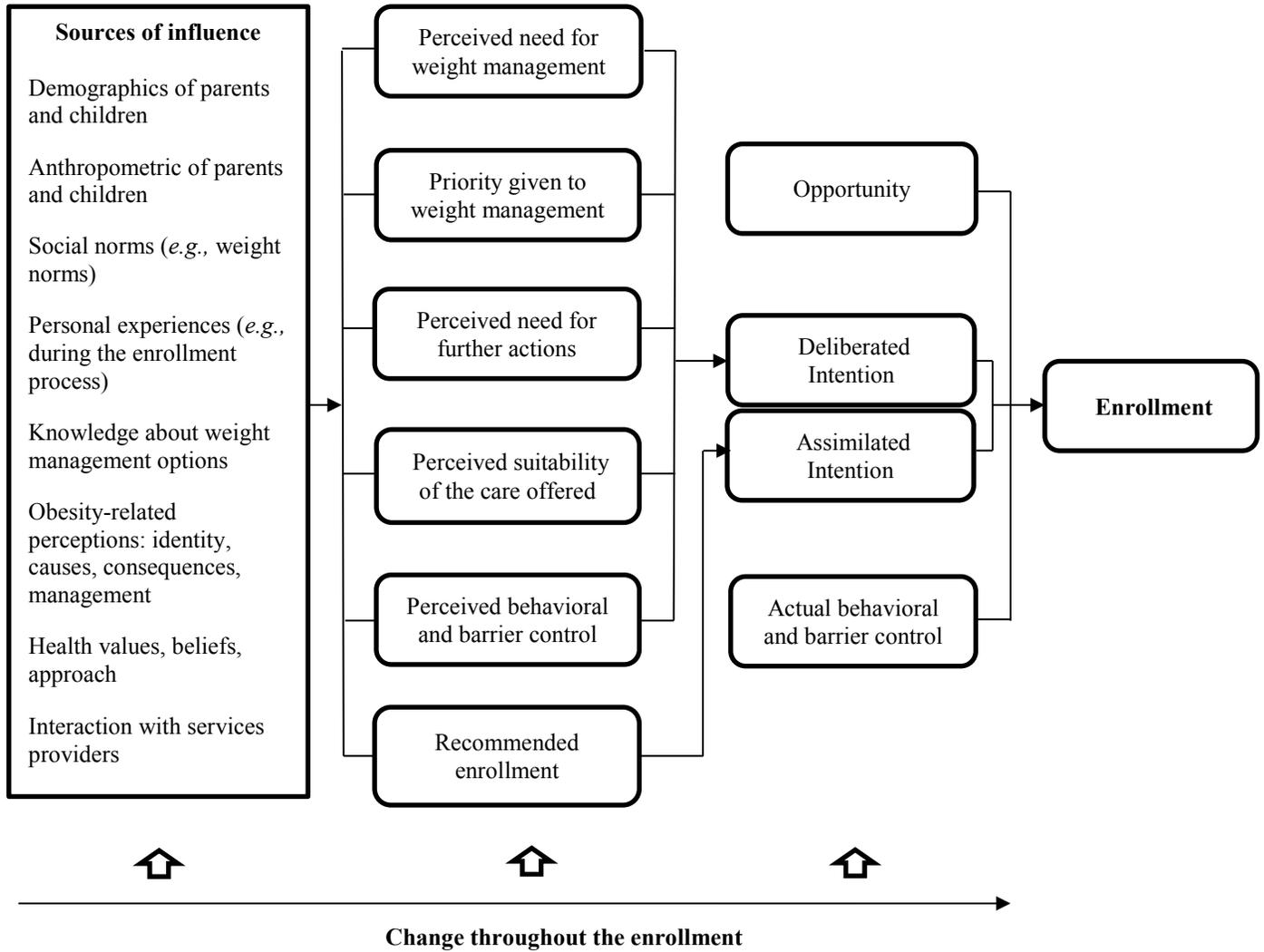
2. Given that the literature on enrollment in interventions for managing pediatric obesity has grown in recent years, a systematic review can be conducted to better define enrollment level, factors underlying enrollment, and enablers of enrollment. This review should differentiate enrollment in weight management *research* from enrollment in weight management *health services*, and enrollment at each stage of care (brief counselling, structured care, multidisciplinary care, and tertiary care) for PWM.
3. A qualitative synthesis of recommendations to enhance enrollment suggested in quantitative and qualitative studies may need to be conducted to determine common recommendations and the quantity and quality of the evidence supporting those recommendations. The results of this synthesis could inform experimental research whereby the feasibility and effectiveness of common recommendations can be determined empirically.
4. Children's actual weight status, treatment clinic, and time period between orientation sessions and first clinical appointment as the only predictors of enrollment in MCC, suggested that additional individual- and context-level variables need to be considered as potential predictors of enrollment. The explanatory framework suggested in this

chapter, which is based on the findings of the four studies conducted as part of my PhD, offers a set of variables that may predict both intended and actual enrollment. Therefore, the explanatory value of its constructs and the framework as a whole need to be tested.

5. Given the low enrollment of children with severe obesity and the scant literature on utilization of weight management services among these children, further research is warranted to explore barriers to and facilitators of enrollment in MCC for weight management within this sub-group, which we know is at higher health risk (Bass & Eneli, 2015) and lower likelihood of achieving successful weight management (Reinehr, 2011).
6. Although my doctoral research provided some insights, engagement in obesity services and key engagement issues including enrollment, retention, and adherence warrant further conceptualization. For example, employing the Delphi method (Hasson et al., 2000) with a panel of experts in these issues may be useful to accomplish this goal. Further, grounded theory method can be used to better understand the decision to enroll in obesity interventions.
7. Based on my doctoral research and studies on enrollment cited in previous chapters, tools can be developed to assess families' readiness for enrollment and barriers to and facilitators of enrollment. As part of obesity prevention and management efforts, experts and organizations (Canadian Task Force on Preventive Health Care, 2015; Barlow et al., 2007) have endorsed a comprehensive assessment of children's (*e.g.*, actual weight status, lab results) and families' (*e.g.*, history of obesity within the family)

characteristics including readiness for treatment. This recommendation has not had a practical and evidence-based translation into enrollment in MCC for PWM. Consequently, the suggested staging system can be refined and empirically tested for this purpose.

Figure 6.1. Explanatory framework of enrollment in multidisciplinary clinical care for pediatric weight management



References

- Ajzen, I. The theory of planned behavior. *Organ Behav Hum* 1991;50:179–211.
- Barlow SE; Expert Committee. Expert committee recommendations regarding the prevention, assessment, and treatment of child and adolescent overweight and obesity: summary report. *Pediatrics* 2007;120 Suppl 4:S164–192.
- Bass R, Eneli I. Severe childhood obesity: an under-recognised and growing health problem. *Postgrad Med J*. 2015;91:639–45.
- Becker MH. The health belief model and sick role behavior. *Health Educ Monogr* 1974;2:409–19.
- Canadian Task Force on Preventive Health Care. Recommendations for growth monitoring, and prevention and management of overweight and obesity in children and youth in primary care. *CMAJ* 2015;187:411–421.
- Fishbein, M. Triandis, H. C., Kanfer, F. H., Becker M., Middlestadt, S. E. and Eichler, A. Factors influencing behavior and behavior change, in A. Baum, T. A. Revenson and J. E. Singer (eds) *Handbook of Health Psychology*. Mahwah, NJ: Lawrence Erlbaum Associates; 2001. p. 3–17.
- Gerards SM, Dagnelie PC, Jansen MW, De Vries NK, Kremers SP. Barriers to successful recruitment of parents of overweight children for an obesity prevention intervention: a qualitative study among youth health care professionals. *BMC Fam Pract* 2012;13:37.
- Glaser BG, Strauss A. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago, IL: Aldine Publishing Co; 1967.

- Gollwitzer PM. Goal achievement: the role of intentions. *Eur Rev Soc Psychol* 1993;4:142–185.
- Grow HM, Hsu C, Liu LL, Briner L, Jessen-Fiddick T, Lozano P, Saelens BE. Understanding family motivations and barriers to participation in community-based programs for overweight youth: one program model does not fit all. *J Public Health Manag Pract*. 2013;19:E1–E10.
- Hasson F, Keeney S, McKenna H. Research guidelines for the Delphi survey technique. *J Adv Nurs*. 2000;32:1008–1015.
- Husserl E. *Ideas Pertaining to a Pure Phenomenology and to a Phenomenological Philosophy: First Book: General Introduction to a Pure Phenomenology.*, M. Nijhoff, Hingham, MA; 1982.
- Miller NH. Motivational interviewing as a prelude to coaching in healthcare settings. *J Cardiovasc Nurs* 2010;25:247–251.
- Nguyen B, McGregor KA, O'Connor J, Shrewsbury VA, Lee A, Steinbeck KS, Hill AJ, Shah S, Kohn MR, Baur LA. Recruitment challenges and recommendations for adolescent obesity trials. *J Paediatr Child Health* 2012;48:38–43.
- Nobles J, Griffiths C, Pringle A, Gately P. Design programmes to maximise participant engagement: a predictive study of programme and participant characteristics associated with engagement in paediatric weight management. *Int J Behav Nutr Phys Act* 2016;13:76.

- Norman M, Paul P. Predicting Health Behavior: A Social Cognitive Approach. In: M. Conner & P. Norman (Eds.), *Predicting Health Behaviour: Research and Practice with Social Cognition Models*. Open University Press, Maidenhead; 2005. p. 81–126.
- Perez AJ, Ball GD. Paradoxically speaking about engagement in pediatric weight management. *Pediatr Obes*. 2017 Feb 16. doi: 10.1111/ijpo.12207. [Epub ahead of print].
- Perez A, Avis J, Holt N, Gokiert R, Chanoine JP, Legault L, Morrison K, Sharma A, Ball G. Why do families enroll in pediatric weight management? A parental perspective of reasons and facilitators. *Child Care Health Dev* 2016;42:278–287.
- Reinehr T. Effectiveness of lifestyle intervention in overweight children. *Proc Nutr Soc* 2011; 70: 494–505.
- Rogers, R.W. A protection motivation theory of fear appeals and attitude change. *J Psychol* 1975;91:93–114.
- Stewart L, Chapple J, Hughes AR, Poustie V, Reilly JJ. Parents' journey through treatment for their child's obesity: a qualitative study. *Arch Dis Child* 2008;93:35–9.
- Whitlock EP, O'Connor EA, Williams SB, Beil TL, Lutz KW. Effectiveness of weight management interventions in children: a targeted systematic review for the USPSTF. *Pediatrics*. 2010;125:e396–418.

Bibliography

- Ajzen I. The theory of planned behavior. *Organ Behav Hum* 1991;50:179–211.
- Alff F, Markert J, Zschaler S, Gausche R, Kiess W, Blüher S. Reasons for (non)participating in a telephone-based intervention program for families with overweight children. *PLoS One* 2012;7:e34580.
- Ambler KA, Hagedorn DW, Ball GD. Referrals for pediatric weight management: the importance of proximity. *BMC Health Serv Res* 2010;10:302.
- Andersen RM. Revisiting the behavioral model and access to medical care: does it matter? *J Health Soc Behav.* 1995;36:1–10.
- American Academy of Pediatrics. Family-centered care and the pediatrician's role. *Pediatrics* 2003;112:691–697.
- Andreyeva T, Puhl RM, Brownell KD. Changes in perceived weight discrimination among Americans, 1995–1996 through 2004–2006. *Obesity* 2008;16:1129–1134.
- Appelhans BM, Moss OA, Cerwinski LA. Systematic review of paediatric weight management interventions delivered in the home setting. *Obes Rev.* 2016;17:977–88.
- Arriscado D, Muros JJ, Zabala M, Dalmau JM. Factors associated with low adherence to a Mediterranean diet in healthy children in northern Spain. *Appetite* 2014;80:28–34.
- August GP, Caprio S, Fennoy I, Freemark M, Kaufman FR, Lustig RH, Silverstein JH, Speiser PW, Styne DM, Montori VM. Prevention and treatment of pediatric obesity: an endocrine society clinical practice guideline based on expert opinion. *J Clin Endocrinol Metab* 2008;93:4576–4599.

- Avis JL, Ambler KA, Jetha MM, Boateng H, Ball GD. Modest treatment effects and high program attrition: the impact of interdisciplinary, individualized care for managing paediatric obesity. *Paediatr Child Health* 2013;18:e59–e63
- Bagozzi RP. The self-regulation of attitudes, intentions, and behavior. *Soc Psychol Quart* 1992;55:178–204.
- Ball GDC, Farnesi BC, Newton AS, Holt NL, Gellar J, Johnson ST, Matteson C, Sharma AM, Finegood DT. Join the conversation! The development and preliminary application of Conversation Cards© in pediatric weight management. *J Nutr Educ Behav* 2013;45:476–8.
- Ball GDC, Perez Garcia A, Chanoine JP, Morrison KM, Legault L, Sharma AM, Gokiert R, Holt NL. Should I stay or should I go? Understanding families' decisions regarding initiating, continuing, and terminating health services for managing pediatric obesity: A qualitative study protocol. *BMC Health Serv Res* 2012;12:486.
- Ball GD, Ambler KA, Chanoine JP. Pediatric weight management programs in Canada: where, what and how? *Int J Pediatr Obes* 2011;6:e58–e61.
- Ball GD, Mackenzie-Rife KA, Newton MS, Alloway CA, Slack JM, Plotnikoff RC, Goran MI. 2011. One-on-one lifestyle coaching for managing adolescent obesity: findings from a pilot, randomized controlled trial in a real-world, clinical setting. *Paediatr Child Health* 2011;16:345–350.
- Bandura, A. Self-efficacy mechanism in human agency. *Am Psychol* 1982;37:122–147.

- Banks J, Cramer H, Sharp DJ, Shield JP, Turner KM. Identifying families' reasons for engaging or not engaging with childhood obesity services: A qualitative study. *J Child Health Care* 2014;18:101–10.
- Barlow SE; Expert Committee. Expert committee recommendations regarding the prevention, assessment, and treatment of child and adolescent overweight and obesity: summary report. *Pediatrics* 2007;120 Suppl 4:S164–192.
- Barlow SE, Ohlemeyer CL. Parent reasons for nonreturn to a pediatric weight management program. *Clin Pediatr* 2006;45:355–360.
- Bass R, Eneli I. Severe childhood obesity: an under-recognised and growing health problem. *Postgrad Med J*. 2015;91:639–45.
- Becker MH. The health belief model and sick role behavior. *Health Educ Monogr* 1974;2:409–19.
- Black JA, Park M, Gregson J, Falconer CL, White B, Kessel AS, Saxena S, Viner RM, Kinra S. Child obesity cut-offs as derived from parental perceptions: cross-sectional questionnaire. *Br J Gen Pract* 2015; 65:e234–e239.
- Blumer H. *Symbolic interactionism: perspective and method*. Englewood Cliffs, NJ: Prentice Hall; 1969.
- Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness. *JAMA* 2002;288:1775–1779.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3:77–101.

- Brook E, Cohen L, Hakendorf P, Wittert G, Thompson C. Predictors of attendance at an obesity clinic and subsequent weight change. *BMC Health Serv Res.* 2014 Feb 20;14:78.
- Butt G, Markle-Reid M, Browne G. Interprofessional partnerships in chronic illness care: a conceptual model for measuring partnership effectiveness. *Int J Integr Care* 2008;8:e08.
- Canadian Task Force on Preventive Health Care. Recommendations for growth monitoring, and prevention and management of overweight and obesity in children and youth in primary care. *CMAJ* 2015;187:411–421.
- Carson V, Spence JC, Cutumisu N, Boule N, Edwards J. Seasonal variation in physical activity among preschool children in a northern Canadian city. *Res Q Exerc Sport.* 2010;81:392–9.
- Center for Advancing Health. A New Definition of Patient Engagement: What is Engagement and Why is it Important? [accessed on January 16, 2011]. Available at http://www.cfah.org/pdfs/CFAH_Engagement_Behavior_Framework_current.pdf.
- Charmaz, K. *Constructing grounded theory: A practical guide through qualitative Analysis.* London: Sage; 2014.
- Cheng JK, Wen X, Coletti KD, Cox JE, Taveras EM. 2-year BMI changes of children referred for multidisciplinary weight management. *Int J Pediatr.* 2014;2014:152586.
- Chomitz VR, Collins J, Kim J, Kramer E, McGowan R. Promoting healthy weight among elementary school children via a health report card approach. *Arch Pediatr Adolesc Med* 2003;157:765–772.

- Committee on Hospital Care. American Academy of Pediatrics. Family-centered care and the pediatrician's role. *Pediatrics* 2003; 112:691–697.
- Corder K, Sharp SJ, Atkin AJ, Andersen LB, Cardon G, Page A, Davey R, Grøntved A, Hallal PC, Janz KF, Kordas K, Kriemler S, Puder JJ, Sardinha LB, Ekelund U, van Sluijs EM; International Children's Accelerometry Database (ICAD) Collaborators. Age-related patterns of vigorous-intensity physical activity in youth: The International Children's Accelerometry Database. *Prev Med Rep* 2016;4:17–22.
- Cote MP, Byczkowski T, Kotagal U, Kirk S, Zeller M, Daniels S. Service quality and attrition: an examination of a pediatric obesity program. *Int J Qual Health Care* 2004;16:165–173.
- Creswell JW, Fetters MD, Ivankova NV. Designing a mixed methods study in primary care. *Ann Fam Med* 2004;2:7–12.
- Creswell JW. *Qualitative research and research design: choosing among five traditions*. Thousand Oaks, CA: Sage Publications; 1997.
- Cruz ML, Shaibi GQ, Weigensberg MJ, Spruijt-Metz D, Ball GD, Goran MI. Pediatric obesity and insulin resistance: chronic disease risk and implications for treatment and prevention beyond body weight modification. *Annu Rev Nutr* 2005;25:435–468.
- Cruz TH, Davis SM, FitzGerald CA, Canaca GF, Keane PC. Engagement, recruitment, and retention in a trans-community, randomized controlled trial for the prevention of obesity in rural American Indian and Hispanic children. *J Prim Prev* 2014;35:135–49.

- Cui Z, Seburg EM, Sherwood NE, Faith MS, Ward DS. Recruitment and retention in obesity prevention and treatment trials targeting minority or low-income children: a review of the clinical trials registration database. *Trials* 2015;16:564.
- Dhaliwal J, Nosworthy NM, Holt NL, Zwaigenbaum L, Avis JL, Rasquinha A, Ball GD. Attrition and the management of pediatric obesity: an integrative review. *Child Obes* 2014;10:461–473.
- Dhingra A, Brennan L, Walkley J. Predicting treatment initiation in a family-based adolescent overweight and obesity intervention. *Obesity (Silver Spring)* 2011;19:1307–10.
- Dilley K, Martin L, Sullivan C, Seshadri R, Binns H. Identification of overweight status is associated with higher rates of screening for comorbidities of overweight in pediatric primary care practice. *Pediatrics* 2007;119:148–155.
- DMTI Spatial. CanMap Content Suite - Platinum Postal Code, 2001-2015 [digital data] <http://www.dmtispatial.com/canmap/> (2016).
- Domecq JP, Prutsky G, Elraiyah T, Wang Z, Nabhan M, Shippee N, Brito JP, Boehmer K, Hasan R, Firwana B, Erwin P, Eton D, Sloan J, Montori V, Asi N, Dabrh AM, Murad MH. Patient engagement in research: a systematic review. *BMC Health Serv Res* 2014;14:89.
- Drieschner KH, Lammers SM, Van Der Staak CP. Treatment motivation: An attempt for clarification of an ambiguous concept. *Clin Psychol Rev* 2004;23:1115–1137.
- Ebbeling CB, Pawlak DB, Ludwig DS. Childhood obesity: public-health crisis, common sense cure. *Lancet* 2002;360:473–482.

- Eckstein KC, Mikhail LM, Ariza AJ, Thomson JS, Millard SC, Binns HJ; Pediatric Practice Research Group. Parents' perceptions of their child's weight and health. *Pediatrics* 2006;117:681–690.
- Edvardsson K, Edvardsson D, Hörnsten A. (2009) Raising issues about children's overweight—maternal and child health nurses' experiences. *J Adv Nurs* 2009;65:2542–51.
- Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs* 2008;62:107–15.
- Esri. ArcGIS Desktop, Release 10.5 [software] <http://www.esri.com> (2015).
- Davis AM, Sampilo M, Gallagher KS, Dean K, Saroja MB, Yu Q, He J, Sporn N. Treating rural paediatric obesity through telemedicine vs. telephone: outcomes from a cluster randomized controlled trial. *J Telemed Telecare* 2016;22:86–95.
- Dawson AM, Brown DA, Cox A, Williams SM, Treacy L, Haszard J, Meredith-Jones K, Hargreaves E, Taylor BJ, Ross J, Taylor RW. Using motivational interviewing for weight feedback to parents of young children. *J Paediatr Child Health* 2014;50:461–470.
- Dhaliwal J, Nosworthy NM, Holt NL, Zwaigenbaum L, Avis JL, Rasquinha A, Ball GD. Attrition and the management of pediatric obesity: an integrative review. *Child Obes* 2014; 10:461–473.
- Dhingra A, Brennan L, Walkley J. Predicting treatment initiation in a family-based adolescent overweight and obesity intervention. *Obesity (Silver Spring)* 2011;19:1307–1310.
- Doolen J, Alpert PT, Miller SK. Parental disconnect between perceived and actual weight status of children: A metasynthesis of the current research. *J Am Acad Nurse Pract* 2009;21:160–166.

- Ebbeling CB, Pawlak DB, Ludwig DS. Childhood obesity: public-health crisis, common sense cure. *Lancet* 2002; 360:473–482.
- Fabricatore AN, Wadden TA, Moore RH, Butryn ML, Gravallesse EA, Erondu NE, Heymsfield SB, Nguyen AM. Attrition from randomized controlled trials of pharmacological weight loss agents: a systematic review and analysis. *Obes Rev* 2009;10:333–341.
- Finley CE, Barlow CE, Greenway FL, Rock CL, Rolls BJ, Blair SN. Retention rates and weight loss in a commercial weight loss program. *Int J Obes* 2007;31:292–298.
- Finne E, Reinehr T, Schaefer A, Winkel K, Kolip P: Overweight children and adolescents—is there a subjective need for treatment? *Int J Public Health* 2009;54:112–116.
- Fishbein M, Yzer M. Using theory to design effective health interventions. *Commun Theor* 2003;13:164–183.
- Fishbein M, von Haften I, Appleyard J. The role of theory in developing effective interventions: Implications from Project SAFER. *Psychol Health Med* 2001;6:223–238.
- Fishbein, M. Triandis, H. C., Kanfer, F. H., Becker M., Middlestadt, S. E. and Eichler, A. Factors influencing behavior and behavior change, in A. Baum, T. A. Revenson and J. E. Singer (eds) *Handbook of Health Psychology*. Mahwah, NJ: Lawrence Erlbaum Associates; 2001, 3–17.
- Fishbein M. The role of theory in HIV prevention. *AIDS Care* 2000;12:273–278.
- Flower KB, Perrin EM, Viadro CI, Ammerman AS. Using body mass index to identify overweight children: barriers and facilitators in primary care. *Ambul Pediatr* 2007;7:38–44.

- Franks PW, Hanson RL, Knowler WC, Sievers ML, Bennett PH, Looker HC. Childhood obesity, other cardiovascular risk factors, and premature death. *N Engl J Med* 2010;362:485–493.
- Freud A. *The ego and the mechanisms of defense*. International Universities Press: New York; 1936.
- Frood S, Johnston LM, Matteson CL, Finegood DT. Obesity, complexity, and the role of the health system. *Curr Obes Rep* 2013;2:320–326.
- Gearing RE, Mian IA, Barber J, Ickowicz A. A methodology for conducting retrospective chart review research in child and adolescent psychiatry. *J Can Acad Child Adolesc Psychiatry* 2006;15:126–134.
- Genovesi S, Giussani M, Faini A, Vigorita F, Pieruzzi F, Strepparava MG, Stella A, Valsecchi MG. Maternal perception of excess weight in children: A survey conducted by paediatricians in the province of Milan. *Acta Paediatrica* 2005;94:747–752.
- Gerards SM, Dagnelie PC, Jansen MW, De Vries NK, Kremers SP. Barriers to successful recruitment of parents of overweight children for an obesity prevention intervention: a qualitative study among youth health care professionals. *BMC Fam Pract* 2012;13:37.
- Germann JN, Kirschenbaum DS, Rich BH. Child and parental self-monitoring as determinants of success in the treatment of morbid obesity in low-income minority children. *J Pediatr Psychol*. 2007;32:111–121.

- Ghai NR, Reynolds KD, Xiang AH, Massie K, Rosetti S, Blanco L, Martinez MP, Quinn VP. Recruitment results among families contacted for an obesity prevention intervention: the Obesity Prevention Tailored for Health Study. *Trials*. 2014;15:463.
- Gillespie J, Midmore C, Hoeflich J, Ness C, Ballard P, Stewart L. Parents as the start of the solution: a social marketing approach to understanding triggers and barriers to entering a childhood weight management service. *J Hum Nutr Diet*. 2015 Suppl 1:83–92.
- Glaser BG, Strauss A. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago, IL: Aldine Publishing Co; 1967.
- Glaserfeld, E. von. *Radical constructivism: A way of knowing and learning*. London: Falmer Press; 1995.
- Glasgow RE, Miller DC. Assessing delivery of the five “As” for patient-centered counseling. *Health Promot Int*. 2006;21:245–255.
- Golan M, Crow S. Parents are key players in the prevention and treatment of weight-related problems. *Nutr Rev* 2004;62:39–50.
- Gollwitzer PM, Bayer UC, McCulluch KC. The control of the unwanted. In: RR Hassin, JS Uleman, JA Bargh, eds. *The New Unconscious*. New York: Oxford University Press 2005:485–515.
- Gollwitzer PM. Goal achievement: The role of intentions. *Euro Rev Social Psychol* 1993;4:141–185.

- Gortmaker SL, Swinburn BA, Levy D, Carter R, Mabry PL, Finegood DT, Huang T, Marsh T, Moodie ML. Changing the future of obesity: science, policy, and action. *Lancet* 2011;378:838–847.
- Greenway FL. Physiological adaptations to weight loss and factors favouring weight regain. *Int J Obes (Lond)* 2015;39:1188–96.
- Grimes-Robison C, Evans RR. Benefits and barriers to medically supervised pediatric weight management programs. *J Child Health Care* 2008;12:329–343.
- Grossi E, Dalle Grave R, Mannucci E, Molinari E, Compare A, Cuzzolaro M, Marchesini G. Complexity of attrition in the treatment of obesity: clues from a structured telephone interview. *Int J Obes* 2006;30:1132–1137.
- Grow HM, Hsu C, Liu LL, Briner L, Jessen-Fiddick T, Lozano P, Saelens BE. Understanding family motivations and barriers to participation in community-based programs for overweight youth: one program model does not fit all. *J Public Health Manag Pract* 2013;19:E1–E10.
- Guba EG, Lincoln YS. Competing paradigms in qualitative research. In: Denzin NK, Lincoln YS, eds. *Handbook of Qualitative Research*. London: Sage Publications; 1994.
- Guba EG, Lincoln YS. Epistemological and methodological bases of naturalistic inquiry. *ECTJ* 1982;30:233–252.
- Guba EG. Criteria for assessing the trustworthiness of naturalistic inquiries. *ECTJ* 1981;29:75–92.

- Hampl S, Paves H, Laubscher K, Eneli I. Patient engagement and attrition in pediatric obesity clinics and programs: results and recommendations. *Pediatrics* 2011;128 Suppl 2:S59-64.
- Hartlieb KB, Jacques-Tiura AJ, Naar-King S, Ellis DA, Jen KL, Marshall S. Recruitment strategies and the retention of obese urban racial/ethnic minority adolescents in clinical trials: the FIT families project, Michigan, 2010-2014. *Prev Chronic Dis* 2015;12:E2
- Hasson F, Keeney S, McKenna H. Research guidelines for the Delphi survey technique. *J Adv Nurs*. 2000;32:1008–1015.
- He M, Piche L, Clarson CL, Callaghan C, Harris SB. Childhood overweight and obesity management: a national perspective of primary health care providers' views, practices, perceived barriers and needs. *Paediatr Child Health* 2010;15:419–426.
- Heinberg LJ, Kutchman EM, Lawhun SA, Berger NA, Seabrook RC, Cuttler L, Horowitz SM. Parent involvement is associated with early success in obesity treatment. *Clinical Pediatrics* 2009; 49:457–465.
- Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Serv Res* 2004;39(4 Pt 1):1005–1026.
- Holt NL, Neely KC, Newton AS, Knight CJ, Rasquinha A, Ambler KA, Spence JC, Ball GD. Families' perceptions of and experiences related to a pediatric weight management intervention: A qualitative study. *J Nutr Educ Behav* 2015;47:427–431.

- Holt NL, Moylan BA, Spence JC, Lenk JM, Sehn ZL, Ball GD. Treatment preferences of overweight youth and their parents in Western Canada. *Qual Health Res* 2008;18:1206–1219.
- Hudson E, McGloin A, McConnon A. Parental weight (mis) perceptions: Factors influencing parents' ability to correctly categorise their child's weight status. *Matern Child Health J* 2012;16:1801–1809.
- Husserl E. *Ideas Pertaining to a Pure Phenomenology and to a Phenomenological Philosophy: First Book: General Introduction to a Pure Phenomenology.*, M. Nijhoff, Hingham, MA; 1982.
- Jain A, Sherman SN, Chamberlin LA, Carter Y, Powers SW, Whitaker RC. Why don't low-income mothers worry about their preschoolers being overweight? *Pediatrics* 2001;107:1138–1146.
- Janssen I, Craig WM, Boyce WF, Pickett W. Associations between overweight and obesity with bullying behaviors in school-aged children. *Pediatrics* 2004;113:1187–1194.
- Janz NK, Becker MH. The Health Belief Model: a decade later. *Health Educ Q* 1984;11:1–47.
- Jeffery AN, Voss LD, Metcalf BS, Alba S, Wilkin TJ. Parents' awareness of overweight in themselves and their children: cross sectional study within a cohort (EarlyBird 21). *BMJ* 2005;330:23–24.
- Jelalian E, Hart CN, Mehlenbeck RS, Lloyd-Richardson EE, Kaplan JD, Flynn-O'Brien KT, Wing RR. Predictors of attrition and weight loss in an adolescent weight control program. *Obesity (Silver Spring)* 2008;16:1318–1323.

- Katz DL. Oblivobesity: Looking over the overweight that parents keep overlooking. *Child Obes* 2015;11:225–226.
- Kitscha CE, Brunet K, Farmer A, Mager DR. Reasons for non-return to a pediatric weight management program. *Can J Diet Pract Res* 2009;70:89–94.
- Kovács E, Hunsberger M, Reisch L, Gwozdz W, Eiben G, De Bourdeaudhuij I, Russo P, Veidebaum T, Hadjigeorgiou C, Sieri S, Moreno LA, Pigeot I, Ahrens W, Pohlabein H, Molnár D; IDEFICS consortium. Adherence to combined lifestyle factors and their contribution to obesity in the IDEFICS study. *Obes Rev* 2015;16:138–150.
- Kraschnewski JL, Sciamanna CN, Stuckey HL, Chuang CH, Lehman EB, Hwang KO, Sherwood LL, Nembhard HB. A silent response to the obesity epidemic: decline in US physician weight counseling. *Med Care* 2013;51:186–192.
- Kuczmarski RJ, Ogden CL, Guo SS, Grummer-Strawn LM, Flegal KM, Mei Z, Wei R, Curtin LR, Roche AF, Johnson CL. 2000 CDC growth charts for the United States: methods and development. *Vital Health Stat* 11 2002;246:1–190.
- Kuczmarski RJ, Ogden CL, Grummer-Strawn LM, Flegal KM, Guo SS, Wei R, Mei Z, Curtin LR, Roche AF, Johnson CL. CDC growth charts: United States. *Adv Data* 2000;(314):1–27.
- Kuhle S, Doucette R, Piccinini-Vallis H, Kirk SF. Successful childhood obesity management in primary care in Canada: what are the odds? *Peer J* 2015;3:e1327.
- Kumanyika S, Grier S. Targeting interventions for ethnic minority and low-income populations. *Future Child*. 2006;16:187–207.

- Kunin-Batson AS, Seburg EM, Crain AL, Jaka MM, Langer SL, Levy RL, Sherwood NE. Household factors, family behavior patterns, and adherence to dietary and physical activity guidelines among children at risk for obesity. *J Nutr Educ Behav* 2015;47:206–215.
- Latner JD, Stunkard AJ. Getting worse: the stigmatization of obese children. *Obes Res* 2003;11:452–456.
- Lau DC, Douketis JD, Morrison KM, Hramiak IM, Sharma AM, Ur E. 2006 Canadian clinical practice guidelines on the management and prevention of obesity in adults and children [summary]. *CMAJ* 2007;176:S1–S13.
- Laws R, Campbell KJ, van der Pligt P, Ball K, Lynch J, Russell G, Taylor R, Denney-Wilson E. Obesity prevention in early life: an opportunity to better support the role of maternal and child health nurses in Australia. *BMC Nurs* 2015;14:26.
- Lengacher CA, Gonzalez LL, Giuliano R, Bennett MP, Cox CE, Reintgen DS. The process of clinical trials: a model for successful clinical trial participation. *Oncol Nurs Forum* 2001;28:1115–1120.
- Lincoln YS, Guba EG. *Naturalistic inquiry*. Newbury Park, CA: Sage; 1985.
- Lowenstein SR. Medical record reviews in emergency medicine: the blessing and the curse. *Ann Emerg Med* 2005;45:452–455.
- Lundahl A, Kidwell KM, Nelson TD. Parental underestimates of child weight: a meta-analysis. *Pediatrics* 2014;133:e689–703.
- Lustig RH. The neuroendocrinology of childhood obesity. *Pediatr Clin North Am* 2001;48:909–930.

- Luttikhuis HO, Baur L, Jansen H, Shrewsbury VA, O'Malley C, Stolk RP, Summerbell CD. Interventions for treating obesity in children. *Cochrane Database Syst Rev* 2009;1:CD001872.
- Mareno N. Parental perception of child weight: A concept analysis. *J Adv Nurs* 2014;70:34–45.
- Markert J, Alff F, Zschaler S, Gausche R, Kiess W, Blüher S. Prevention of childhood obesity: recruiting strategies via local pediatricians and study protocol for a telephone-based counselling program. *Obes Res Clin Pract* 2013;7:e476–486.
- Maxwell J, Loomis D. Mixed methods design: An alternative approach. In A. Tashakkori & C. Teddlie (eds.) *Handbook of mixed methods in social & behavioral research*. Thousand Oaks, CA: Sage; 2003. p. 241–272.
- Miller NH. Motivational interviewing as a prelude to coaching in healthcare settings. *J Cardiovasc Nurs* 2010;25:247–251.
- Modi AC, Loux TJ, Bell SK, Harmon CM, Inge TH, Zeller MH. Weight-specific health-related quality of life in adolescents with extreme obesity. *Obesity (Silver Spring)* 2008;16:2266–2271.
- Mokdad AH, Marks JS, Stroup DF, Gerberding JL. Actual causes of death in the United States, 2000. *JAMA* 2004;291:1238–1245.
- Markert J, Alff F, Zschaler S, Gausche R, Kiess W, Blüher S. Prevention of childhood obesity: Recruiting strategies via local paediatricians and study protocol for a telephone-based counselling programme. *Obes Res Clin Pract* 2013;7:e476–486.

- Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. *Patient Educ Counsel* 2006;60:301–312.
- Miller WR, Rollnick S. *Motivational Interviewing: Preparing People for Change*, 2nd edn. New York: The Guilford Press; 2002.
- Morris TT, Northstone K, Howe LD. Examining the association between early life social adversity and BMI changes in childhood: a life course trajectory analysis. *Pediatr Obes* 2016;11:306–312.
- Morse JM, Field PA. *Qualitative research methods for health professionals*. 2nd edition. Thousand Oaks, CA: Sage; 1995.
- Neumark-Sztainer D1, Wall M, Story M, van den Berg P. Accurate parental classification of overweight adolescents' weight status: does it matter? *Pediatrics* 2008;121:e1495–e1502.
- Newson L, Povey R, Casson A, Grogan S. The experiences and understandings of obesity: families' decisions to attend a childhood obesity intervention. *Psychol Health* 2013;28:1287–305.
- Newton MS, Lovely JJE, Premji S, Goldfield G, Spence JC, Ball GDC. *Addressing Childhood Obesity through Research and Networking (ACORN): A summary of a think tank convened by pediatric weight management centers in Canada*. Edmonton, AB; 2007.
- Nguyen B, McGregor KA, O'Connor J, Shrewsbury VA, Lee A, Steinbeck KS, Hill AJ, Shah S, Kohn MR, Baur LA. Recruitment challenges and recommendations for adolescent obesity trials. *J Paediatr Child Health* 2012;48:38–43.

- Nobles J, Griffiths C, Pringle A, Gately P. Design programmes to maximise participant engagement: a predictive study of programme and participant characteristics associated with engagement in paediatric weight management. *Int J Behav Nutr Phys Act* 2016;13:76.
- Nock MK, Photos V. Parent motivation to participate in treatment: Assessment and prediction of subsequent participation. *J Child Fam Stud* 2006;15:345–358.
- Norman M, Paul P. Predicting Health Behavior: A Social Cognitive Approach. In: M. Conner & P. Norman (Eds.), *Predicting Health Behaviour: Research and Practice with Social Cognition Models*. Open University Press, Maidenhead; 2005. p. 81–126.
- O'Connor J, Steinbeck K, Hill A, Booth M, Kohn M, Shah S, Baur L. Evaluation of a community-based weight management program for overweight and obese adolescents: The Loozit study. *Nutrition & Dietetics* 2008;65:121–7.
- Ogden CL, Carroll MD, Lawman HG, Fryar CD, Kruszon-Moran D, Kit BK, Flegal KM. Trends in obesity prevalence among children and adolescents in the United States, 1988-1994 through 2013-2014. *JAMA* 2016;315:2292–2299.
- Ogden CL, Carroll MD, Kit BK, Flegal KM. Prevalence of childhood and adult obesity in the United States, 2011–2012. *JAMA* 2014;311:806–814.
- Ogden CL, Carroll MD, Kit BK, Flegal KM. Prevalence of obesity and trends in body mass index among US children and adolescents, 1999-2010 *JAMA* 2012;307:483–490.
- Ogden CL, Carroll MD, Curtin LR, Lamb MM, Flegal KM. Prevalence of high body mass index in US children and adolescents, 2007–2008 *JAMA* 2010;303:242–249.

- Olshansky SJ, Passaro DJ, Hershow RC, Layden J, Carnes BA, Brody J, Hayflick L, Butler RN, Allison DB, Ludwig DS. A potential decline in life expectancy in the United States in the 21st century. *N Engl J Med* 2005;352:1138–1145.
- Oude Luttikhuis H, Baur L, Jansen H, Shrewsbury VA, O'Malley C, Stolk RP, Summerbell CD. Interventions for treating obesity in children. *Cochrane Database Syst Rev* 2009;CD001872.
- Patton MQ. *Qualitative evaluation and research methods*. 3rd edition. Newbury Park, CA: Sage; 2002.
- Patton M. Enhancing the qualitative and credibility of qualitative analysis. *Health Serv Res* 1999;34(5 Pt 2):1189–208.
- Patton MQ. *Qualitative Evaluation and Research Methods*, 2nd edn. Sage, Newbury Park, CA, US; 1990.
- Perez A, Kebbe M, Holt N, Gokiart R, Chanoine JP, Legault L, Morrison KM, Sharma AM, Ball GDC. Parent recommendations to enhance enrollment in multidisciplinary care for pediatric weight management. *Acad Pediatr* 2017 [Accepted].
- Perez A, Ball GDC. Paradoxically speaking about engagement in pediatric weight management. *Pediatr Obes* 2017.
- Perez A, Avis J, Holt N, Gokiart R, Chanoine JP, Legault L, Morrison K, Sharma A, Ball G. Why do families enroll in pediatric weight management? A parental perspective of reasons and facilitators. *Child Care Health Dev* 2016;42:278–287.

- Perez A, Holt N, Gokiart R, Chanoine JP, Legault L, Morrison K, Sharma A, Ball G. Why don't families initiate treatment? A qualitative multicentre study investigating parents' reasons for declining pediatric weight management. *Paediatr Child Health* 2015;20:179–84.
- Perez A, Ball GDC. Beyond 'oblivobesity': Seven myths about parental misperceptions of children's weight. *Child Obes* 2015b;11:735–737.
- Pescud M, Pettigrew S, McGuigan MR, Newton RU. Factors influencing overweight children's commencement of and continuation in a resistance training program. *BMC Public Health* 2010;10:709.
- Puhl RM, Peterson JL, Luedicke J. Weight-based victimization: bullying experiences of weight loss treatment-seeking youth. *Pediatrics* 2013;131:e1–e9.
- Puhl RM, Moss-Racusin CA, Schwartz MB, Brownell KD. Weight stigmatization and bias reduction: perspectives of overweight and obese adults. *Health Educ Res* 2008;23:347–358.
- Puhl RM, Latner JD. Stigma, obesity, and the health of the nation's children. *Psychol Bull* 2007;133:557–580.
- Quattrin T, Liu E, Shaw N, Shine B, Chiang E. Obese children who are referred to the pediatric endocrinologist: characteristics and outcome. *Pediatrics* 2005;115:348–351.
- Raynor HA, Osterholt KM, Hart CN, Jelalian E, Vivier P, Wing RR. Evaluation of active and passive recruitment methods used in randomized controlled trials targeting pediatric obesity. *Int J Pediatr Obes* 2009;4:224–32.

- Reid M. Debrief of a study to identify and explore parental, young people's and health professionals' attitudes, awareness and knowledge of child healthy weight. NHS Health Scotland: Edinburgh, UK; 2009.
- Reilly JJ, Methven E, McDowell ZC, Hacking B, Alexander D, Stewart L, Kelnar CJ. Health consequences of obesity. *Arch Dis Child* 2003;88:748–52.
- Reinehr T. Effectiveness of lifestyle intervention in overweight children. *Proc Nutr Soc* 2011; 70:494–505.
- Rice J, Thombs D, Leach R, Rehm R. Successes and barriers for a youth weight-management program. *Clin Pediatr* 2008;47:143–7.
- Rieder J, Khan UI, Heo M, Mossavar-Rahmani Y, Blank AE, Strauss T, Viswanathan N, Wylie-Rosett J. Evaluation of a community-based weight management program for predominantly severely obese, difficult-to-reach, inner-city minority adolescents. *Child Obes* 2013;9:292–304.
- Rietmeijer-Mentink M, Paulis WD, van Middelkoop M, Bindels PJ, van der Wouden JC. Difference between parental perception and actual weight status of children: A systematic review. *Matern Child Nutr* 2013;9:3–22.
- Roberts KC, Shields M, de Groh M, Aziz A, Gilbert J. Overweight and obesity in children and adolescents: results from the 2009 to 2011 Canadian health measures survey. *Health Rep* 2012;23:37–41.

- Robson SM, Bolling C, McCullough MB, Stough CO, Stark LJ. A preschool obesity treatment clinical trial: reasons primary care providers declined referrals. *J Pediatr*. 2016;177:262–266.
- Rodd C, Sharma AK. Recent trends in the prevalence of overweight and obesity among Canadian children. *CMAJ* 2016;188:E313–20.
- Rogers, R.W. A protection motivation theory of fear appeals and attitude change. *J Psychol* 1975;91:93–114.
- Salawi HA, Ambler KA, Padwal RS, Mager DR, Chan CB, Ball GD. Characterizing severe obesity in children and youth referred for weight management. *BMC Pediatr*. 2014;14:154.
- Sandelowski M. Focus on research methods: whatever happened to qualitative description? *Res Nurs Health* 2000;23:334–340.
- Shaffer LA, Brothers KB, Burkhead TA, Yeager R, Myers JA, Sweeney B. Factors associated with attendance after referral to a pediatric weight management program. *J Pediatr* 2016; 172:35–39.
- Sharma AM and Padwal R. Obesity is a sign – over-eating is a symptom: an aetiological framework for the assessment and management of obesity. *Obes Rev* 2010;11:362–370.
- Sheeran P, Sarah M, Webb TL, Gollwitzer PM. Implementation intentions and health behaviors. In: Coner M, Norman P, eds. *Predicting health behavior: research and practice with social cognitive models*. Buckingham: Open University Press; 2005:276–323.
- Sim LA, Lebow J, Wang Z, Koball A, Murad MH. Brief primary care obesity interventions: A meta-analysis. *Pediatrics* 2016;138.pii:e20160149.

Singh AS, Mulder C, Twisk JW, van Mechelen W, Chinapaw MJ. Tracking of childhood overweight into adulthood: a systematic review of the literature. *Obes Rev* 2008;9:474–488.

Skelton JA, Irby MB, Beech BM, Rhodes SD. Attrition and family participation in obesity treatment programs: clinicians' perceptions. *Acad Pediatr* 2012;12:420–428.

Skelton JA, Beech BM. Attrition in paediatric weight management: a review of the literature and new directions. *Obes Rev* 2011;12:e273–e281.

Skinner AC, Perrin EM, Skelton JA. Prevalence of obesity and severe obesity in US children, 1999–2014. *Obesity (Silver Spring)* 2016;24:1116–1123.

Skinner AC, Skelton JA. Prevalence and trends in obesity and severe obesity among children in the United States, 1999–2012. *JAMA Pediatr* 2014;168:561–6.

Skinner AC, Mayer ML, Flower K, Perrin EM, Weinberger M. Using BMI to determine cardiovascular risk in childhood: how do the BMI cutoffs fare? *Pediatrics* 2009;124:e905–e912.

Smith KL, Kerr DA, Howie EK, Straker LM. Do overweight adolescents adhere to dietary intervention messages? Twelve-month detailed dietary outcomes from Curtin University's activity, food and attitudes program. *Nutrients* 2015;7:4363–4382.

Smith KL, Straker LM, McManus A, Fenner AA. Barriers and enablers for participation in healthy lifestyle programs by adolescents who are overweight: a qualitative study of the opinions of adolescents, their parents and community stakeholders. *BMC Pediatr*. 2014;14:53.

- Spear BA, Barlow SE, Ervin C, Ludwig DS, Saelens BE, Schetzina KE, Taveras EM. Recommendations for treatment of child and adolescent overweight and obesity. *Pediatrics* 2007;120(Suppl 4):S254–S288.
- Stake RE. *The Sage handbook of qualitative research*. 3rd edition. Thousand Oaks, CA: Sage; 2005.
- Statistics Canada. Census and Intercensal Road Network. Statistics Canada Catalogue no. 92-500-X [digital data]. 92-500-X <http://www12.statcan.gc.ca/census-recensement/2011/geo/RNF-FRR/index-eng.cfm> (2016).
- Statistics Canada. <http://www.statcan.gc.ca/eng/subjects/standard/sgc/notice/sgc-06>. 2011.
- Stewart L, Chapple J, Hughes AR, Poustie V, Reilly JJ. Parents' journey through treatment for their child's obesity: A qualitative study. *Arch Dis Child* 2008;93:35–39.
- Stewart ST, Cutler DM, Rosen AB. Forecasting the effects of obesity and smoking on U.S. life expectancy. *N Engl J Med* 2009;361:2252–2260.
- Stockton MB, McClanahan BS, Lanctot JQ, Klesges RC, Beech BM. Identification of facilitators and barriers to participation in weight gain prevention research by African American girls. *Contemp Clin Trials* 2012;33:38–45.
- Story M, Sherwood NE, Obarzanek E, Beech BM, Baranowski JC, Thompson NS, Owens AS, Mitchell M, Rochon J. Recruitment of African-American pre-adolescent girls into an obesity prevention trial: the GEMS pilot studies. *Ethnicity and Disease* 2003;13:78–87.
- Straker LM, Howie EK, Smith KL, Fenner AA, Kerr DA, Olds TS, Abbott RA, Smith AJ. The impact of Curtin University's activity, food and attitudes program on physical activity,

- sedentary time and fruit, vegetable and junk food consumption among overweight and obese adolescents: a waitlist controlled trial. *PLoS One* 2014;9:e111954.
- Taylor SE, Brown JD. Illusion and well-being: A social psychological perspective on mental health. *Psychol Bull* 1988;103:193–210.
- Taylor RW, Williams SM, Dawson AM, Taylor BJ, Meredith-Jones K, Brown D. What factors influence uptake into family-based obesity treatment after weight screening? *J Pediatr* 2013;163:1657–1662.
- Tershakovec AM, Kuppler K. Ethnicity, insurance type, and follow-up in a pediatric weight management program. *Obes Res* 2003;11:17–20.
- The Team to Address Bariatric Care in Canadian Children (Team ABC3): Team Grant Study Protocol. *BMC Research Notes* (In Review).
- Thomas R. Symposium III. Metabolic health, weight management and obesity prevention in childhood and adolescent. Effectiveness of lifestyle intervention in overweight children. *Proc Nutr Soc* 2011;70:494–505.
- Thorne S, Reimer-Kirkham S, O’Flynn-Magee K. The Analytic Challenge in Interpretive Description. *Int J Qual Methods* 2004;3:1–11.
- Tremblay M, Perez AJ, Rasquinha AM, Avis JL, Morrison KM, Chanoine JP, Legault L, Holt NL, Gokiert R, Sharma AM, Ball GD. Recommendations from parents to improve health services for managing pediatric obesity in Canada. *Acad Pediatr* 2016;16:587–93.

- Tremblay MS, Shields M, Laviolette M, Craig CL, Janssen I, Gorber SC. Fitness of Canadian children and youth: results from the 2007–2009 Canadian Health Measures Survey. *Health Rep* 2010;21:1–14.
- Twiddy M, Wilson I, Bryant M, Rudolf M. Lessons learned from a family-focused weight management intervention for obese and overweight children. *Public Health Nutr* 2012;15:1310–1317.
- van't Riet J, Sijtsema SJ, Dagevos H, De Bruijn GJ. The importance of habits in eating behaviour. An overview and recommendations for future research. *Appetite* 2011; 57:585–596.
- Wagner EH, Austin BT, Davis C, Hindmarsh M, Schaefer J, Bonomi A. Improving chronic illness care: translating evidence into action. *Health Aff* 2001;20:64–78.
- Wagner EH, Davis C, Schaefer J, Von Korff M, Austin B. A survey of leading chronic disease management programs: are they consistent with the literature? *Manag Care Q* 1999;7:56–66.
- Wang F, Wild TC, Kipp W, Kuhle S, Veugelers PJ. The influence of childhood obesity on the development of self-esteem. *Health Rep* 2009;20:21–27.
- Weston WW. Informed and shared decision-making: the crux of patient centred care. *CMAJ* 2001;165:438–440.
- Whitlock EP, O'Connor EA, Williams SB, Beil TL, Lutz KW. Effectiveness of weight management interventions in children: a targeted systematic review for the USPSTF. *Pediatrics* 2010;125:e396–e418.

WHO, 2009 (<http://www.who.int/growthref/tools/en/>).

Withrow D, Alter DA. The economic burden of obesity worldwide: a systematic review of the direct costs of obesity. *Obes Rev* 2011;12:131–41.

Williams NA, Coday M, Somes G, Tylavsky FA, Richey PA, Hare M. Risk factors for poor attendance in a family-based pediatric obesity intervention program for young children. *J Dev Behav Pediatr* 2010;31:705–712.

Wolfenden L, Holt NL. Talent development in elite junior tennis: perceptions of players, parents, and coaches. *J Appl Sport Psychol* 2005;17:108–126.

Woolford SJ, Clark SJ, Gebremariam A, Davis MM, Freed GL. Physicians' perspectives on referring obese adolescents to pediatric multidisciplinary weight management programs. *Clin Pediatr (Phila)* 2010;49:871–875.

Zabinski MF, Saelens BE, Stein RI, Hayden-Wade HA, Wilfley DE. Overweight children's barriers to and support for physical activity. *Obes Res* 2003;11:238–246.

Zeller MH, Reiter-Purtill J, Modi AC, Gutzwiller J, Vannatta K, Davies WH. Controlled study of critical parent and family factors in the obesigenic environment. *Obesity* 2007;15:126–136.

Zeller M, Kirk S, Claytor R, Khoury P, Grieme J, Santangelo M, Daniels S. Predictors of attrition from a pediatric weight management program. *J Pediatr* 2004;144:466–470.

Appendices

Appendix A. Commentary article

Perez A, Ball GDC. Paradoxically speaking about engagement in pediatric weight management. *Pediatr Obes.* 2017. doi: 10.1111/ijpo.12207. [Epub ahead of print]

Consistent with previous research showing that childhood obesity is more prevalent in low-income children (Skinner et al., 2016), a paper recently published in *Pediatric Obesity* reported a positive relationship between children's BMI and social adversities including financial difficulties in families (Morris et al., 2016). In the present article, we argue that children representing ethnic minority populations and lower-income families are not only at greater risk of obesity but also at heightened risk of poor engagement and utilization of pediatric weight management services.

Along with effective interventions, optimal engagement of children and families is required to address pediatric obesity and its adverse medical (e.g. risk of type 2 diabetes), emotional (e.g. depression) and social (e.g. isolation) consequences (Ebbeling et al., 2002). Engagement in pediatric weight management, broadly defined as treatment-related decisions and actions that may or may not benefit patients, is characterized by low enrolment, high attrition and poor adherence (Shaffer et al., 2016; Smith et al., 2015; Dhaliwal et al., 2014). It is our view that three paradoxes related to engagement might help to explain why many children and families fail to achieve optimal outcomes in pediatric weight management.

The enrolment paradox: those who are more likely to enroll are less likely to benefit from treatment

Enrolment in obesity interventions varies depending on children's age, sex and weight status as well as parents' income, education and perceptions of their children's lifestyle behaviours (Alff et al., 2012; Finne et al., 2009). Older children and children with obesity are more likely to be (i) seen by their parents as having a weight problem (Black et al., 2015) and (ii) referred to and enrolled in obesity interventions compared with their younger and leaner peers (Shaffer et al., 2016; Woolford et al., 2010). However, children who are younger and less overweight are more likely to benefit from care (Reinehr, 2011).

The inverse relationship between the likelihood of benefitting from treatment and the likelihood of enrolling in care does not suggest that more effort and resources should be devoted to address overweight as opposed to obesity. Conversely, it highlights the importance of obesity prevention in children who are overweight through early screening of excess weight and timely enrolment in health services or interventions to help children.

The adherence paradox: those for whom greater adherence to behavioural advice is necessary to manage excess weight are the least likely to act accordingly

In the context of managing childhood obesity, behavioural advice can be delivered in the form of guidelines or treatment recommendations. These two forms of advice are not mutually exclusive because treatment goals may reflect guideline recommendations or intermediate steps to meet recommended guidelines. Little is known about patient adherence to pediatric weight management (Smith et al., 2015); however, some data suggest that children

who adhere to dietary and/or physical activity guidelines are more likely to be normal weight (vs. overweight or obese) (Kovács et al., 2015), younger (vs. older) (Kovács et al., 2015) and Caucasian (vs. ethnic minority) (Corder et al., 2016).

Compared with their peers, children who adhere to recommendations are also more likely to come from higher income families and have parents with higher levels of education (Kunin-Batson et al., 2015; Arriscado et al., 2014). Studies that examined proxy measures of treatment adherence, including programme completion, motivation to make lifestyle changes, and perceived barriers and support, have reported that *(i)* non-completers (vs. completers) are more likely to be heavier (Jelalian et al., 2008), older, of ethnic minority, and with a lower income (Williams et al., 2010; Zeller et al., 2004) and *(ii)* children with obesity (vs. less obese children) are less ready as well as perceive more barriers and less support to make healthy lifestyle changes (Rieder et al., 2013; Zabinski et al., 2003).

Taken together, these findings suggest that children who are less likely to adhere to dietary and physical activity guidelines are more affected by or at a higher risk of obesity. Additionally, adolescents' independence in making their own lifestyle choices increases the complexity of obesity management in this group because parents, in general, tend to have less direct influence during this period of growth and development.

The attrition paradox: those who would potentially benefit the most from remaining in care longer are more likely to leave care prematurely

Because obesity is a chronic condition that requires making and maintaining healthy lifestyle habits, children with obesity are likely to need (and benefit from) long-term care and

support. Attrition from weight management interventions, generally defined as leaving care prematurely, has been associated with socio-demographic, anthropometric and contextual factors (Dhaliwal et al., 2014). Specifically, children with obesity who are older, of ethnic minority, and low income are more likely to discontinue care compared to their peers (Dhaliwal et al., 2014). Further, those who leave care prematurely may not attempt to seek care again if they become less confident in obesity management (Skelton et al., 2012). Because pediatric obesity disproportionately affects children who are older, of ethnic minority and lower income (Skinner et al., 2016), those more likely to drop out of care may also benefit the most from long-term support for weight management.

In the field of pediatric weight management, little attention has been given to engagement management, which is essential to plan, deliver and evaluate health services and interventions for managing obesity. Engagement in pediatric weight management is multifactorial, often modifiable, and needs to be understood as multiple engagements that include children, parents, family members and healthcare professionals. Evidence-based strategies, either as stand-alone quality improvement efforts or built into randomized controlled trials designed to evaluate intervention effectiveness, are needed to enhance engagement, especially among children who are less likely to initiate, continue and adhere to health services and interventions for managing pediatric obesity.

References

- Skinner AC, Perrin EM, Skelton JA. Prevalence of obesity and severe obesity in US children, 1999–2014. *Obesity (Silver Spring)* 2016;24:1116–1123.
- Morris TT, Northstone K, Howe LD. Examining the association between early life social adversity and BMI changes in childhood: a life course trajectory analysis. *Pediatr Obes* 2016;11:306–312.
- Ebbeling CB, Pawlak DB, Ludwig DS. Childhood obesity: public-health crisis, common sense cure. *Lancet* 2002;360:473–482.
- Shaffer LA, Brothers KB, Burkhead TA, Yeager R, Myers JA, Sweeney B. Factors associated with attendance after referral to a pediatric weight management program. *J Pediatr* 2016;172:35–39.
- Smith KL, Kerr DA, Howie EK, Straker LM. Do overweight adolescents adhere to dietary intervention messages? Twelve-month detailed dietary outcomes from Curtin University’s activity, food and attitudes program. *Nutrients* 2015;7:4363–4382.
- Dhaliwal J, Nosworthy NM, Holt NL, Zwaigenbaum L, Avis JL, Rasquinha A, Ball GD. Attrition and the management of pediatric obesity: an integrative review. *Child Obes* 2014; 10:461–473.
- Finne E, Reinehr T, Schaefer A, Winkel K, Kolip P. Overweight children and adolescents—is there a subjective need for treatment? *Int J Public Health* 2009;54:112–116.

- Alff F, Markert J, Zschaler S, Gausche R, Kiess W, Blüher S. Reasons for (non)participating in a telephone-based intervention program for families with overweight children. *PLoS One* 2012;7:e34580.
- Black JA, Park M, Gregson J, Falconer CL, White B, Kessel AS, Saxena S, Viner RM, Kinra S. Child obesity cut-offs as derived from parental perceptions: cross-sectional questionnaire. *Br J Gen Pract* 2015;65:e234–e239.
- Woolford SJ, Clark SJ, Gebremariam A, Davis MM, Freed GL. Physicians' perspectives on referring obese adolescents to pediatric multidisciplinary weight management programs. *Clin Pediatr (Phila)* 2010; 49:871–875.
- Reinehr T. Effectiveness of lifestyle intervention in overweight children. *Proc Nutr Soc* 2011;70:494–505.
- Kovács E, Hunsberger M, Reisch L, Gwozdz W, Eiben G, De Bourdeaudhuij I, Russo P, Veidebaum T, Hadjigeorgiou C, Sieri S, Moreno LA, Pigeot I, Ahrens W, Pohlmann H, Molnár D; IDEFICS consortium. Adherence to combined lifestyle factors and their contribution to obesity in the IDEFICS study. *Obes Rev* 2015;16:138–150.
- Corder K, Sharp SJ, Atkin AJ, Andersen LB, Cardon G, Page A, Davey R, Grøntved A, Hallal PC, Janz KF, Kordas K, Kriemler S, Puder JJ, Sardinha LB, Ekelund U, van Sluijs EM; International Children's Accelerometry Database (ICAD) Collaborators. Age-related patterns of vigorous-intensity physical activity in youth: The International Children's Accelerometry Database. *Prev Med Rep* 2016;4:17–22.

- Kunin-Batson AS, Seburg EM, Crain AL, Jaka MM, Langer SL, Levy RL, Sherwood NE. Household factors, family behavior patterns, and adherence to dietary and physical activity guidelines among children at risk for obesity. *J Nutr Educ Behav* 2015;47:206–215.
- Arriscado D, Muros JJ, Zabala M, Dalmau JM. Factors associated with low adherence to a Mediterranean diet in healthy children in northern Spain. *Appetite* 2014;80:28–34.
- Jelalian E, Hart CN, Mehlenbeck RS, Lloyd-Richardson EE, Kaplan JD, Flynn-O'Brien KT, Wing RR. Predictors of attrition and weight loss in an adolescent weight control program. *Obesity (Silver Spring)* 2008;16:1318–1323.
- Zeller M, Kirk S, Claytor R, Khoury P, Grieme J, Santangelo M, Daniels S. Predictors of attrition from a pediatric weight management program. *J Pediatr* 2004;144:466–470.
- Williams NA, Coday M, Somes G, Tylavsky FA, Richey PA, Hare M. Risk factors for poor attendance in a family-based pediatric obesity intervention program for young children. *J Dev Behav Pediatr* 2010;31:705–712.
- Rieder J, Khan UI, Heo M, Mossavar-Rahmani Y, Blank AE, Strauss T, Viswanathan N, Wylie-Rosett J. Evaluation of a community-based weight management program for predominantly severely obese, difficult-to-reach, inner-city minority adolescents. *Child Obes* 2013;9:292–304.
- Zabinski MF, Saelens BE, Stein RI, Hayden-Wade HA, Wilfley DE. Overweight children's barriers to and support for physical activity. *Obes Res* 2003;11:238–246.
- Skelton JA, Irby MB, Beech BM, Rhodes SD. Attrition and family participation in obesity treatment programs: clinicians' perceptions. *Acad Pediatr* 2012;12:420–428.

Appendix B. Letter to the editor

Perez A, Ball GD. Beyond oblivobesity: seven myths about parental misperception of children's weight. *Child Obes* 2015;11:735-7

To the Editor:

In a recent editorial in *Childhood Obesity*, Katz commented on the phenomenon of parents' misperception of children's excess weight (Katz, 2015). Although the editorial focused on engaging children and their families in obesity management, he challenged a common belief in the weight misperception literature, which is to combat misperception of excess weight with objective information. Upon review of the misperception literature, we believe there is value in going "beyond oblivobesity" to consider a number of misunderstandings related to the conceptualization, interpretation, and attempt to address the discrepancy between perceived and actual weight status of children.

1. Parents are unaware of their children's obesity

Most studies on parental weight misperception have relied on anthropometric measures (*e.g.*, BMI) to determine children's weight status (Rietmeijer-Mentink et al., 2013). Given that these metrics only provide an indirect estimate of obesity, parental unawareness of child obesity can only ever be estimated indirectly as well. Further, unawareness is just one aspect of weight misperception; the latter not only implies that parents are unaware of their children's actual weight status, but also that they assign to their children a weight status other than the actual status. Compared to unawareness, misperception may exert a greater influence on whether

parents choose to “accept” objective data (*e.g.*, BMI plotted on a growth chart) showing that their children meet the clinical definition for obesity.

2. Parents fail to recognize their children’s weight problem

Conceptually, it is important to differentiate between misclassifying the identity of a condition (which is the main focus of studies on perceived weight status) and being concerned about a condition (perceiving it as a problem). Health concern in general, and weight concern in particular, depend on (Katz, 2015) the severity attached to the consequences of the condition and (Rietmeijer-Mentink et al., 2013) the perceived personal susceptibility to those consequences. In this regard, accurate recognition of excess weight is necessary, but not sufficient, to be concerned about obesity. For instance, both Genovesi and colleagues (2005) and Jain and colleagues (2001) found that most parents in their studies were aware of, but not concerned about, their children’s excess weight.

3. Parents will not take preventive actions to address obesity unless a weight problem is recognized

Compared to parents who failed to recognize their children’s excess weight, Neumark-Sztainer and colleagues (2008) found that those who recognized it correctly were not more likely to promote healthier lifestyle behaviors for their children. Qualitative evidence has shown that children’s psychosocial well-being and quality of life were more common reasons for parents to engage in pediatric weight management versus concerns about children’s weight and physical health (Gillespie et al., 2015; Stewart et al., 2008). It is sometimes forgotten in the dominant discourse about nutrition, physical activity, and obesity that individuals may perform

healthy lifestyle behaviors not because a problem exists or because one is expected, but for the simple sake of living a healthy and enjoyable life.

4. Parents who do not recognize their children's obesity are in denial

Given that children's excess weight is visually apparent, it is often assumed that parents should recognize it unless they are in denial. As a defense or coping mechanism (Freud, 1936), denial denotes a causal attribution to account for weight misperception that cannot be demonstrated by simply comparing the perceived and actual weight status. Misperception needs to be differentiated from its attributed factors for two main reasons. First, it leaves open the possibility of alternative explanations for the discrepancy between the subjective and objective weight status. Second, it highlights the need for further data to determine whether parents are in denial or whether their weight misperception is owing to other factors. Although researchers' attributions to misperception have been reported in the literature, little is known about healthcare providers' attributions, which can play a key role in healthcare decisions. For instance, healthcare providers might act differently depending on whether they attribute misperception to parents' lack of understanding of obesity or to denial, and if attributed to denial, whether they perceive it as a moral failure or a coping mechanism.

5. Accurate information will correct parental misperception of child excess weight

Parents should be informed about their children's weight status, but providing anthropometric data (Katz, 2015) may not correct weight misperceptions, (Rietmeijer-Mentink et al., 2013) may have unintended consequences, and (Genovesi et al., 2005) may not lead to expected behavioral changes. Indeed, parents may distrust growth charts as a method of

determining whether their children meet the criteria for obesity (Jain et al., 2001), while negative feedback is more likely to be subject to biases than confirmatory information (Taylor & Brown, 1988). Qualitative research has shown that how and by whom anthropometric data are shared can influence families' perceptions of this information (Reid, 2009). As highlighted by Katz (2015), if not delivered in a sensitive manner, accurate information about weight status may embarrass or stigmatize children and blame parents. Informing parents about their children's actual weight status can increase their awareness about excess weight, but the impact of this knowledge on weight concern and preventive behaviors is limited (Chomitz et al., 2003). Focusing exclusively on providing objective information when parents do not feel confident to address children's excess weight may lead parents to discredit the source of information, misperceive children's weight status, or downplay the severity of the problem, all of which can represent as coping strategies.

6. Parents' misperceptions represent a personal failure to correctly assess children's actual weight status

Several factors have been suggested to account for parents' misperception of excess weight in their children, including the normalization of excess weight as it has become more common in society, visual recognition and social comparison as unreliable methods of weight assessment, reluctance to use clinical terms ("obese") owing to perceptions of bias and stigma, denial of excess weight to avoid the responsibility of taking corrective actions, misunderstanding obesity, and weight size preferences across ages, sexes, and ethnicities (Mareno, 2014; Doolen et al., 2009). Although individual-level factors might exert a direct

influence on parental weight misperceptions, societal factors, including weight-related values and norms, are also influential, which highlights the complexity of the phenomenon.

7. Obesity management should focus on improving children's lifestyle habits to enhance health rather than on weight

Providing family-centered care includes respecting the values, needs, and desires of children and their families (Committee on Hospital Care. American Academy of Pediatrics, 2003). Although the foundation of pediatric weight management includes a focus on healthy nutrition and physical activity, parents may decline treatment if they perceive their children to already practice healthy lifestyle habits (Perez et al., 2015). Whether focusing on improving lifestyle habits or weight management per se, this dichotomy predetermines the focus of conversations with families. Motivation for undertaking preventive actions varies from family to family, so it is necessary for healthcare professionals to explore parents' and children's values in order to identify what matters most to them; subsequently, weight management can be linked to their values, which might relate to health, lifestyle habits, weight loss, social acceptance, having their clothes fit better, and so on. This approach is consistent with the philosophy and practice of motivational interviewing, which is an effective tool to enhance motivation for weight management (Dawson et al., 2014).

In summary, parents should be informed, in a sensitive, clear, and objective manner, about their children's weight status and associated health risks. However, it is important to recognize that this information may not correct misperceptions, and even if perception accuracy improves, this change may not translate into preventive actions. Emphasis must be placed on

motivating parents and children to manage excess weight with awareness of excess weight as just one pathway. Ultimately, the primary issue may not be if or how to address misperception, but how to enhance motivation for pediatric weight management.

References

- Chomitz VR, Collins J, Kim J, Kramer E, McGowan R. Promoting healthy weight among elementary school children via a health report card approach. *Arch Pediatr Adolesc Med* 2003;157:765–772.
- Committee on Hospital Care. American Academy of Pediatrics. Family-centered care and the pediatrician's role. *Pediatrics* 2003;112:691–697.
- Dawson AM, Brown DA, Cox A, Williams SM, Treacy L, Haszard J, Meredith-Jones K, Hargreaves E, Taylor BJ, Ross J, Taylor RW. Using motivational interviewing for weight feedback to parents of young children. *J Paediatr Child Health* 2014;50:461–470.
- Doolen J, Alpert PT, Miller SK. Parental disconnect between perceived and actual weight status of children: A metasynthesis of the current research. *J Am Acad Nurse Pract* 2009;21:160–166.
- Freud A. *The ego and the mechanisms of defense*. International Universities Press: New York, 1936.
- Genovesi S, Giussani M, Faini A, Vigorita F, Pieruzzi F, Strepparava MG, Stella A, Valsecchi MG. Maternal perception of excess weight in children: A survey conducted by paediatricians in the province of Milan. *Acta Paediatrica* 2005;94:747–752.
- Gillespie J1, Midmore C, Hoeflich J, Ness C, Ballard P, Stewart L. Parents as the start of the solution: A social marketing approach to understanding triggers and barriers to entering a childhood weight management service. *J Hum Nutr Diet* 2015;28(Suppl 1):83–92.

- Jain A, Sherman SN, Chamberlin LA, Carter Y, Powers SW, Whitaker RC. Why don't low-income mothers worry about their preschoolers being overweight? *Pediatrics* 2001;107:1138–1146.
- Katz DL. Oblivobesity: Looking over the overweight that parents keep overlooking. *Child Obes* 2015;11:225–226.
- Mareno N. Parental perception of child weight: A concept analysis. *J Adv Nurs* 2014;70:34–45.
- Neumark-Sztainer D, Wall M, Story M, van den Berg P. Accurate parental classification of overweight adolescents' weight status: does it matter? *Pediatrics* 2008;121:e1495–e1502.
- Perez A, Holt N, Gokiart R, Chanoine JP, Legault L, Morrison K, Sharma A, Ball G. Why don't families initiate treatment? A qualitative multicentre study investigating parents' reasons for declining paediatric weight management. *Paediatr Child Health* 2015;20:179–184.
- Reid M. Debrief of a study to identify and explore parental, young people's and health professionals' attitudes, awareness and knowledge of child healthy weight. NHS Health Scotland: Edinburgh, UK; 2009.
- Rietmeijer-Mentink M, Paulis WD, van Middelkoop M, Bindels PJ, van der Wouden JC. Difference between parental perception and actual weight status of children: A systematic review. *Matern Child Nutr* 2013;9:3–22.
- Stewart L, Chapple J, Hughes AR, Poustie V, Reilly JJ. Parents' journey through treatment for their child's obesity: A qualitative study. *Arch Dis Child* 2008;93:35–39.

Taylor SE, Brown JD. Illusion and well-being: A social psychological perspective on mental health. *Psychol Bull* 1988;103:193–210.

Appendix C. Protocol paper

Ball GD, Perez Garcia A, Chanoine JP, Morrison KM, Legault L, Sharma AM, Gokiert R, Holt NL. Should I stay or should I go? Understanding families' decisions regarding initiating, continuing, and terminating health services for managing pediatric obesity: the protocol for a multi-center, qualitative study. *BMC Health Serv Res* 2012;12:486.

Abstract

Background: At least two million Canadian children meet established criteria for weight management. Due to the adverse health consequences of obesity, most pediatric weight management research has examined the efficacy and effectiveness of interventions to improve lifestyle behaviors, reduce co-morbidities, and enable weight management. However, little information is available on families' decisions to initiate, continue, and terminate weight management care. This is an important knowledge gap since a substantial number of families fail to initiate care after being referred for weight management while many families who initiate care discontinue it after a brief period of time. This research aims to understand the interplay between individual, family, environmental, and systemic factors that influence families' decisions regarding the management of pediatric obesity.

Methods: Individual interviews will be conducted with children and youth with obesity (n = 100) and their parents (n = 100) for a total number of 200 interviews with 100 families. Families will be recruited from four Canadian multi-disciplinary pediatric weight management centers in Vancouver, Edmonton, Hamilton, and Montreal. Participants will be purposefully-sampled

into the following groups: *(i)* Non-Initiators (5 families/site): referred for weight management within the past 6 months and did not follow-up the referral; *(ii)* Initiators (10 families/site): referred for weight management within the past 6 months and did follow-up the referral with at least one clinic appointment; and *(iii)* Continuers (10 families/site): participated in a formal weight management intervention within the past 12 months and did continue with follow-up care for at least 6 months. Interviews will be digitally recorded and analyzed using an ecological framework, which will enable a multi-level evaluation of proximal and distal factors that underlie families' decisions regarding initiation, continuation, and termination of care. Demographic and anthropometric/clinical data will also be collected.

Discussion: A better understanding of family involvement in pediatric weight management care will help to improve existing health services in this area. Study data will be used in future research to develop a validated survey that clinicians working in pediatric obesity management can use to understand and enhance their own health services delivery.

Background

Few pediatric health issues have attracted as much attention in recent years as pediatric obesity. The volume of obesity-related research focused on epidemiology, etiology, and health consequences increased markedly over the past few decades. While many questions remain unanswered regarding how best to prevent and manage obesity in children, the magnitude of obesity and obesity-related health risks are clear. For instance, the Canadian Health Measures Survey (Tremblay et al., 2010) reported that the proportion of boys classified as overweight or obese increased from 14 to 31% between 1981 and 2009; among girls, excess weight increased from 14 to 25%. These trends represent dramatic increases for both boys (+120%) and girls (+79%). Longitudinal data from the US showed that the most striking changes in unhealthy weight gain in recent years have impacted children and youth who are already at high health risk because of their excess weight. Between 1999–2009, the proportions of individuals classified as overweight or obese remained relatively stable; however, trend analyses revealed a significant rise in the prevalence of severe obesity (Ogden et al., 2010). This change is clinically important since boys and girls with severe obesity are very likely to *(i)* remain obese into adulthood (Singh et al., 2008) and *(ii)* suffer from adverse metabolic health consequences including an increased risk of type 2 diabetes, cardiovascular disease, hypertension, nonalcoholic fatty liver disease, and the metabolic syndrome (Skinner et al., 2009; Cruz et al., 2005). Beyond metabolic health, childhood obesity can negatively impact a number of other areas including physical function (Tremblay et al., 2010), psychosocial health (Wang et al., 2009; Puhl & Latner, 2007; Zeller et al., 2007; Janssen et al., 2004), and life expectancy

(Stewart et al., 2009; Mokdad et al., 2004; Olshansky et al., 2005). Viewed collectively, this body of evidence establishes pediatric obesity as a chronic condition that requires targeted, innovative approaches to reduce obesity-related health risks in order to optimize both quantity and quality of life (Franks et al., 2010).

Although the ideal weight management care model is not yet agreed upon, key principles have been described. Clinical practice guidelines (Lau et al., 2007) and expert recommendations (Grimes-Robison et al., 2008; Barlow et al., 2007; Spear et al., 2007) emphasize the value of taking a long-term, family-centered approach while combining lifestyle, behavioral, and cognitive techniques to improve dietary quality, increase physical activity, reduce physical inactivity, and improve psychosocial and familial health outcomes. These approaches can be used to describe most of the services offered by pediatric weight management centers across Canada (Ball et al., 2011). Viewing obesity as a chronic care issue (Wagner et al., 2001) is increasingly being used to guide weight management care (Lau et al., 2007; Barlow et al., 2007); this viewpoint encourages obesity-related health services to move away from a traditional, paternalistic framework, which was designed historically to manage acute health issues towards establishing a more collaborative, long-term partnership between clinicians and families, one that extends beyond the clinical setting to include community-based resources and supports. The Chronic Care Model (CCM) acknowledges the chronicity of obesity and commonalities between individuals regarding symptomatology, emotional impacts, lifestyle adjustments, and obtaining effective health care. Many families struggle with the physical, psychological, and social demands of obesity with limited help or support (Wagner et

al., 1999). Most often, the help received (while well-intentioned) fails to optimize clinical care or meet families' needs to effectively self-manage obesity. Consistent with the CCM, effective obesity management requires health service delivery that enables productive interactions between clinicians and families over time (Butt et al., 2008). The well-established high levels of intervention attrition (Fabricatore et al., 2009; Grossi et al., 2006) and weight-related bias (Andreyeva et al., 2008; Puhl et al., 2008) indicate that researchers and clinicians must strive to better understand individuals' and families' experiences and improve obesity-related health services. A primary challenge for professionals providing health services for pediatric weight management relates to factors that influence families' decisions regarding the initiation, continuation, and termination of care.

To our knowledge, limited data are available related to families' reasons for not initiating weight management care; however, a number of surveys and medical record reviews have examined factors related to families' attrition from pediatric obesity treatment. In one study (Barlow & Ohlemeyer, 2006), families who attended one or two visits at a multidisciplinary weight management clinic before discontinuing care reported unmet treatment needs, far distance from the clinic, scheduling conflicts, and a lack of medical insurance as primary reasons for their discontinuation. Another survey (Cote et al., 2004) showed that families that prematurely discontinued the first phase of an intensive behavioral treatment program did so because of excessive program length, lack of adequate transportation, unmet expectations, and their child's desire to terminate. A large medical record review (Tershakovec & Kuppler, 2003) examined attrition in children and youth with obesity who

attended only one appointment at a specialized clinic and found that African-Americans and those with managed care insurance were more likely to dropout than Caucasians and those with indemnity insurance coverage. A second medical record review (Zeller et al., 2004) compared children who did or did not finish a four-month intensive treatment program, which reported that non-completers were more likely to be Medicaid recipients, African-American, older, and self-report greater depressive symptomatology and lower self-concept than completers. One small Canadian study reinforces many of these findings. Of families that discontinued outpatient nutrition counselling for weight management after one appointment (Kitscha et al., 2009), parents' reasons for non-return included clinic location, limited parking options, low satisfaction with the clinical environment, and counseling approach (*e.g.*, intervention focus on the child rather than the family). While the aforementioned studies provide some insight into factors that impacted families' termination of care, they also underscore the clear need for additional research to establish a stronger evidence base upon which to guide administrative and clinical decision-making related to pediatric weight management. This is especially important given that most of the research to date has been conducting in the US, which means issues that impact attrition such as health services funding and demographic characteristics are not generalizable to other countries.

With the aforementioned issues in mind, the overarching aim of the current study is to investigate the factors influencing families' decisions regarding initiating, continuing, and terminating pediatric weight management care. This focus will allow our team to identify issues that can help to optimize the delivery of health services for managing pediatric obesity in

Canada. Specifically, this research protocol was developed to answer to the following question: After being referred for pediatric weight management, what micro (*e.g.*, child, parent, family), meso (*e.g.*, clinicians, clinic environment), and macro (*e.g.*, health care system, environment) level factors are involved in families' decisions regarding whether or not to initiate, continue, or terminate health services for managing pediatric obesity?

The collective experience of our team suggests that approximately 50% of all boys and girls referred for specialized health services to manage pediatric obesity fail to attend an initial clinical appointment. By failing to initiate care, a substantial number of children miss out on opportunities for clinical evaluations and interventions that can (*i*) identify underlying medical, behavioral, and mental health issues and (*ii*) support families in making positive lifestyle changes. Developing a comprehensive understanding of families' decisions regarding their initiation (or lack thereof) of health services will generate valuable data regarding whether potential barriers can be mitigated or opportunities can be enhanced to increase the likelihood that families initiate weight management care. Our real-world observations also suggest that among those families that do initiate care, most only do so for a short period of time. This issue is clinically relevant since long-term care enhances weight management success [Lau et al., 2007; Barlow et al., 2007; Finley et al., 2007). Families' reasons for either continuing or terminating care are likely to be complex, extend beyond simple, intrapersonal factors, and may not necessarily correspond to weight management success. The long-term continuation of care is important for weight loss maintenance, but also has important implications for health service delivery since a common challenge among pediatric weight management centers in Canada is

limited resource availability (*e.g.*, economic, personnel, time), which can limit treatment options (Newton et al., 2007).

Methods

Methodology

Our research will use a multiple qualitative case study methodology (Wolfenden & Holt, 2005). Data will be collected from four distinct research sites with each of the following sites representing a case: *(i)* Pediatric Centre for Weight and Health in Edmonton, Alberta; *(ii)* Centre for Healthy Weights in Vancouver, British Columbia; *(iii)* Metabolism, Obesity and Health Program at McMaster Children's Hospital, Hamilton, Ontario; and *(iv)* Healthy Weight Clinic in Montreal, Quebec. A case study approach is appropriate for this research since the topic of interest is represented within each selected case, and each case represents a population within the topic of interest (Wolfenden & Holt, 2005). Within each case, the unit of analysis will be the family members who were referred or received weight management care (*e.g.*, a child/youth and a parent). By collecting perspectives from multiple families, we will be able to create an account that represents each of the four cases. Commonalities and differences between and within cases will then be identified. Ultimately, this will enable us to provide detailed information about experiences and decisions regarding families' initiation, continuation, and termination of care that are relevant to centers across the country. The multiple qualitative case study methodology is appropriate for this study for several reasons. First, the research questions require detailed information about participants' perceptions and experiences; such data could not be obtained through quantitative measures (*e.g.*, questionnaires). Second, it is important to

study multiple cases across Canada in order to establish local level variations in addition to common factors that influence families' decisions to initiate, continue, and terminate care. Finally, case study methodology is appropriate for studying 'bounded' social systems. In the proposed study, each site is a bounded system with specific rules and norms of social interaction. Using this approach, researchers can obtain data to identify key issues relevant to each case (and shared between cases), triangulate key findings for interpretation, consider alternative explanations, and develop assertions about the cases (Stake, 2005; Creswell, 1997). The four multidisciplinary pediatric weight management centers represented in this study were selected based on their existing administrative and research infrastructure, national leadership roles of their program directors, diverse demographic characteristics of the communities they serve, and similar philosophical approaches to providing family-centered care.

Study sample

A total of 100 families ($n = 25/\text{site}$) will be recruited for this study. The number of families per site has been estimated based on a previous study (Holt et al., 2008) in which an adequate level of saturation was reached after interviewing families at one weight management center. The inclusion of a broader sample usually requires additional data to achieve saturation than would be required with a more tightly defined sample [Morse & Field, 1995). A purposeful sampling approach will be used, a strategy that is designed to identify the most information-rich cases from which to learn about issues that are fundamental to the purpose of the research (Patton, 2002). Given the aims of the study, families will be recruited based on whether they satisfy the following eligibility criteria:

1. Non-Initiators (n = 5 families/site; 20 families total): Families in this group will include a child with obesity who was referred for weight management within the past six months, but did not follow-up the referral by attending a clinical appointment. We anticipate this group of families will be more difficult to recruit and enroll, which is reflected in the smaller sample size. This group of families will allow us to explore issues related to decisions regarding initiation of care.
2. Initiators (n = 10 families/site; 40 families total): Families in this group will include a child with obesity who was referred for weight management within the past six months, who did follow-up the referral by attending at least one clinical appointment, and discontinued care following a brief period of time. This group of families will allow us to explore issues related to both the initiation and premature termination of care.
3. Continuers (n = 10 families/site; 40 families total): Families in this group will have a child with obesity who was referred for weight management and completed a formal weight management intervention within the past 12 months and will have continued with follow-up care for at least six months. This group of families will allow us to explore issues related to both the initiation and continuation of care.

Inclusion criteria

Families will be eligible for this study if children with obesity were (i) referred for weight management to one of the four multidisciplinary pediatric weight management centers, (ii) 10–17 years old at the time of referral, and (iii) possessed an age- and sex-specific body mass index (BMI) $\geq 97^{\text{th}}$ percentile at the time of referral. Parents (mothers, fathers, and legal

guardians) will be eligible for this study if they self-identify as the primary caregiver of a child with obesity. Families will determine the adult who can, in their view, best represent their family's experiences and perceptions regarding pediatric weight management.

Recruitment

To enhance our ability to successfully recruit families into all three categories from all four sites, we will apply three main strategies. First, we will offer families the option of holding interviews at times (*e.g.*, evenings, weekends) and locations (*e.g.*, weight management center, family residence) that are most convenient for them. Second, we will offer each family a \$100 gift card at a local business or shopping mall as an incentive to participate and acknowledgement of the time, effort, and (potential) time away from work. Finally, we will work collaboratively across our four sites to enhance recruitment. At study initiation, we will develop a site-specific recruitment timeline, which will include milestones and a clear plan to document all successful and unsuccessful recruitment approaches. We will collectively discuss and develop study promotional materials and family recruitment letters, so similar information (both in English and French) will be used across study sites. Families in the Non-Initiator and Initiator groups will be contacted by regular mail with additional correspondence by telephone or e-mail, when appropriate, because they will not be attending regular clinic appointments. Following institutional ethics approvals, mailing addresses for potential participants will be retrieved from patient registries that are maintained by all four study centers. Families in the Continuers group will be contacted in person by a member of each center's administrative staff during a scheduled clinical appointment. Study promotional materials will be shared with

families at this time. If families express interest in the study, follow-up (either in-person, by telephone or email) for study recruitment will be initiated by research coordinators (RCs) at each site. Once inclusion criteria are confirmed, RCs will complete the informed consent and assent procedures with parents and children, respectively.

Data collection

Participants (children and parents) will engage in one individual semi-structured interview each. Assuming that we interview one child and one parent per family, there will be a total of 200 interviews. Interviews will be conducted at each site by trained Graduate Research Assistants (GRAs) and/or RCs. Interviews will be 30 (child) to 60 (parent) minutes in length and will be digitally recorded using Olympus Digital Voice Recorders (WS-400S). Interviews will include open-ended questions about factors related to the initiation, continuation, and/or termination of care, reasons for making those decisions, who was involved in making those decisions, and how they feel about those decisions. Information about the micro (*e.g.*, child, parent, family), meso (*e.g.*, clinicians, clinical setting), and macro (*e.g.*, health care system, environment) factors will be gathered; probes regarding perceptions, experiences, examples, and preferences related to decision-making will be used. Preferences, perceived strengths and limitations, and areas for improvement regarding health services for managing pediatric obesity will be explored. Participants will be asked to provide specific examples of challenges and opportunities they faced. A closing discussion will probe perceptions of need for long-term support, how support should be delivered, and expectations for maintaining changes initiated during and following treatment.

Demographic and anthropometric/clinical information will also be obtained for contextual purposes. Demographic variables will include mailing address (to calculate geographic distance between weight management centers and families' residences), dates of birth, sex, relationship between child and parent, ethnicity, and socioeconomic status. Anthropometric/clinical variables will include weight, height, waist circumference, BMI, BMI percentile (child only), BMI z-score (child only), presence/absence of obesity-related comorbidities, and family history of chronic disease. Portable medical scales, stadiometers, and tape measures will be used to collect up-to-date weight, height, and waist circumference data, respectively, from all participants, which will be particularly important when interviews are conducted away from clinical settings. Demographic and clinical data will be collected by site-specific GRAs and RCs from several sources including weight management referral forms and research or medical charts for boys and girls who attended one of our centers. The accuracy and completeness of data gleaned from referral forms and charts will be confirmed with families upon study enrolment. Methodological rigor will be enhanced by adhering to evidence-based protocols for medical record review research (Gearing et al., 2006; Lowenstein, 2005).

Data analysis

Digitally-recorded interview data from all centers will be submitted electronically to the Comma Police (www.commapolice.com) for transcription. Subsequently, transcribed data will be entered verbatim into N-VIVO 8 (QSR, Melbourne, Australia) for data management and analysis. Interviews held in Vancouver, Edmonton, and Hamilton will be conducted in English whereas interviews in Montreal will be conducted in either English or French. Data will be

transcribed to text in the original language of the interview (English or French). At the final stage of analysis, results from both languages will be compared and contrasted. Data analysis will commence as soon as the first transcripts are received. Initial coding will be performed by GRAs and RCs at each of the four sites under the guidance of the principal and co-investigators. Although all data will be subjected to the same coding procedures (described below), analysis will be conducted on a case-by-case basis to identify specific issues based on participants' experiences from each of the four research sites. Stake (2005) categorical aggregation method for case study methodology will be used. First, transcripts will be read using line-by-line coding to identify specific themes. This process requires examining, questioning, and corroborating themes throughout the analysis. As themes are identified, similar instances or occurrences will be aggregated to create a basic coding schema. A written description will then be constructed to explain each category. During the final stages of coding, data from each center will be aggregated to establish common themes and specific local variations. Consistent with case study methodology (Stake, 2005), several techniques have been built into the research design to enhance the methodological rigor of the analysis. First, obtaining data from multiple sources (children and parents) across four sites will allow us to triangulate the findings (Stake, 2005; Patton, 2002). Second, data analysis will be corroborated by the research team who will compile a quarterly report of the findings to date, which will be discussed with all team members during quarterly team meetings. This process will also be repeated with the final results, which will allow us to corroborate the analysis and remain sensitive to local, contextual issues. Third, a member checking protocol (Lincoln & Guba, 1985) will be used. Participants in each of the

four research sites will receive a summary of the findings and be asked to evaluate whether the analysis reflects their personal experiences in pediatric weight management care. Finally, the sample size is substantial and will enhance our ability to attain data saturation, which will allow us to draw meaningful conclusions from the data.

Information retrieved from referral forms and medical charts will include contextual data from children and parents. Data will be retrieved from these sources (and supplemented by information collected from families during individual interviews) using standardized case report forms that will be developed with input from all team members. Quantitative data will be analyzed using SPSS 17.0 (SPSS Inc.; Chicago, IL). Continuous variables will be described by univariable summaries (*e.g.*, means, medians, ranges, SDs) and frequency distributions will be determined for categorical variables. For key outcome variables, 95% confidence intervals will be reported for means and proportions. To display continuous variables, box plots and histograms will be used; bar charts will be used for categorical variables.

Discussion

Childhood obesity has emerged as a priority health concern in Canada, but the manner with which health services are delivered for its management has received very little research attention. There is a clear need to gain a better understanding of how health services can be optimized for children with obesity (and their families) given that most research in this area has examined intervention efficacy and effectiveness, foci that leave several knowledge gaps remaining. A key research issue with relevance to pediatric weight management care is family engagement; in its absence, even the most effective intervention will be unlikely to bring about

positive changes in health outcomes. In response to this lack of evidence, the present study is designed to understand the variety of factors at multiple levels that influence families' decision regarding initiation, continuing, and terminating the management of pediatric obesity.

Some information exists related to factors that predict or influence families' decisions to terminate pediatric weight management care (attrition) (Skelton & Beech, 2011). Study findings have been mixed with respect to factors that predict attrition (*e.g.*, children's BMI, sex), but practical issues including scheduling difficulties and services not meeting families' expectations have been reported as common reasons for terminating care. It is noteworthy that most of the evidence on attrition is derived from US-based research, which limits generalizability to other countries given demographic and health care system differences. For instance, insurance coverage (or lack thereof) may influence attrition in the US, but in jurisdictions with universal health care coverage (*e.g.*, Canada, United Kingdom, Australia, New Zealand), other factors are likely to be more salient. In addition, any differences in attrition that exist along racial or ethnic lines are likely to vary between nations given inter-country differences in cultural diversity and immigration patterns. These observations reinforce the importance of acquiring attrition-related data from health care settings beyond the US.

In contrast to the growing body of literature on attrition, currently, there is scant information available on issues related to families' decisions regarding their initiation of pediatric weight management care. Determinants of non-initiation are of particular importance given that, in our team's clinical experience, a substantial number of children and families fail to initiate care, which includes choosing to not follow-up their clinician's referral to a weight

management clinic or deciding to not self-refer themselves into clinic- or community-based services. Such decisions mean that families miss out on opportunities to benefit from weight management care, which can include *(i)* identifying underlying obesity-related co-morbidities (*e.g.*, hypertension, dyslipidemia, fatty liver disease) that may require additional specialized health services and *(ii)* participating in family- and lifestyle-based interventions that are known to be effective in helping children with obesity (and their families) to improve their weight and health (Luttikhuis et al., 2009).

By applying a qualitative research approach, we will obtain rich, contextual information across our four study sites that cannot be gleaned from brief surveys or medical record reviews. Qualitative methodology provides an excellent means of understanding the meaning behind reports that have linked attrition to parents' perceptions of quality of care and unfulfilled treatment needs (Skelton & Beech, 2011). Our decision to include both children and parents is noteworthy since we cannot assume that factors which determine the initiation, continuation, and termination of care are similar for all family members. Given differences in age and stage, salient concerns for parents (*e.g.*, current or future medical health risks) may not resonate with children (and vice versa). Further, this study also acknowledges the roles that children play in their self-management, a key feature of managing obesity as a chronic condition. Building on research to date, our study will investigate families' perceptions, experiences, and needs at both ends of the treatment continuum (when it is initiated and when it is discontinued). Speaking with families at different levels of motivation to change lifestyle and behavioral issues and with

unique experiences in clinical weight management will enable our team to better understand how to optimize health services for managing pediatric obesity.

Through our search of the literature and collaborative efforts in developing the current research, we identified gaps in evidence that are demanding new theoretical and methodological developments. Consequently, psychosocial factors that affect initiation, continuation, and termination of pediatric weight management care will not only be defined, but also understood to which a grounded theory of parental involvement in different stages of pediatric management care will be developed. The study is also ideally-suited for instrument building and data triangulation (Creswell et al., 2004). Interview and contextual (*e.g.*, anthropometry, demography) data will be used to develop two new surveys (one for parents, one for children) that will be developed, piloted, and validated in follow-up research. These tools will be broadly available for researchers, clinicians, and decision-makers to administer in order to study (as well as mitigate or manage) factors related to the initiation, continuation, and termination of pediatric weight management care. Ultimately, this information can inform how health services should evolve to better meet the needs of children with obesity and their families.

References

- Andreyeva T, Puhl RM, Brownell KD. Changes in perceived weight discrimination among Americans, 1995–1996 through 2004–2006. *Obesity* 2008;16:1129–1134.
- Ball GDC, Ambler KA, Chanoine JP. Pediatric weight management programs in Canada: where, what and how? *Int J Pediatr Obes* 2011;6:e58–e61.
- Barlow SE, Expert Committee. Expert committee recommendations regarding the prevention, assessment, and treatment of child and adolescent overweight and obesity: summary report. *Pediatrics* 2007;120(Suppl 4):S164–S192.
- Barlow SE, Ohlemeyer CL. Parent reasons for nonreturn to a pediatric weight management program. *Clin Pediatr* 2006;45:355–360.
- Butt G, Markle-Reid M, Browne G. Interprofessional partnerships in chronic illness care: a conceptual model for measuring partnership effectiveness. *Int J Integr Care* 2008;8:e08.
- Cote MP, Byczkowski T, Kotagal U, Kirk S, Zeller M, Daniels S. Service quality and attrition: an examination of a pediatric obesity program. *Int J Qual Health Care* 2004;16:165–173.
- Creswell JW, Fetters MD, Ivankova NV. Designing a mixed methods study in primary care. *Ann Fam Med* 2004;2:7–12.
- Creswell JW. *Qualitative research and research design: choosing among five traditions*. Thousand Oaks, CA: Sage Publications; 1997.
- Cruz ML, Shaibi GQ, Weigensberg MJ, Spruijt-Metz D, Ball GD, Goran MI. Pediatric obesity and insulin resistance: chronic disease risk and implications for treatment and prevention beyond body weight modification. *Annu Rev Nutr* 2005;25:435–468.

- Fabricatore AN, Wadden TA, Moore RH, Butryn ML, Gravalles EA, Erondu NE, Heymsfield SB, Nguyen AM. Attrition from randomized controlled trials of pharmacological weight loss agents: a systematic review and analysis. *Obes Rev* 2009;10:333–341.
- Finley CE, Barlow CE, Greenway FL, Rock CL, Rolls BJ, Blair SN. Retention rates and weight loss in a commercial weight loss program. *Int J Obes* 2007;31:292–298.
- Franks PW, Hanson RL, Knowler WC, Sievers ML, Bennett PH, Looker HC. Childhood obesity, other cardiovascular risk factors, and premature death. *N Engl J Med* 2010;362:485–493.
- Gearing RE, Mian IA, Barber J, Ickowicz A. A methodology for conducting retrospective chart review research in child and adolescent psychiatry. *J Can Acad Child Adolesc Psychiatry* 2006;15:126–134.
- Grimes-Robison C, Evans RR. Benefits and barriers to medically supervised pediatric weight management programs. *J Child Health Care* 2008;12:329–343.
- Grossi E, Dalle Grave R, Mannucci E, Molinari E, Compare A, Cuzzolaro M, Marchesini G. Complexity of attrition in the treatment of obesity: clues from a structured telephone interview. *Int J Obes* 2006;30:1132–1137.
- Holt NL, Moylan BA, Spence JC, Lenk JM, Sehn ZL, Ball GD. Treatment preferences of overweight youth and their parents in Western Canada. *Qual Health Res* 2008;18:1206–1219.
- Janssen I, Craig WM, Boyce WF, Pickett W. Associations between overweight and obesity with bullying behaviors in school-aged children. *Pediatrics* 2004;113:1187–1194.

- Kitscha CE, Brunet K, Farmer A, Mager DR. Reasons for non-return to a pediatric weight management program. *Can J Diet Pract Res* 2009;70:89–94.
- Lau DC, Douketis JD, Morrison KM, Hramiak IM, Sharma AM, Ur E. 2006 Canadian clinical practice guidelines on the management and prevention of obesity in adults and children [summary]. *CMAJ* 2007;176:S1–S13.
- Lincoln YS, Guba EG. *Naturalistic inquiry*. Newbury Park, CA: Sage; 1985.
- Lowenstein SR. Medical record reviews in emergency medicine: the blessing and the curse. *Ann Emerg Med* 2005;45:452–455.
- Luttikhuis HO, Baur L, Jansen H, Shrewsbury VA, O'Malley C, Stolk RP, Summerbell CD. Interventions for treating obesity in children. *Cochrane Database Syst Rev* 2009;1:CD001872.
- Mokdad AH, Marks JS, Stroup DF, Gerberding JL. Actual causes of death in the United States, 2000. *JAMA* 2004;291:1238–1245.
- Morse JM, Field PA. *Qualitative research methods for health professionals*. 2nd edition. Thousand Oaks, CA: Sage; 1995.
- Newton MS, Lovely JJE, Premji S, Goldfield G, Spence JC, Ball GDC. *Addressing Childhood Obesity through Research and Networking (ACORN): A summary of a think tank convened by pediatric weight management centers in Canada*. Edmonton, AB; 2007.
- Ogden CL, Carroll MD, Curtin LR, Lamb MM, Flegal KM. Prevalence of high body mass index in US children and adolescents, 2007–2008. *JAMA* 2010;303:242–249.

- Olshansky SJ, Passaro DJ, Hershow RC, Layden J, Carnes BA, Brody J, Hayflick L, Butler RN, Allison DB, Ludwig DS. A potential decline in life expectancy in the United States in the 21st century. *N Engl J Med* 2005;352:1138–1145.
- Patton MQ. *Qualitative evaluation and research methods*. 3rd edition. Newbury Park, CA: Sage; 2002.
- Puhl RM, Moss-Racusin CA, Schwartz MB, Brownell KD. Weight stigmatization and bias reduction: perspectives of overweight and obese adults. *Health Educ Res* 2008;23:347–358.
- Puhl RM, Latner JD. Stigma, obesity, and the health of the nation's children. *Psychol Bull* 2007;133:557–580.
- Singh AS, Mulder C, Twisk JW, van Mechelen W, Chinapaw MJ. Tracking of childhood overweight into adulthood: a systematic review of the literature. *Obes Rev* 2008;9:474–488.
- Skelton JA, Beech BM. Attrition in paediatric weight management: a review of the literature and new directions. *Obes Rev* 2011;12:e273–e281.
- Skinner AC, Mayer ML, Flower K, Perrin EM, Weinberger M. Using BMI to determine cardiovascular risk in childhood: how do the BMI cutoffs fare? *Pediatrics* 2009;124:e905–e912.
- Spear BA, Barlow SE, Ervin C, Ludwig DS, Saelens BE, Schetzina KE, Taveras EM. Recommendations for treatment of child and adolescent overweight and obesity. *Pediatrics* 2007;120(Suppl 4):S254–S288.
- Stake RE. *The Sage handbook of qualitative research*. 3rd edition. Thousand Oaks, CA: Sage; 2005.

- Stewart ST, Cutler DM, Rosen AB. Forecasting the effects of obesity and smoking on U.S. life expectancy. *N Engl J Med* 2009;361:2252–2260.
- Tershakovec AM, Kuppler K. Ethnicity, insurance type, and follow-up in a pediatric weight management program. *Obes Res* 2003;11:17–20.
- Tremblay MS, Shields M, Laviolette M, Craig CL, Janssen I, Gorber SC. Fitness of Canadian children and youth: results from the 2007–2009 Canadian Health Measures Survey. *Health Rep* 2010;21:1–14.
- Wagner EH, Austin BT, Davis C, Hindmarsh M, Schaefer J, Bonomi A. Improving chronic illness care: translating evidence into action. *Health Aff* 2001;20:64–78.
- Wagner EH, Davis C, Schaefer J, Von Korff M, Austin B. A survey of leading chronic disease management programs: are they consistent with the literature? *Manag Care Q* 1999;7:56–66.
- Wang F, Wild TC, Kipp W, Kuhle S, Veugelers PJ. The influence of childhood obesity on the development of self-esteem. *Health Rep* 2009;20:21–27.
- Wolfenden L, Holt NL. Talent development in elite junior tennis: perceptions of players, parents, and coaches. *J Appl Sport Psychol* 2005;17:108–126.
- Zeller MH, Reiter-Purtill J, Modi AC, Gutzwiller J, Vannatta K, Davies WH. Controlled study of critical parent and family factors in the obesigenic environment. *Obesity* 2007;15:126–136.
- Zeller M, Kirk S, Claytor R, Khoury P, Grieme J, Santangelo M, Daniels S. Predictors of attrition from a pediatric weight management program. *J Pediatr* 2004;144:466–470.