

Exploring the Perceptions of Bariatric Surgery for Adolescents Living with Severe Obesity

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ABSTRACT

Exploring the Perceptions of Bariatric Surgery for Adolescents living with Severe Obesity

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The purpose of this thesis is to provide insights into the treatment and management of youth living with severe obesity within Quebec through the perspective of key stakeholders with a focus on the decision-making process for adolescent bariatric surgery. Semi-structured interviews were conducted with pediatricians (n=8), bariatric surgeons (n=5), healthcare administrators (n=4), and adolescents contemplating bariatric surgery (n=7). Adolescents also produced body map collages following the interview. This art-based method involves youth outlining their perceived body shape on a piece of paper (16"x20") and using drawings and/or magazine images to represent their embodied experience with weight management. Interview results were transcribed and analysed inductively to identify emerging themes. Body maps were analysed using collage in conceptualization which resulted in the creation of an analytical collage by grouping related images from the body maps.

Results are presented as five papers: (1) findings from a pilot study examining the feasibility of using body-map storytelling with adolescents; (2) the perceptions of pediatricians on obesity as a disease and the practice implications; (3) the perceptions of pediatricians on adolescent bariatric surgery; (4) the factors adolescents consider when deciding on bariatric surgery; and (5) a multi-stakeholder perspective on bariatric surgery for adolescents living with severe obesity.

There was a generally positive perception regarding bariatric surgery for adolescents with medically urgent needs across all four stakeholder groups. There were also points of divergence regarding pre-requisites for the surgery, and which factors are considered in the decision to refer, finance, or undergo the procedure. Comparison of the stakeholders demonstrated that the acceptability of bariatric surgery was inherent to a healthcare context that offered no other alternative to primary care management for adolescents struggling with weight. Thus the pathway to bariatric surgery was perceived as skipping some key steps in the care pathway. Interestingly, a group of pediatricians and adolescents did not view obesity as a

disease. Implications from this study include the need for improved availability of behavioural interventions with a team of weight management experts to address the gap between primary care counseling and tertiary care surgical intervention.

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This thesis is built on the kindness of all the study participants who agreed to share their time and experiences with me. I hope this research is just the beginning of finding ways to improve the care for adolescents living with severe obesity.

Lastly, to the family and friends who kept asking if I was done yet, well I can finally give you an answer... Yes, I am! Your ongoing support and belief has been much appreciated.

DEDICATION

This thesis is dedicated to my mother who has unwaveringly supported me throughout my life so that I could achieve my dreams, entirely at the expense of her own. This immense sacrifice has not gone un-noticed and I am beyond grateful. I hope I've been a worthwhile investment! My DNA may only be 50% hers, but I am 100% my mother's daughter and I consider that one of the greatest honors.

“Sono così felice, ballerò su una gamba sola.” – Nonna Luchetta

This thesis also goes out to my favorite person in the entire world, my little munchkin Luca. If it weren't for you, my thesis would probably have been completed sooner, but I would never trade the endless hours of playing Legos, dressing up in Peter Pan costumes, and having you teach me all the different superheroes and whether they are DC or Marvel... Spiderman is DC right? I'm looking forward to many more adventures together.

“The best aunts aren't substitute parents. They're co-conspirators.” – Daryl Gregory

CONTRIBUTION OF AUTHORS

My supervisor and three committee members have worked with me throughout the different phases of my doctoral dissertation. Therefore their involvement has been similar across each of the papers. They are as follows:

Biagina-Carla Farnesi contributed to the study design, performed the data collection and analysis, and prepared the manuscripts.

Simon L Bacon, Kim L Lavoie, Laurent Legault, and Rosemary Reilly contributed to the design, interpretation of the results, and provided critical feedback on the manuscripts.

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CHAPTER 1: Introduction

Adolescent bariatric surgery is an emerging area of research and it has only been an option in Canada for a small minority of patients since 2009. This reality is reflected in the literature where there is general reluctance by healthcare professionals to endorse the idea of surgically intervening in a youth population and in the gaps documenting the experiences of adolescents who undergo the procedure. Therefore, this exploratory thesis aims to contribute to this body of literature by focusing on the perspective of adolescents, paediatricians, bariatric surgeons, and healthcare administrators from Quebec, Canada regarding adolescent bariatric surgery.

Literature Review

Prevalence of Obesity

While the prevalence of youth living with obesity has stabilized in the past several years, approximately 13% of youth in Canada continue to live with obesity (Rodd & Sharma, 2016). Despite the problematic nature of body mass index (BMI) in representing the adiposity of individuals (Nuttall, 2015), it continues to be used as a way of tracking population trends and as part of different clinical assessment criteria's. Different definitions of severe obesity exist, but a widely accepted definition is a body mass index (BMI) > 120% of the 95th BMI percentile for age and sex (Flegal et al., 2009). Unfortunately, there is currently no known standard reported national prevalence of Canadian adolescents living with severe obesity. A recent study from Ontario found the prevalence of severe obesity (defined as zBMI > 3 in the study) was 3.7% in youth aged 15-18 years old (Carsley et al., 2019).

In the United States there is evidence that the severity of obesity continues to increase. Data from 1999 to 2016 from the National Health and Nutrition Examination Survey (NHANES) for individuals aged 2 to 19 years old shows a positive linear trend for the prevalence of class II

obesity¹ (p=0.019) and class III obesity² (p>0.001) (Skinner, Ravanbakht, Skelton, Perrin, & Armstrong, 2018).

The prevalence of youth living with obesity raises a public health concern due not only its direct effects on individuals but also its association with the development of numerous co-morbid conditions. There is also a mental toll of living with excess weight. Youth with obesity are more likely to be teased (Zeller, Reiter-Purtill, & Ramey, 2008), depressed, discriminated against, and experience a lower quality of life (Puhl & Latner, 2007). Obesity has also been linked to the development of hypertension, type II diabetes, dyslipidemia, coronary heart disease, and osteoporosis (Dietz, 1998). Given that up to 77% of youth living with obesity will grow up to be an adult with obesity, it is important to intervene at a young age (Dietz, 1998; Whitaker, Wright, Pepe, Seidel, & Dietz, 1997).

Current Weight Management Approaches and Outcomes

Canadian clinical practice guidelines issued in 2006 provide recommendations on the screening, treatment, and management of youth living with obesity. Included in the treatment section are modifications to nutritional intake (decrease calories) and physical activity (decrease sedentary time, increase exercise duration and frequency). It also encourages the engagement of a team of healthcare professionals to develop a comprehensive weight management strategy (Lau et al., 2007).

Adolescence is a time when youth assert their autonomy and demonstrate a capacity to make informed decisions about their health (Boutelle, Feldman, & Neumark-Sztainer, 2012; Weithorn & Campbell, 1982). Therefore, while the family remains the primary target of weight interventions, there is a diminished role for the parents (Golan, 2006). When it comes to actual weight loss, a review of available treatment options of pediatric severe obesity concluded that bariatric surgery is the only option that has demonstrated a significant impact on weight loss that is sustainable in the long term (Ryder, Fox, & Kelly, 2018).

¹ Class II Obesity is defined as BMI > 120% of the 95th BMI percentile for age and sex or a BMI≥35 kg/m² (whichever is lower)

² Class III Obesity is defined as BMI > 140% of the 95th BMI percentile for age and sex or a BMI≥40 kg/m² (whichever is lower)

Adolescent Bariatric Surgery

Bariatric surgery is an invasive procedure that involves either reducing or restricting the stomach or causing malabsorption to promote weight loss in patients (Madura li & DiBaise, 2012). Canadian statistics on bariatric surgery in youth is limited. Currently, there are only two sites that offer an adolescent program: the Sick Kids Hospital in Toronto, ON and the Montreal Children's Hospital in Quebec. As of 2014, the Toronto site had published data on 18 completed surgeries (Davies et al., 2014). Through communication with the two sites, it is estimated that the total number of surgeries ever completed will be around 65 by the end of 2020.

Only short-term data is available on the outcomes of adolescent bariatric surgery. American data shows improvements in psychological functioning, such as reduction in depressive symptoms and increase in quality of life, were observed at one year post-surgery and largely sustained at three years (Inge et al., 2016). Five years post-surgery outcomes from a clinical trial in the United States have shown that the patients experienced drastic weight loss with a mean percent weight loss of 26% and the majority of patients had remission from their co-morbidities like type 2 diabetes (Inge et al., 2019). Conversely, bariatric surgery is accompanied by the risk of complications and mortality. Complications can be short-term, (i.e., immediately following surgery) like urinary tract events, post-operative bleeding (with and without transfusion) and bowel obstruction (Inge et al., 2014), or a persistent by-product of the surgery like chronic micronutrient deficiency (Inge et al., 2019). The incident of death was 1.6% at 5 years in the aforementioned clinical trial (Inge et al., 2019).

Given the potential benefits and risks associated with adolescent bariatric surgery, one of the key emerging issues is the importance of selecting the right patients for the procedure. The 2018 guidelines by the American Society for Metabolic and Bariatric Surgery (ASMBS) show an evolution from previous versions (Pratt et al., 2018). The most recent indications for adolescent bariatric surgery can be found in Table 1-1. Three key changes in the most recent guidelines are no longer requiring patients to: (1) have reached Tanner stage IV or V; (2) have completed at least 95% of estimated growth; and (3) demonstrate evidence of treatment 'failure' following a minimum of 6 months of behavioural lifestyle intervention.

Table 1-1 2018 ASMBS Guidelines (Pratt et al., 2018)

<p>Indications for adolescent MBS include</p> <ul style="list-style-type: none">- BMI \geq 35 kg/m² or 120% of the 95th percentile with clinically significant co-morbid conditions such as obstructive sleep apnea (AHI \geq 45), T2D, IIH, NASH, Blount's disease, SCFE, GERD, or hypertension; or BMI \geq 40 kg/m² or 140% of the 95th percentile (whichever is lower).- A multidisciplinary team must also consider whether the patient and family have the ability and motivation to adhere to recommended treatments pre- and postoperatively, including consistent use of micronutrient supplements.
<p>Contraindications for adolescent MBS include</p> <ul style="list-style-type: none">- A medically correctable cause of obesity- An ongoing substance abuse problem (within the preceding year)- A medical, psychiatric, psychosocial, or cognitive condition that prevents adherence to postoperative dietary and medication regimens.- Current or planned pregnancy within 12 to 18 month of the procedure

The majority of the interviews for this thesis were completed prior to the release of these updated guidelines. Therefore, the perceptions shared by the participants may not align with the latest changes in part because they had not been published yet. Likewise, it is unknown what level of agreement or resistance they may have had to the new guidelines.

The missing perspective: Adolescents Bariatric Surgery Patients

The reasons that may draw adolescents to bariatric surgery are complex and until recently there had been no research with this population to understand their experiences signaling a critical need for corroborating evidence. Deciding on bariatric surgery for an adolescent is described as a balancing of the potential risks alongside the anticipated benefits (Inge, Zeller, Lawson, & Daniels, 2005). However, noticeably absent is the recognition that what is perceived as a risk or a benefit, and the relative importance of each, is highly individual and involves value judgments that are not necessarily shared by all individuals (Hofmann, 2013; van Geelen, Bolt, & van Summeren, 2010). In consultations with youth specifically, it can be misleading for a healthcare provider to assume a shared understanding about health, weight, and obesity between themselves and their patient, when in fact their contexts are fundamentally different (van Geelen et al., 2010).

The motivation for desiring surgery can shape the way risks and benefits are perceived by adolescents. Adolescents (especially those that live with overweight) express the importance of having the 'right' body, one that would not stand out among their peers (Booth, Wilkenfeld, Pagnini, Booth, & King, 2008). This does not necessarily mean wanting to look like a supermodel, but rather to 'fit in' and participate in social activities without fear of being ridiculed for being different (Lofrano-Prado et al., 2013; Murtagh, Dixey, & Rudolf, 2006). Therefore, youth that are overweight strive to be accepted (Mériaux, Berg, & Hellström, 2010) and believe that by changing their body shape they can achieve that goal. In this context, bariatric surgery can be the pathway that leads to social acceptance for adolescents. Indeed, a common theme in the recently published literature with adolescent bariatric surgery patients is that part of the decision to have surgery is the desire to be included and to improve peer relationships (Childerhose, Eneli, & Steele, 2018; Doyle, Colville, Brown, & Christie, 2018; Nordin, Brorsson, & Ekblom, 2018).

Equally, this desire can set up youth to have unrealistic expectations about how bariatric surgery will affect their body shape and size. Rapid weight loss following bariatric surgery can have a damaging effect on the physical body. In a retrospective study, the authors found that, although youth reported improvements following bariatric surgery a sub-group expressed dissatisfaction with their bodies due to the excess skin following weight loss. This resulted in their hesitancy to show their bodies (Capella & Capella, 2003). Therefore, the risk exists that adolescents will remain unsatisfied with their bodies as they lose weight quickly and their body shape does not match their expectations. In fact, a qualitative study with adolescent patients noted that one of the pre-surgical pre-occupations adolescents had was how their appearance would change with rapid weight loss and the extra skin that may occur (Childerhose et al., 2018). Likewise, following surgery, adolescents reported being satisfied with the overall experience but the main problem faced was excess skin even though they had been promised plastic surgery to remedy the situation (Nordin et al., 2018).

Adolescents' motivation and perhaps unrealistic expectations can also have implications for their assessment of risk. One study found that when it comes to risk assessments, adolescents tried to normalize the risk of complications by reducing the low prevalence to zero as a coping strategy. Also, they reported compartmentalising the uncertainty around the surgery and avoided thinking about the risks because it would be a source of anxiety (Doyle et al., 2018). While adolescents are driven to bariatric surgery to fit in with their peers, healthcare

providers may be focused on medically-oriented outcomes such as resolving co-morbid conditions like diabetes, thereby creating a gap in understanding between the two groups.

A study on adolescents seeking weight loss found a high level of internalised weight bias that increased with body weight (Puhl & Himmelstein, 2018). Given that these youth hold negative beliefs about themselves because of their body size, it is likely that obesity contributes to other mental health issues. Youth living with obesity are more likely to have low self-esteem and diminished self-confidence (Morinder, Biguet, Mattsson, Marcus, & Larsson, 2011). Youth also express feelings of self-blame (Morinder et al., 2011) and there are high rates of mental health issues in this population, especially the presence of depressive symptoms (Zeller, Modi, Noll, Long, & Inge, 2009). However it remains unclear how healthcare providers factor in these conditions in determining whether they should refer an adolescent for surgery and if they have the capacity to provide consent to the procedure.

Healthcare Providers Resistance to Adolescent Bariatric Surgery

The reluctance to accept bariatric surgery for adolescents among health professionals has been documented by a few studies. Surveys of US-based healthcare providers demonstrate that approximately half of the participants would be unlikely to and/or never refer an adolescent for bariatric surgery (Iqbal, Kumar, Iqbal, & Ishitani, 2009; Woolford, Clark, Gebremariam, Davis, & Freed, 2010). Another survey with American pediatric healthcare providers reported that less than 1% of respondents considered referral for bariatric surgery evaluation as part of their treatment plan for obesity with adolescent patients (Vanguri, Lanning, Wickham, Anbazhagan, & Bean, 2014).

The underlying reasons included unknown side-effects of the surgery, risks related to the operation, poor cognitive function of the youth, belief that non-operative approaches are a better choice (Iqbal et al., 2009), as well as cost, potential complications, believing it were not indicated in a pediatric population (Vanguri et al., 2014). Similar skepticism about the use of bariatric surgery was reported in one study with Canadian healthcare providers. The participants felt there was a need for establishing long-term follow-up and a transition plan to adult care before there would be a change in attitude towards the procedure. Negative attitudes towards individuals living with obesity were not explored in any of the papers despite research indicating the prevalence of weight bias among healthcare providers (Schwartz, Chambliss, Brownell,

Blair, & Billington, 2003) and that obesity stigma manifests itself in the way healthcare providers work with patients (Phelan et al., 2015). The participants also stressed it had to include a multi-disciplinary team, be family-centered, and required close monitoring and follow-up of the patient (Bailey, Pemberton, & Frankfurter, 2013). When examining reasons to refer a patient for bariatric surgery, these included significant weight-related comorbidities, lack of treatment effectiveness, need for sustainable weight loss, and psychosocial issues (Iqbal et al., 2009).

With regards to pre-requisites for surgery, studies have shown that healthcare providers endorse the completion of a behavioural weight management program prior to considering surgery. Although there is a lack of consensus on the duration (Woolford et al., 2010), one year in length was cited by a majority (Penna et al., 2014; Vanguri et al., 2014).

One of the limitations of this literature on healthcare providers perceptions is that all these studies are from 2014 or before, and there has been an increasing amount of research in this field that may impact their perceptions and clinical practice. Moreover, given the lack of focus on the Canadian context, which is unique due to the single payer health care system, it would be beneficial to corroborate earlier findings which have predominantly come for the US. Documenting the perceptions of bariatric surgery and the reasons that inform such viewpoints will be important in understanding how patients who may be eligible for bariatric surgery can access this procedure.

Bariatric Surgery and the Healthcare System

Obesity management happens within a larger healthcare context that plays an important role in shaping individual perceptions and behaviours. As a publically funded healthcare system, Canada is faced with an economic reality that differs significantly from the business-oriented model found in the American private insurance system. Public funds are limited and decisions about where to allocate the money can be challenging.

Evidence suggests there is a long-term incentive to investing in obesity prevention and management. For example, a study looking at the economic impact of obesity reports that a, “1% point reduction in [prevalence] both overweight and obese adolescents aged 16–17 years today could reduce the number of obese adults by 52,821 in the future. As a result, lifetime medical costs would decrease by \$586.3 million” (Wang, Denniston, Lee, Galuska, & Lowry, 2010, p. 472). As for bariatric surgery, a study looking at the potential long term cost savings by

comparing adults who had bariatric surgery to a matched cohort of patients who received conventional obesity management found that the surgery group used more inpatient and non-primary outpatient care during the first six years but not after (Neovius et al., 2012). Furthermore, in the follow-ups from seven to 20 years following surgery, overall drug cost was lower in the bariatric group.

Despite such findings, there is currently a scarcity of pediatric weight management programs available in Canada (Ball, Ambler, & Chanoine, 2011) and only two adolescent bariatric programs. Engaging healthcare administrators in research about obesity management and specifically adolescent bariatric surgery is needed to better understand how decisions are made regarding services offered and identifying any other factors that might be relevant to informing perceptions about adolescent bariatric surgery.

Aims and Object of the Thesis

The goal of this thesis was to provide new and novel insights into the treatment and management of adolescents living with severe obesity in Canada through the perspective of key stakeholders with a focus on the decision-making process for adolescent bariatric surgery. The specific questions this thesis answered included:

1. What is the experience of youth who are contemplating or have completed bariatric surgery?
2. What are the perceptions of bariatric surgeons and pediatricians with regards to adolescent bariatric surgery?
3. How do healthcare administrators make decisions about the delivery of healthcare services like bariatric surgery, and what factors (policies, resources, personnel) influence those decisions?

Organization of the Thesis

This thesis is organized into seven chapters, of which five are papers and the publication status can be seen in Table 1-2.

To begin, the methodology used for the thesis, qualitative description is presented in chapter 2. This chapter includes contextual details with regards to the decision to include body map collage as part of the data collection with adolescents following the conduct of a pilot study.

Chapter three presents the findings from the pilot study that tested the feasibility of adapting body-map storytelling, a multi-day data collection method, to approximately 60-90 minutes. The lessons shared in this chapter served to adapt and refine the study protocol that was subsequently used in the main study with the adolescent participants deciding whether to undergo bariatric surgery. The findings from the interviews and body mapping with adolescents are reported in chapter four of the thesis. Using the concept of re-storying, the results are presented through three patient stories and an analytical collage put together using images and words from the body maps. The interviews with adolescents provided insight on how they perceived bariatric surgery for themselves and for others. Focusing on the factors that were part of the decision-making process can inform how providers engage with this group in the preparation for surgery.

In order to better understand provider's perspectives on adolescent bariatric surgery, it was deemed important to capture whether they viewed obesity as a disease, as their beliefs may influence their attitude towards bariatric surgery. Chapter five addresses pediatricians' view of whether obesity is a disease and the practice implications of this. Results from this study demonstrated that half of the sample did not view obesity as a disease, but had similar approaches to behavioural weight management and perceptions of adolescent bariatric surgery. Chapter six documents the level of acceptability for adolescent bariatric surgery and the recommended conditions under which pediatricians believed it should occur. These perceptions were explored alongside those of bariatric surgeons, health administrators, and adolescents in chapter six. The inclusion of healthcare administrators also served a secondary purpose by providing contextual understanding by identifying the factors that impact healthcare delivery. Through these multiple perspectives points of commonality and divergence were more readily identified regarding the approach towards adolescent bariatric surgery and identified potential gaps in the ways adolescents with severe obesity were managed. The concluding chapter highlights the key findings from the thesis, outlines the strengths and limitations, and recommends future research directions.

Table 1-2 Manuscript Status

Paper / Chapter	Targeted Journal	Status
Chapter 2: Lessons learned for a pilot study on the feasibility of using a condensed approach to body-map storytelling with adolescents.	<i>Arts and Health</i>	Ready for submission
Chapter 3: The experience of adolescents in deciding on whether to pursue bariatric surgery.	<i>Qualitative Health Research</i>	Ready for submission
Chapter 4: Pediatricians perceptions of obesity as a chronic disease and the practice implications	<i>Clinical Obesity</i>	Submitted
Chapter 5: Pediatricians perceptions of adolescent bariatric surgery and reasons to refer their patients	<i>Pediatric Obesity</i>	Submitted
Chapter 6: Discussion on the overall perception of adolescent bariatric surgery from a multi-stakeholder perspective and implications for the management of severe obesity	<i>International Journal of Obesity</i>	In preparation

CHAPTER 2: Methodology

Qualitative Description

Given the exploratory nature of the thesis and its focus on capturing the perspectives of multiple stakeholders on adolescent bariatric surgery, the methodology that was best suited to address this purpose was qualitative description (Sandelowski, 2000). Qualitative description seeks to discover and understand a phenomenon, a process, or the perspectives of the people involved by providing straight, but rich description. It has been used in healthcare to gain patient, caregiver, and provider perspectives as well as system-based understanding (Bradshaw, Atkinson, & Doody, 2017). The goal of qualitative description is not to build on existing theoretical constructs and only requires an adherence to naturalistic inquiry that is inherent to qualitative research. The focus is on pragmatic outcomes that can be readily integrated into healthcare decisions or used as a basis for a more extensive study. Qualitative description is low inference in comparison to traditional qualitative methods, but has the benefit of staying close to the text for a comprehensive summary in the terms of the participants and is easier to gain consensus between researchers (Sandelowski, 2000). Additionally, the findings from qualitative description can be further explored through multiple theoretical lenses to illuminate additional meanings and contextualize them within a larger framework relevant to the research area (Sandelowski, 2000).

As Sandelowski (2000) explains qualitative description utilises a naturalistic approach, which means examining the experiences in the context that they occur. Ontologically, qualitative description follows the theory of relativism. There is no single reality that exists because reality is subjective and varies from person to person. As such how knowledge is produced is based on the notion of subjectivism, where there is no single truth rather we come to know through individual experiences. The reality of objects is entirely based on how individuals perceive them.

Qualitative description can also have overtones of other approaches, as is the case in this thesis. Borrowing from arts-based research, the thesis sought to integrate a visual method with the adolescent participant group. Arts-based research in healthcare has been used for knowledge generation and dissemination (Fraser & al Sayah, 2011). The advantages of arts-based approaches are their capacity to be adapted to all age groups, disease conditions, and

can render the outcomes easily accessible to a range of audiences. These approaches also allow for the capture of experiences that may not have yet been fully articulated by the participant. This is particularly relevant given that previous research with a similar group of adolescents found that it was difficult to gather quality data through interviews only (Dhaliwal et al., 2017). Arts-based research approaches also lends itself to increased participant engagement thereby disrupting the traditional dynamic of researcher led data collection (Fraser & al Sayah, 2011).

The initial intention for the thesis was to use collage inquiry alongside interviews with adolescents given that it is less intimidating than drawings, inexpensive, and can be accomplished in a short timeframe. However, after attending a presentation on body-map storytelling that was used with a group of aboriginal women on healing, this approach offered the potential to go further than simply increasing adolescent reflection and engagement by highlighting important intersections between the body, health, and culture that underlie obesity management (Gastaldo, Magalhães, Carrasco, & Davy, 2012; Rich & Evans, 2005). This was viewed as a potentially more substantive contribution to the study of adolescent bariatric surgery.

Body-map Storytelling

Body-map storytelling is, “primarily a data generating research method used to tell a story that visually reflects social, political and economic processes, as well as individuals’ embodied experiences and meanings attributed to their life circumstances that shape who they have become” (Gastaldo et al., 2012, p. 10). By meeting with the presenter to better understand the method and reviewing the facilitators guide from the original paper on body-map storytelling (Gastaldo et al., 2012), a key obstacle was how to adapt the method to a shorter timeframe since it was designed to take place over multiple days. The need to shorten the protocol reflected the reality that adolescents already had multiple appointments at the clinic in preparation for bariatric surgery and it was considered too much of a participant burden to ask for a multi-day commitment. Moreover, the targeted pool of participants was small (9 patients), therefore a priority was placed on facilitating participation to optimize the number of interested adolescents.

A pilot study was put together (see chapter 3) to assess the feasibility of reducing the time while also examining the integration of collage inquiry. Due to the limited number of adolescents who are currently on the pathway towards bariatric surgery, recruiting from this population for the pilot would jeopardize the availability of participants for the main study. Since the pilot was intended to focus on the process and execution of the protocol versus the content, the conclusion was to target individuals of the same age range, but not necessarily involved in weight management.

Outcomes from this pilot were clear that several concessions had to be made around the depth of the inquiry and the ways in which the maps were being constructed. It was evident that the thesis could not claim to use body-map storytelling in the new abbreviated version of the final protocol. However, the experience from the pilot demonstrated that the body map activity had the potential to provide research value and meet the initial goals that prompted an interest in arts-based research, namely alternative means of expression and increased participant engagement. Moreover, body maps have been used in research as the sole or complementary data collection approach with the intent of highlighting the contribution patients make to the understanding of health and illness (Solomon, 2007). For example, body maps have been used with women in Zimbabwe around reproductive health (Cornwall, 1992). Therefore, following the pilot study the term 'body map collage' was used to represent what was being done in the thesis. However, the inclusion of the pilot study illustrates the process that informed the final thesis protocol with adolescents eligible for bariatric surgery.

The implications are that the body maps simply act as complementary to the interviews with regards to data collection and serve to engage adolescents into ownership and representation of their experiences. Ultimately there was a sacrifice made in the type of data that was going to be collected by not being able to use body-map storytelling. Had it been easier to have extended meetings with the adolescents to follow the multi-day protocol, there would have been the opportunity for the life-sized body maps to have been made. This would have produced a much more impactful art product to be shared with a larger audience. Additionally, there would have been more time for participants to reflect on specific aspects of their experience around bariatric surgery through prolonged facilitation and homework activities. In doing so, the body maps could have taken on a larger symbolic meaning and perhaps a more personalized one as they spent longer time creating a representation of themselves. However, by being responsive to the realities of data collection limitations highlighted in the pilot and

making subsequent adjustments, it contributes to the quality of the entire research and did not compromise the initial purpose of the study (Morse, Barrett, Mayan, Olson, & Spiers, 2002).

A comparison between the experiences of conducting the body map activity in the pilot with the main study reveals that the learnings from the pilot proved useful to optimize the data collection in the main. For example, some of the adolescents in the main study were pleased to have body silhouettes available for tracing. Similarly, conducting the interview first was helpful in orienting the adolescents throughout the activity and providing artistic guidance.

Establishing Rigor

Verification is the process of checking in order to have confidence in the research outcomes. It ensures the reliability and validity of a study and is used to establish rigor. In order to accomplish this goal, Morse et al. (2002) provide verification strategies that should be employed throughout the research project.

First the study should have methodological congruence. This means ensuring that the research question and the parts of the method are an appropriate fit and are re-visited as the project unfolds. In this thesis the purpose of the research led to the selection of qualitative description as the methodology of choice. Within qualitative description, purposeful sampling is recommended and an inductive approach to analysis is central. Additionally, the pilot study allowed the data collection to be re-oriented for the main study thereby demonstrating responsiveness to maintaining methodological congruence.

Second, appropriate sampling must be done by selecting participants that are best suited to speak about a particular phenomenon. This is often accomplished by using purposeful sampling as was done in this thesis. Additionally, an indication of saturation also supports the notion that the sampling was adequate. In this thesis data saturation was defined as informational redundancy. This meant that although not all categories were necessarily well circumscribed, there was evidence that similar ideas were being shared as new participants were recruited within the principle themes.

Third, the study should be conducted through an iterative process of data collection and analysis. This allows the researcher to know where the data is at and what information needs to be further collected. Data collection and analysis for the thesis was done over the period of

approximately 12 months during which the transcripts of the interviews were coded and new interviews were being held.

Fourth is thinking theoretically by evaluating how emerging ideas are being reconfirmed in new data and conversely how insights from new data fits in with what was previously collected. This shift from a close reading of the text to larger theoretical views is ongoing and ensures that the analysis is built on a solid foundation. For this thesis, writing memos in combination with ongoing discussions with the committee members of emerging themes helped to ensure there was a deliberate evolution of the themes and they were being confirmed in new data.

A final verification strategy is theory development and/or an assessment of the contribution to the existing knowledge in the field of study. Given the nature of the thesis, the latter was used by examining how the findings from the current study compares to the existing literature on the subject (Richards & Morse, 2007). Similarities between studies serves as an indication of validity, while new findings are examined to determine if they provide a logical extension to what is already known. In this way, the researcher is able to articulate the significance of their study. An example of this verification strategy in the thesis was examining how the findings with adolescents compared to four previous qualitative studies with adolescents considering bariatric surgery. Indeed, there were commonalities between the thesis findings and the literature regarding lack of self-efficacy to lose weight, the burden of living with obesity, and incorporating experiences from others into the adolescents' decision-making process thus highlighting the validity of the study. In terms of new findings, our study noted the lack of quality programming available for adolescents which may partially explain why adolescents perceived such a lack of self-efficacy to lose weight and contributed to their feeling that surgery was their only option thereby contributing to the existing literature.

Reflexivity and Researcher Position in Qualitative Research

A critical aspect of qualitative research is reflexivity. "Reflexivity can be defined as thoughtful, conscious self-awareness. Reflexive analysis in research encompasses continual evaluation of subjective responses, intersubjective dynamics, and the research process itself" (Finlay, 2002, p. 532). Although there are differing perspectives about what is reflexivity based on theoretical positions, "at a minimum level, it means acknowledging the existence of

researcher bias and explicitly locating the researcher with the research process” (Finlay, 2002, p. 536). Reflexivity should be demonstrated throughout the research process, including prior to the start of the project (Finlay, 2002). Consistent with this, Finlay (2002) writes that at the start, “researchers could fruitfully examine their motivations, assumptions, and interests in the research as a precursor to identifying forces that might skew the research in particular directions” (p. 536). Following this personal examination, my position as a researcher and my own journey that leads me to this project is explained.

My interest in youth weight management stems from my early research experience in exercise physiology as an undergraduate student in Exercise Science at Concordia University. There was an opportunity to volunteer as a personal trainer for a study on childhood obesity and I immediately became interested in the field. While I enjoyed my work, I was constantly being told stories by parents about their negative experiences with healthcare providers regarding weight management. I was more compelled by these stories than by the numbers and statistics that I was compiling for the research study. This is unsurprising as I was simultaneously doing a second major in Women Studies, where feminist research methods place a premium on individual experiences and the importance of representation. For my master’s I engaged in my first qualitative study exploring the collaboration between families and providers in the context of pediatric weight management. As such, I have never identified within a particular discipline, preferring to be pragmatic in my approaches unconstrained by disciplinary boundaries. However, my affinity to qualitative research does lend itself to a world view that our reality is socially constructed. Social constructionism rejects the notion of a single truth or reality that one can access through inquiry and that knowledge is historically and culturally contingent (Jørgensen & Phillips, 2002).

When it comes to the topic of this thesis, adolescent bariatric surgery, my position is always evolving. I became interested in the topic after witnessing several cases of adolescents living with severe obesity with multiple physical and mental health issues. I felt that these adolescents deserved immediate intervention and that behavioural weight management was unlikely to provide the clinically meaningful weight loss they needed. This led me to look at the literature in adolescent bariatric surgery and discovered that there had been no studies documenting the experiences of adolescents who had gone through the procedure. Thus, it was clear there was a need for further inquiry and my primary goal with this thesis was to share the perspective of adolescents. Recently, I have been the research administrator in a clinic that

offers a pathway to adolescent bariatric surgery. This requires constant reflection on my part to distinguish between what I observe in the clinic versus what stories are emerging from the data to ensure I minimize the impact my own experiences have on the outcomes. Ultimately the goal of the thesis was not to endorse adolescent bariatric surgery, but rather understand how different individuals within healthcare perceived the procedure.

CHAPTER 3: Lessons learned from a pilot study on the feasibility of using a condensed approach to body-map storytelling with adolescents in a healthcare setting

Targeted Journal: Arts and Health

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Abstract:

The purpose of this paper was to report the findings of a pilot study to test the feasibility of combining collage inquiry with a condensed version of body-map storytelling to assist adolescents in speaking about health, weight, and their bodies during an interview. Four participants (13-21 years old) were scheduled for 60-minute interviews where they responded to questions and looked through magazines for images or words that represented their responses. Participants drew an outline of their perceived body on a sheet of paper where the chosen images were subsequently glued inside or outside the outline depending on the questions posed. Findings from the pilot study included: it was preferable to start or end with the image search so as to optimize time; to provide artistic guidance without prescribing how the artwork should develop; to have sample body shapes that can be traced; to have an example body map available on a different topic for inspiration; to conceptualize the body map holistically versus a direct representation of each question; and to decide if the body map is a facilitation tool, an artwork, or both. Although using an arts-based approach presents unique challenges, it can successfully aide researchers in obtaining a more in-depth understanding of the meaning participants give to their experiences.

Keywords: Body maps, Body-map Storytelling, Collage, Art-based Research

Introduction

Understanding patients' experiences of living with a chronic condition is valuable to improving quality of care (Thorne et al., 2002) and youth should not be excluded from sharing their perceptions because of their age. In the context of youth living with obesity, traditional interviews can be successful in documenting their experience with weight management (Doyle et al., 2018). Yet, it can also be difficult to obtain quality data from interviews only (Dhaliwal et al., 2017).

In preparing for a study on the experiences of youth living with severe obesity and their perceptions about bariatric surgery in an upcoming project, the pairing of traditional interviews with a complementary, youth-centered method to generate data was needed. The emerging use of arts-based research as part of knowledge generation and dissemination in health research provided multiple possibilities (Fraser & al Sayah, 2011). Research using creative data collection approaches, like photo voice, have been shown to be effective for engaging youth participants in research (Dennis, Gaulocher, Carpiano, & Brown, 2009; Lachal et al., 2012; Phelan & Kinsella, 2011). Arts-based research with youth can help shift the dynamic of the interview from a researcher-directed process to one that is youth-driven (Carter & Ford, 2013). Additionally, art generation can be a more accessible form of communication for youth because they can highlight their feelings through different types of visuals, even if they are not able to verbally articulate their experiences (Carter & Ford, 2013).

Given that obesity is inherently a corporal affliction that cannot be hidden from public viewing; the arts-based approach selected would need to highlight the body not only as the location of the disease, but more importantly as the medium through which youth interact with the world rendering it a product of the socio-cultural context (Azzarito, 2010). As such, body maps, more specifically body-map storytelling (Gastaldo et al., 2012), was used to guide the approach.

To collect data on youth's experiences of weight and health during interviews the intention was to use body-map storytelling. Body-map storytelling is, "primarily a data generating research method used to tell a story that visually reflects social, political and economic processes, as well as individuals' embodied experiences and meanings attributed to their life circumstances that shape who they have become" (Gastaldo et al., 2012, p. 10). Body-map storytelling has been used with aboriginal women in their experience of leisure and healing

(Yuen, 2016), with youth who have complex support needs (Dew, Dillon Savage, Smith, & Collings, 2018), and illegal migrant workers (Gastaldo et al., 2012). These populations demonstrate how it can be used with vulnerable and marginalized groups.

Key features of the body mapping process includes the testimonio, the body map, and the body map key (Gastaldo et al., 2012). The testimonio is the story provided by the participant about who they are and the context from which the body map was developed. The body map is the art work itself that cannot be understood without having the body map key. The participant describes each element in the body map and what it symbolizes for them developing the body map key, which can include choice of colors, placement, design, and/or items.

While body-map storytelling was originally conducted through multi-day workshops (Gastaldo et al., 2012), in order to facilitate participant involvement, this pilot study was limited to one session of approximately 60 minutes in order to facilitate participation by the adolescents. As such, several modifications were made to accommodate for the time available. Rather than use a life-size outline of the participant's body, the research team decided that participants would draw their body outline on a smaller sheet of paper (16 inches x 20 inches). While Gastaldo et al. (2012) had a binder of pre-selected images from which participants could choose from in addition to magazines, in this pilot study only magazines were used. The intention of using magazines was to embrace the concept of collaging as part of the body map development. Using art-based approaches like creating body maps and collaging has an informality that can increase participants' comfort by focusing on making 'art' instead of being in a 'research interview' (Carter & Ford, 2013).

Collage is a type of art that involves cutting and sticking selected items onto a surface to produce an overall effect through the juxta-positioning of these items (Butler-Kisber, 2010). From a logistical standpoint, collage is user-friendly and requires basic skills such as cutting and gluing that most individuals acquire early on in life (Butler-Kisber, 2010). One of the strengths of collage is the way participants bring together various elements stemming from an inner feeling that has not yet translated into a fully developed thought or level of consciousness required when verbally answering questions in traditional interviews. Through the assembly of different images, words, and textures, it reveals an individual's perception and experience. This was congruent with the overall goal of finding alternative ways for youth to express themselves.

Therefore, the goal of this pilot study was to examine how this adapted body-map storytelling process could be accomplished within approximately 60 minutes while maintaining the integrity of the research method. Specifically, the pilot study used an iterative structure to test the feasibility of a condensed version of body-map storytelling to assist adolescents in “speaking” about health, weight, and their bodies during an interview.

Method

Youth were recruited through general advertisement and invited to contact the study coordinator if they were interested in participating. Each participant was screened and an interview was scheduled if they were eligible. The inclusion criterion were: ability to communicate in English; and aged between 13 and 21 years. There were no weight or BMI criteria for participation in this pilot study as the primary focus of the pilot was on the process instead of the content. Prior to the start of the interview, participants and their parents (if applicable) were given time to review the information sheet and informed consent as well as ask any questions they may have had. Once the consent was signed, the 60-minute ‘mock’ interview was conducted. At the conclusion, participants were asked to provide feedback. This feedback, in combination with the observations of the interviewer, informed how the subsequent interview in the pilot study was conducted.

Four different interview iterations were completed: (1) looking for images throughout the interview; (2) asking all interview questions followed by searching for all images at once; (3) asking participants to locate images based on four themes related to the interview (Health, Weight, Influencers, Bariatric Surgery) followed by the interview questions; and (4) conducting the interview and then asking participants to search for images based on the aforementioned four themes.

Interviews were digitally recorded and saved in a password protected file for the researcher to consult if needed. Debrief notes were written at the conclusion of each interview and used to justify the changes being made to the interview process. The body maps were photographed and stored in a portfolio.

Ethics approval was obtained by the human ethics committee at the CIUSSS du Nord-de-l’Île-de Montréal – Hôpital du Sacré-Coeur de Montréal.

Lessons Learned

Four pilot interviews were conducted. Participant demographics are detailed in table 3-1. The interviews raised six key issues that were addressed in order to refine the interview guide and overall approach for the main study.

First, searching for images in magazines throughout the interview was found to be lengthy and disruptive by participants. In this iteration of the interview, participants were taking between 10 to 15 minutes to identify an image that reflected their idea or sentiment. Considering there were eight times during the interview when the participant was asked to look for images, the duration quickly surpassed the scheduled 60 minutes. Moreover, it felt inefficient as the participant kept looking over the same magazine each time. Consequently, it was determined that the search for images in the main study should be done all at once, either at the start or at the end of interview questions.

Second, three participants expressed uncertainty about whether they were doing it “right” and seemed to lack confidence in their ability to put together a body map that was representative of their ideas. In order to encourage participants, broad artistic guidance was provided without prescribing how the artwork should look. For example, the interviewer would remind them that they could use markers to draw if they could not find an image they identified with, or they could alter the way an image looked. The interviewer also discussed how the use of color or how the placement of an item could reflect different meanings. Providing artistic guidance, including words of support and acceptance of all art skills, was added to the instructions that were prepared for the main study to address this potential issue.

Third, the first three participants struggled to draw the body outline. The only directive given by the interviewer was that the body outline should ideally cover most of the page and have enough space to stick images inside the shape. All these participants appeared self-conscious of drawing the body outline, which is likely what prompted them to recommend prepared body shapes they could simply select and trace from. Following their idea, six body shapes of various sizes were prepared (3 of each sex). The final participant was offered to use the shapes or draw their own; with them opting for a pre-defined body shape. This practice was adopted for the main study.

Fourth, the first participant expressed confusion about what a body map was, despite the interviewer providing a verbal description. Using this feedback, an example body map was developed on a different topic and was presented to the future participants to help their understanding. The remaining participants all agreed it was helpful to see an example prior to developing their own.

Fifth, the body map protocol had to be reduced to addressing a few key themes. In the first two interviews, participants were asked to look for eight different types of images and told where on the paper they should go (either inside or outside the body outline). However, observations of these interviews revealed that the types of images were too specific (i.e., images regarding health status and images regarding health challenges) and seemingly defeated the purpose of using an arts-based approach. In order to be efficient and have a body map that was reflective of the participant experiences, it was determined that the search for images should be done following the interview. Additionally, the directions for the types of images were broadened to general issues discussed in the interviews. These were perceptions of health, weight management experiences, influencers in their decision-making, and bariatric surgery. Consequently, the final two pilot interviews that used this approach produced body maps that were a more general representation of the interview answers versus a literal translation of them.

Lastly, given the time constraints, the body maps were rudimentary and not artistically elaborate. However, the experience with conducting the interviews before making the body maps re-enforced the value of providing youth the opportunity to express themselves not only verbally, but visually as well as the instruction for the body map was simply to represent their experiences around weight management and decision regarding bariatric surgery. While the final iteration of the body map protocol has several adaptations from body-map storytelling, it still provided additional insight into the participant experience, which is the goal of including an art-based data collection approach in this research.

Discussion

Using body maps as an arts-based data generation approach in health research proved to be feasible through key adaptations to body-map storytelling. However, adapting a method designed to require several hours into a 60-minute session had several challenges as shown by

the pilot study. The shorter duration can account for some of the experiences encountered, but not for all, such as participants' uncertainty about doing the body maps 'the right way'.

In Gastaldo et al. (2012), the interviewer had the participants do homework activities like developing a personal symbol and work on the narrative of the story expressed by the body maps. This was an opportunity for prolonged reflection on behalf of the participants that was not available in this pilot. It may be part of the reason why the body maps were rudimentary, since participants did not have the chance to evolve their thinking about an issue or topic.

Another outcome of the aforementioned homework activities and having the additional time was the ability to cover a number of topics with participants like their experiences of migrating to a new country, their support structures, and the future they hope for. Each topic was given 10-20 minutes to discuss and subsequently work on the body maps. Similarly, other studies using body mapping conducted the data collection over a number of days (Dew et al., 2018). With only 60 minutes available in our pilot study, it is fitting that the maps represent a holistic view of the participant experience versus more specific, concrete issues.

While lack of time might limit the ability for participants to produce artistically elaborate body maps, Gastaldo et al. (2012) also noted that it is to be expected that some participants are less artistically inclined than others. Therefore, even if more time was allocated in the main study, it may not affect the artistic outcomes. Rather, the focus should be on encouraging all participants to do their best regardless of their artistic abilities. As Walker, Caine-Bish, and Wait (2009) noted in their work with children, re-enforcing the idea that they will not be judged on the quality of their artwork is key to putting participants at ease. Providing reassurance to participants in the pilot study helped to alleviate their uncertainty and lack of confidence.

The first participant expressed hesitancy about what was expected from their body map, and kept asking if they were doing it 'right'. In the HIV art therapy group that used body maps, time was spent familiarizing the patients with the different art tools available and how to use them (Solomon, 2002). Borrowing from this approach, in the second and subsequent pilot interviews, the interviewer explained to participants how they could select different images, colors and placement of items to express their ideas. Including a short 'orientation' at the start of the body map process in later iterations of the interview protocol helped participants tap into their creative selves. The body map example that was prepared after the first participant interview also illustrated these techniques and provided a concrete idea for participants to refer

to throughout subsequent interviews. While Dew et al. (2018) shared the concern that having an example may influence the participants own work, the authors did not find it to be the case in practice.

The difficulty youth experienced in having to draw their body shape was an unexpected finding. In the limited number of interviews, it was difficult to determine whether it was due to a lack of confidence in their drawing ability, or if it was related to a deeper issue regarding their relationship with their body. The rapid changing period of adolescence could play a potential role in explaining the struggle the participants faced. Literature on body size perception also indicates that adolescents can overestimate their height and under estimate their weight (Fonseca et al., 2010), which could be another reason for being unsure on how to draw their body shape. Alternatively, it could also reflect discomfort in not wanting to acknowledge their size by drawing it on a piece of paper. It will be interesting to see how this manifests itself in the clinical population of patients living with severe obesity due to the corporal nature of the disease. The decision to have sample body shapes that participants can chose to trace in order to address this issues was also presented as an option in a study with youth having complex support needs, as the researchers felt the participants may feel threatened in lying down on the floor to outline their bodies but this was not the case (Dew et al., 2018).

In completing this pilot study, it was evident that while inspiration was taken from body-map storytelling, the actual data collection process strayed significantly from the method and intention as described by Gastaldo et al (2012). To recognize this, the name “body map collage” felt more representative of the protocol that was developed, and refined, through this process. The final protocol still engages participants in visually mapping the body while traditional interviewing serves to document their personal experience of health and illness.

Limitations

Given the small sample size in the pilot, and the fact that each participant was subject to different iterations of the interview protocol, it is possible that the issues raised were unique to the participant and not a reflection of the protocol itself. While the sample was 75% female, there was no indication that the sex of the participant impacted engagement. Moreover, given this was a non-clinical population who were not engaged in weight management, different issues may arise in the main study that will require further adjustments to the protocol.

Conclusion

The findings from the pilot provided guidance on different factors to consider when developing a protocol with body-map storytelling. These included providing an example body map, having different silhouettes available for tracing, and limiting the scope of the interview content to allow participants an opportunity to address the development of their maps. Additionally, the pilot study demonstrated that it was well received by youth and young adult participants and provided them with an alternate or additional way of communicating their experiences about weight and health.

Table 3-1 Pilot Study Participant Demographics

Participant	Sex	Age
Participant 1	Male	21 yrs
Participant 2	Female	15 yrs
Participant 3	Female	15 yrs
Participant 4	Female	18 yrs

CHAPTER 4: The experience of Canadian adolescents deciding on bariatric surgery using body map collages

Targeted Journal: Qualitative Health Research

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Abstract:

Bariatric surgery is increasingly being considered as part of the treatment and management strategy for adolescents living with severe obesity. The purpose of this study was to describe how adolescents decide whether to pursue bariatric surgery using body map collage. Adolescents considering bariatric surgery were recruited to participate in semi-structured interviews and develop a body map collage. The participants (n=7) had a mean age of 15.7 years old and body mass index of 50.3 kg/m², with just over half being male. Analysis using inductive thematic analysis and collage in conceptualization produced vignettes and a collage that represented three emerging themes: Bariatric surgery was recommended to adolescents versus being self-referred; the decision to have surgery was multi-factorial; and Bariatric surgery is not for everyone. The findings reveal that the decision regarding bariatric surgery is multi-factorial and unique to each adolescent and they should be involved in the decision-making process.

Keywords: Bariatric surgery, Obesity, Adolescents

Introduction

While the prevalence of Canadian youth that are living with obesity has stabilized at 13% (Rodd & Sharma, 2016), the severity of obesity continues to increase (Ogden, Carroll, Kit, & Flegal, 2012). Severe obesity, currently defined as a body mass index (BMI) $\geq 120\%$ of the 95th percentile (Gulati, Kaplan, & Daniels, 2012), is associated with the development of multiple physical (Dietz, 1998) and psychosocial issues (Puhl & Latner, 2007; Zeller, Roehrig, Modi, Daniels, & Inge, 2006). Currently, health behaviour interventions are the primary treatment option for youth living with severe obesity in Canada (Lau et al., 2007). However, this approach as well as the inclusion of pharmacotherapy does not result in significant changes in weight (Ryder et al., 2018). Bariatric surgery for a select group of adolescents living with severe obesity shows promising health-related outcomes. Results from a US-based clinical trial found that at three years post-surgery patients had a mean weight reduction of 27%. Additionally patients had remission of several co-morbidities including 95% of type 2 diabetes cases, and improvement on quality of life scores (Inge et al., 2016). While much has been reported about the weight and metabolic outcomes related to adolescent bariatric surgery, less is known about the perceptions of adolescents who have undergone surgery.

When deciding on surgery, adolescents report a combination of psychosocial and medical reasons. Adolescents believe the surgery will result in the cessation of bullying by peers, increase self-esteem (Willcox et al., 2016), allow them to be socially accepted (Childerhose et al., 2018; Doyle et al., 2018), and generally live a fuller life (Willcox et al., 2016). The primary medical reason for choosing this procedure was avoiding future health problems (Childerhose et al., 2018; Doyle et al., 2018).

One of the main concerns adolescents expressed pre-operatively was related to how their bodies would look after the surgery, especially the worry about excess skin (Childerhose et al., 2018; Doyle et al., 2018). The risk associated with the surgery was mentioned in two studies, one of which explained that adolescents would equate very low risk with no risk as a way to manage the uncertainties related to the surgery. Adolescents also opted to focus on the benefits rather than the risks associated to the surgery (Childerhose et al., 2018; Doyle et al., 2018).

Adolescents perceived bariatric surgery as a last resort and the decision to undergo the procedure was not impulsive. Studies highlight the large amount of time adolescents spent

deliberating on the decision (Childerhose et al., 2018; Doyle et al., 2018; Nordin et al., 2018). In fact, one of the challenges adolescents face is the criticism and judgment of other people who feel they 'cheated' by opting for the surgery. This negative response from others leads them to keep the surgery a secret (Childerhose et al., 2018; Doyle et al., 2018).

Due to the emerging nature of adolescent bariatric surgery in Canada and the lack of knowledge on reasons why patients opt to not have surgery, the goal of this paper is to understand how Canadian adolescents living with severe obesity and referred to a tertiary care centre for weight management decide whether to undergo bariatric surgery or not.

Methods

Qualitative description was used for this study to provide practical insights on adolescents experiences by staying close to the surface of the text (Sandelowski, 2000). Purposive sampling (Richards & Morse, 2007) was used to recruit participants in this study. To be included, participants had to be between the ages of 13 and 21 years old, living with obesity and actively engaged in weight management. Participants were patients at a tertiary care clinic for adolescents with severe obesity, who had already consented to being contacted for research projects. They were approached in person by the study coordinator (BCF) and provided with the study information sheet. If they were interested in participating, they were subsequently scheduled for an interview. All the interviews were conducted by a doctoral student with 10 years of qualitative research experience (BCF).

Prior to the interview, the participants and their parents (when applicable) had the opportunity to review the study information sheet and consent form. If they had any questions or concerns, they were able to discuss with the researcher.

Ten patients were approached and nine agreed to participate. However, two cancelled the interview and opted not to re-schedule. The reasons for not participating were the adolescent's lack of interest and the parent was worried about the impact the interview would have on their child.

Data for this study were collected through semi-structured interviews with adolescents in combination with a body map collage, a method inspired from body-mapping storytelling (Gastaldo et al., 2012). The body map collage was used as a supplemental data collection tool

since it affords an additional dimension to the interviews. The body maps allowed for externalized reflection by the participants that can contribute to the co-construction of meaning between the participant and research like that of deciding on bariatric surgery. Body map collages supply symbols unique to each participant, providing a broader significance to the collage creator's overall story and experience. As well, it is particularly suited to research with adolescents (De Jager, Tewson, Ludlow, & Boydell, 2016).

Prior to the start of the interview, participants were shown a sample body map and explained what was involved so that they could start thinking about their own body map. The researcher started the process by asking the participant questions about their weight management history, when they first heard about bariatric surgery and how they made their decision regarding the procedure (see Table 3-1 for guide). After the interview, the participant was given a sheet of paper (16" x 20") and they could draw an outline of their body or choose a body-shape stencil that had been pre-made. There were three different body shapes of each sex to accommodate different body sizes. Afterwards, the researcher provided the participant with colored paper, markers, crayons, glue, scissors and a stack of magazines. When showing the participants the different supplies, the researcher discussed how they could be used in order to help the participant feel more comfortable with the process of art-generation. The researcher reviewed the main ideas shared by the participant and encouraged them to visually represent them and/or how they felt about it using the art supplies. The researcher sometimes assisted the participant by asking questions if it appeared the participant was not sure what to do. Sample questions could be: are you looking for a specific image? If you could represent your emotion as a color what would it be? Etc.

Once the participant was satisfied with the body map, the researcher asked the participant to go through the different items and explain their meaning or what they represented and why and where they were placed as such on the body. The participants were also asked if they would like a paper or digital version of their body maps. Most participants opted to take a picture of their body map on their phone at the end of the interview.

All the interviews about adolescents decision regarding bariatric surgery were audio-recorded, transcribed, and imported into N'Vivo 10 (QSR International). Modified thematic analysis was used to analyze the transcripts. This process involved reducing the raw information into the main ideas and then looking within and across participants for emerging

themes and patterns relating to decision-making about opting for bariatric surgery (Boyatzis, 1998). Three patient vignettes were written in lieu of presenting patient quotations throughout the results. Informed by narrative inquiry and the principle of restorying, each story is designed to highlight the complexity of deciding on surgery using the transcripts and themes to build the elements of each story (Nasheeda, Abdullah, Krauss, & Ahmed, 2019). Moreover, it provides additional confidentiality given the small number of participants.

To analyze the body maps, collage in conceptualization (Butler-Kisber, 2010) was used. This approach includes creating a series of collages that respond to the research question(s). In this case, images from the participants' body maps were used to produce an analytic collage. This reflects a similar restorying process that was used for the vignettes. In this paper the analytical collage was used to triangulate the data from the interviews.

In order to establish rigour and ensure the reliability and validity of the study, five verification strategies were used throughout. These include maintaining methodological congruence, using appropriate sampling, following an iterative process of data collection and analysis, reconfirming emerging ideas in new data, and moving through theory development by shifting from a micro to macro perspective of the data (Morse et al., 2002).

Ethics approval was granted by the ethics committee at the CIUSSS du Nord-de-l'Île-de Montréal (#2015-1167).

Results

The participants had a mean age of 15.7 years old with a range from 14 to 17 years old and a mean body mass index of 50.3kg/m^2 , with just over half being male ($n=4$, 57%). Individual data is not provided due to the small sample size to prevent individual participants from being identifiable (Childerhose et al., 2018; Milette et al., 2018).

Three emerging themes were identified in the interview analysis: (1) bariatric surgery was recommended to adolescents versus being self-referred; (2) the decision to have surgery was multi-factorial; and (3) bariatric surgery is not for everyone. The analytical collage that was produced can be found in Figure 1 and five categories of images were identified that supported the sub-themes from the interview including the burden of living with obesity, perceptions of

bariatric surgery, improvements in psychosocial functioning, changes in physical health, and increase in physical activity.

Theme #1 Bariatric surgery was recommended to adolescents

Adolescents first heard about bariatric surgery through family members and/or acquaintances. Only one participant mentioned they learned about it from an online source as they came across a video while looking for information on liposuction. In all cases, they did not consider bariatric surgery as applicable to them. The majority of adolescents were offered the option of surgery through the recommendations of healthcare professionals and not through self-referral. These healthcare professionals were either treating a different health condition or were following the patient within the scope of a weight management intervention. This theme was not represented in the body maps.

Theme #2 Multi-factorial deliberation prior to deciding on bariatric surgery

Adolescents identified a number of factors that they considered when making their decision about whether surgery was the appropriate pathway for them. These factors were evaluated within a 'risk'-benefit analysis; however, the relative value of each factor varied based on the individual. Those who opted not to have surgery felt it was not to their advantage at the moment. The factors include: (1) perception of self-efficacy to impact weight without surgery; (2) evaluation of their health status; (3) experiences of people who had undergone surgery; (4) concerns regarding the surgical procedure, including complications; (5) ability to adhere to post-surgical nutrition guidelines; and (6) the expected benefits from getting bariatric surgery.

Perception of self-efficacy

Adolescents' perceptions of self-efficacy to change their weight informed their decision to have surgery. All the participants in the study reported that their issues with weight were a chronic experience since they were children, although one participant cited a major health illness as being the trigger for weight gain. While all participants described attempts at weight management, there was a clear lack of coordinated interventions. Only one adolescent mentioned participating in structured programs which were Weight Watchers and a 12-month multi-disciplinary community program. The remaining participants cited brief encounters with

dietitians and one participant worked with a mental health professional because they were also being treated for depression. In these cases, the weight management efforts were coordinated by parents. Therefore, most of the attempts described were either self-directed or parent-driven.

The focus of adolescents' previous weight management attempts were centered on trying to increase physical activity levels or making changes to eating habits. These changes varied from walking everyday around their neighborhood to undertaking more drastic approaches like water fasting. These attempts were often transient and described as ineffective. Five participants explained that they found their attempts had counter-intuitive results whereby they felt they gained more weight. These experiences led to frustration and feelings of helplessness by the adolescents. In light of these experiences, participants framed bariatric surgery as the last opportunity for success. The one participant who did not desire surgery mentioned a different experience, whereby they saw changes in their body after just one week of increased physical activity. This made them hopeful that by being committed to this approach long-term, it would generate positive changes.

Evaluation of their health status

In considering bariatric surgery, participants were asked to evaluate their current state of health on a scale of one (poor) to ten (perfect). The majority of participants rated their health as middling with five being the most common rating, and also noted that a ten was likely impossible for anyone to achieve. They felt their health was primarily impacted by the existence of co-morbidities and the excess weight, but emphasized that they were not that compromised because they retained most of their functional capacity. The primary challenge to improving their health status was pre-existing conditions or current situational context (i.e., lack of physical activity opportunities). The body map collages emphasized the burden that obesity placed on the adolescents' bodies and mind. Most participants included an image or word that represented this experience. For example, one participant selected an image of a knee because they were experiencing chronic knee pain. Another selected the word 'endocrinology' to symbolize their diabetes.

Participants had mixed perceptions on whether they considered obesity to be a disease. The majority framed obesity as a condition. One participant compared it to autism (for which they had been diagnosed), while another likened it to a disability. About a third felt it was not a

disease because there was no pharmaceutical treatment; there is no medication patients can take to cure obesity. The majority of adolescents also made the distinction between being a larger individual with obesity and being '600lbs' and unable to leave the house. Many distanced themselves from a fictional super obese person describing them as being really sick and unhealthy. They argued that this was not their reality and did not understand how individuals could allow themselves to get to that point.

Experiences of people who had undergone surgery

Direct and/or indirect interactions with individuals who had received surgery affected how youth related to the idea of having bariatric surgery. The majority of participants reported knowing at least one person who had bariatric surgery. The level of interaction with those individuals varied from having personal discussions with them to anecdotal stories. One participant mentioned an adult coming to talk to them at work to share the positive ways surgery changed his life, which showed the adolescent the potential future they could have. The majority of participants discussed knowing extended family members who had gone through the procedure and in some cases spoke about the complications they heard about through general family communication. This did not discourage adolescents from considering the surgery. In some cases, it served as a cautionary tale and re-enforced the importance of making sure they were ready for the post-surgical adaptations they would have to make.

Concerns regarding the surgical procedure

A minority of participants expressed concerns related to having an invasive procedure, including potential complications. It was unclear whether this was due to a lack of discussion regarding complications in the preparation for surgery. Their concerns included a fear of needles, general anesthesia, and viewing the stitches from the incision. Meanwhile, only one adolescent discussed potential complications from bariatric surgery citing blood clots, blurry vision and hair loss as important issues to consider in making the decision. Concern about what would happen to their skin was mentioned as a major concern by one female participant.

Ability to adhere to post-surgical nutrition guidelines

On the contrary, all participants expressed concern about the long-term impact bariatric surgery would have on their eating habits. Fear of being restricted in their food selection and not being able to eat the things they love was commonly raised. This was especially true

around food they deemed as being 'unhealthy' like sweets and pizza. Adolescents' capacity to adapt to smaller portions and not drinking with meals were part of their contemplation on whether they could adhere to the post-surgical guidelines. In the case of the participant who did not want surgery, their love for food was a key determinant in their decision. This participant used the body map collage to further illustrate this point by including a picture of donuts, one of their favorite foods.

The expected benefits from getting bariatric surgery

The anticipated benefits of the surgery varied across participants and represented a combination of physiological, physical, and psychosocial advantages. Resolving sleep apnea and diabetes were reported as a priority. However, one participant drew a wheel of fortune to emphasize the unknown nature of the outcomes related to the surgery.

Improving functional capacity was mentioned by a majority of participants. Being able to physically keep up with their family and peers was discussed, as well as being able to accomplish daily tasks like crouching down and tying their shoes with ease. Reducing pain associated with mobility was discussed by two participants. The primary goal for one participant was to reach a specific weight at which point they could be approved for a second non-bariatric surgery that they needed to improve their functional capacity. Most participants expressed this point by selecting images related to physical activity and sports. By losing weight, they believed they could move more easily, thus facilitating engagement with physical activity.

All participants reported that the weight loss would make them feel better about themselves and many expected to be happier after surgery. This was expressed as desiring weight loss to be more attractive (albeit not too skinny or disproportionate), reducing the bullying from peers, not being stared at when in public because of their body size, fitting in amusement park rides, and being able to sit between two people on the bus. In the body maps, a participant reflected these experiences with the word 'intimidation' ('bullying' in French) with a red cross over it. Most participants also opted to use inspirational words or phrases in their body maps to represent their hopes for a better life following surgery. These included 'stay strong', 'empowerment', and 'mieux-vivre' (living better).

Theme #3 Bariatric surgery is not for everyone

There was a lack of consensus on who should be eligible to have bariatric surgery. In terms of age, most participants agreed that older adolescents (15 years old and above) would be optimal. They felt that younger than 15 years old, adolescents are less likely to follow nutrition guidelines and may not understand the implications of the surgery. One participant reflected this belief with a pacifier on their collage.

Two participants believed that under 18 years old was too young; however, they had different rationales. One participant reported that adolescents did not have the level of maturity to make such a decision, while the other participant believed that during this developmental period youth should be able to live their life without the eating restrictions set by the surgery. Only one participant believed there should not be age restrictions by stating that the decision should be determined by medical need and waiting for a specific age can cause more harm than good.

Participants agreed that bariatric surgery should be the last option offered to adolescents and that patients need to have tried some health behaviour changes first. Some of the changes mentioned included talking to a dietitian, getting a personal trainer, working with doctors, and trying sports. They described these attempts as being important since bariatric surgery was a permanent decision that should not be entered lightly. The permanent body change was drawn as a stomach with a star on it by one participant. Another also picked the words 'coup de pouce' ('boost' or 'help' in French) as a reminder that the surgery is not a solution but rather an aid, and patients who undergo the procedure have to understand this distinction.

Patient Stories

In order to highlight the individuality of each decision, three patient stories were prepared to represent the emerging themes. The stories represent various trajectories: a patient who decided to have surgery; one that was initially ambivalent but eventually opted for the procedure; and a third that decided surgery was not for them at this time. Pseudonyms are used and are purposely gender-neutral.

Alex – A 16 year old patient that has decided bariatric surgery is the right option for them

Well, I remember when I was in grade 2 or 3 I had trouble, you know, keeping up with my friends in gym class and stuff. So I knew then that I was different and that I had problems. But no one really spoke to me about it, I mean a doctor, until maybe like the end of primary school. The doctor, well my family doctor, was like you need to lose weight. So I know my mom started buying different foods and things like that, but uh, I didn't see any changes. I remember going to see a person to discuss like not drinking pop and eating more vegetables. But that was like maybe twice. I didn't find it very helpful. I just kept getting bigger. It was so frustrating. Then like last year I read online about this water fast thing, where you just drink water for I don't know, maybe three days and you are supposed to lose all this weight. But when I did it like after one day I was gaining weight. So I just stopped, I mean all I am doing is drinking water and it's making me gain weight.

I think I heard about bariatric surgery for the first time from my dad talking about an aunt who had done some kind of weight loss surgery thing. And now she is married and stuff with kids. So obviously that went well for her. She was young when she had it.

I didn't think about getting the surgery for myself until the doctor who looks after my diabetes mentioned it could help me. I thought well like if it worked for my aunt then maybe it's going to be a good thing for me. I mean it's like this surgery thing has to work because I feel like I've tried everything else. I need some help because nothing works and I can't keep going on like this. I just feel my health keeps getting worse you know. Like my entire body hurts.

I am doing this surgery for my future health. Like I know if I don't do this now, things are not going to get better. I need to make a change now so that I can be healthier. After the surgery I want to be able to keep up with my family, you know. Like be able to go for walks with them and not have pains. And it would be nice if my diabetes would be resolved. I also want people to stop staring at me. I hate that, it gets me really mad. Obviously I have some concerns about the surgery. I don't like operations and don't like needles. They get me nervous. Oh and I don't want to see the stitches, I hope there won't be many.

I don't think surgery is for everyone. Like you really have had to try for a while, like maybe two years and if you still can't lose weight then yeah maybe consider the surgery.

Riley – A 17 year old patient who is ambivalent about bariatric surgery and eventually decides to undergo the procedure

I never really thought about my weight, everyone in my family is pretty big, right? And it's not like I was staying home and just playing video games all day. I was always out with my bike and stuff. I could do stuff. Like I see these people on television who are like 600lbs and can't leave the house. That's not me, right? I would be worried if I was like 400-500lbs. I don't get how people allow themselves to get that big. I mean I'm healthy it's just my weight that's a problem. Umm, so yeah I guess my weight became a focus when I got depressed and I was eating a lot of junk. Like fast food and stuff. At some point I got hospitalized for water in my lungs and it was there that the doctor mentioned that bariatric surgery would be good for me.

I didn't really know much about the surgery. I mean, I know some people in my town that got it done. But not like anything really specific. I mean I knew that they had lost a lot of weight, but like that's it. At first I was like hell no about the surgery. My mom thought it was something to consider. I get it, like she doesn't want me to be, you know, getting sick from my weight. She wasn't going to force me to do it, but I knew she thought I should.

I was just worried, what would happen after the surgery? Sure I want to lose weight and stuff, but what happens if I lose weight in some weird way and my body looks deformed? And what happens to my skin? Will I have all this extra skin or because I'm young will it like not hang and stuff? And then I like sweets. If they tell me I can't eat sweets anymore I am going to get really upset. Actually I don't think I could do the surgery if I had to give up my favorite foods. It's hard, having to think about what you're eating all the time after having surgery. Sure, there are some advantages to getting it like losing weight and it would be nice to be able to sit on the bus or fit in amusement park rides. It's embarrassing being the only friend who doesn't fit in a seat for a roller coaster.

I guess someone I work with found out I was thinking about having the surgery and they came to see me because they had it done in the past. They told me it changed their life, they felt they were able to do so much more than before and you get used to the eating smaller portions. I don't know... it's a lot to think about. In the end I will probably do it, better now than later but I don't see how anyone under 18 should get surgery. It's just such a big decision for someone that is young, but maybe they are like me.

Harper – A 16 year old patient who does not think bariatric surgery is the solution to their weight problem

Well my weight is a complicated thing. I wasn't always this size, but I wasn't super skinny either. I don't know, I was just chubby. My parents put me in a lot of sports when I was young, but I was still a bigger kid compared to other people my age. No one really talked to me about weight or anything like that. No one called me fat or said I had to lose weight. But I guess I have been gaining more weight recently. I was referred to this weight clinic thing by my family doctor because apparently there is something problematic about my liver. The doctor didn't really explain to me though what they were referring me to.

So I met the team there [tertiary care weight management clinic] and that's where they were like 'you should do this, have surgery to lose weight.' I thought they were crazy. I mean I am young and yeah I might be bigger than some kids, but I am a nice person, I am smart, I don't get why people of the opposite sex don't like me. They want those thin people who aren't even nice to them. No one ever looks at me that way.

I feel that at this age I should be able to enjoy life without worrying about the food I can and cannot eat. And it's not just the eating, you get surgery and then suddenly there are all these other problems that come up. You could get blood clots and die. That's not really better is it? You can also lose hair. I don't want that. One of my friend's mother got this surgery done. She hasn't really lost weight because she's still drinking beer and eating all this stuff like fries and burgers. Like what was the point of doing the surgery then? I've seen people do well and they seem happy, but they are older than me. I don't really know anyone who has been through this at my age.

For sure having the surgery would probably help me get a little healthier, maybe I go from a six to an eight out of ten. But I don't think I need to do the surgery for that. Just last week I played tennis with my sister like almost every day and I could tell if I did this every week then I could probably be successful. I haven't been able to keep it up though because the tennis courts are usually booked by clubs and my sister is heading back to university. So I have no one to play with anymore.

I told the team at the clinic that this wasn't for me. I just don't think the benefits are really worth the sacrifices and the risks. I feel that older teens, like end of high school is probably ok

to have surgery because you are older and can understand what you need to do. But maybe if you are eight years old and already 300lbs then their might be a real medical need. It's not obvious.

Discussion

Bariatric surgery in adolescents continues to be a contentious issue (Beamish & Reinehr, 2017; Wulkan & Durham, 2005). Long-term data on the impact surgery will have on youth, metabolically and psychologically, as they progress into adulthood has been the primary research focus, but consideration also needs to be given to the patients who are living the experience. In order to contextualize the longitudinal data, we have to engage youth in research and not extrapolate from the adult data. This study is part of only a handful of research with this patient group, and the first in Canada, and contributes to an important need for more in-depth exploration.

Our findings demonstrate that the decision taken by adolescents regarding bariatric surgery is characterized by reflexivity and deliberation of multiple factors. These include their self-efficacy to lose weight, current health status, interactions with other individuals who had surgery, concerns about the surgical procedure, ability to adhere to post-surgery guidelines and expected benefits. Many of these themes were further supported in their representation in the participants' selection of images, words, and drawings for their body map collages.

Our study found that how risks and benefits are evaluated by each adolescent is highly individual where they attribute a different level of importance to the factors mentioned, many of which were not health related. While the medical literature suggests that the decision on whether to pursue bariatric surgery should be based on the outcomes of a multi-disciplinary assessment and balancing the health risks with the potential health benefits (Inge et al., 2005), an existing critique is that risk-benefit analysis is highly subjective and assumes shared values between all parties involved (Hofmann, 2013; van Geelen et al., 2010). What is conceived as a risk or benefit will vary based on the individual as shown in this study. In consultations with youth specifically, it can be misleading for healthcare professionals to assume a shared understanding about health, weight, and obesity between themselves and their patient, when in fact their relative positions are fundamentally different (van Geelen et al., 2010). Therefore, when making the decision regarding surgery, healthcare professionals should actively engage

adolescents to better understand what is informing their position and recognize that their own clinical-based judgment might be significantly different than their patients' assessments.

One of the key contributors to having surgery in our study is the perceived lack of self-efficacy to manage weight outside of surgery and the repeated feeling of failing at weight loss. This is a similar experience to what was documented by Childerhose et al. (2018) whereby adolescents report consistently not encountering weight loss success even with multiple tries. Moreover, a study in the Netherlands with youth in a weight management program found that the participants who felt that they could successfully lose weight by making health behaviour changes and believed they just needed to be more motivated to change, were less likely to endorse the idea of surgery (van Geelen, Bolt, van der Baan-Slootweg, & van Summeren, 2013). Unfortunately, what is evident from our study is that the previous attempts described by the adolescents were of poor quality and it emphasizes how little support these youth have received. Other than working with a family physician, adolescents had limited encounters with other health professionals and they were framed as being brief and ineffective. Only one participant had been involved in a comprehensive one-year multi-disciplinary program. This is not surprising given the scarcity of weight management programs in Canada (Ball et al., 2011). Consequently, there is a significant healthcare gap for youth who are living with severe obesity that require expertise beyond primary care management. Adolescents find themselves opting for surgery partly because they have been set up for failure by the healthcare system which does not invest resources to address the unique needs of this population (Sharma & Salas, 2018). However, it is important to recognize that the findings are based on what was reported by the participants, and it is possible that more organized attempts were done which they are not aware of (e.g., parent only in attendance) or remember.

Participants in our study learned about surgery through family, peers and health professionals, and incorporated this information in their deliberation process as reported in previous research (Doyle et al., 2018). Receiving information informally through personal reflections of adults may not be optimal to ensure that correct medical information is provided. Therefore, facilitated peer support groups might be a favorable option for adolescents as they could speak to someone within their age group who has been through the process, and it could help ensure the quality and appropriateness of the health information being shared. In fact, one study found that adolescents who had surgery thought that talking to someone who had this surgery before and after their own surgery could be helpful to them (Willcox et al., 2016).

Interestingly, none of the participants actively asked for bariatric surgery before it was introduced to them as an option. This might be due to the relative newness of bariatric surgery for adolescents and specifically the surgical program in Quebec, Canada which is only two years old.

The minimal amount of consideration for surgical complications and side-effects for most participants in our study suggests that the reality of the current complications from living with obesity were perceived as much greater than a hypothetical post-surgery medical issue. However, another potential explanation is the propensity of adolescents who have a higher BMI to engage in more extreme forms of weight management attempts like laxatives and prolonged fasting without much consideration of the risks (Neumark-Sztainer, 2002). Given the lack of self-efficacy to lose weight and weariness expressed by the participants in our study, bariatric surgery might present itself as an extreme, but worthwhile form of weight management for which they are willing to assume the risks. On the contrary, when it came to post-surgical dietary adherence it was evident that the participants were carefully considering whether the food/eating restrictions imposed by the surgery was going to be too much of an adjustment given their current feeding practices. The focus on changes in eating behaviours versus medical complications and side-effects might be indicative of a deep relationship between food and emotional eating. Adolescents are not willing to give up their favorite foods as they may act as a source of comfort or coping in light of the struggles they face on a daily basis. Additionally, surgical complications may appear more abstract and statistically less likely to happen.

Participants expressed how their current weight hampers their functional capacity and the desire that post-surgery they will be able to accomplish the simple tasks, such as crouching down to tie their shoes. This is consistent with studies that show adolescents living with obesity have lower quality of life both physically and mentally, (Modi et al., 2008; Zeller et al., 2006). Similarly, the hope of resolving chronic issues like diabetes and sleep apnea was reported as one of the benefits to having surgery. From this standpoint, the participants will likely be satisfied with the surgical outcomes given the high resolution rates that have been observed in a US clinical trial (Inge et al., 2016).

The other benefits participants anticipated were in relation to psychosocial issues. The prevalence of weight-based bullying and teasing is well documented in the literature (Economos et al., 2014; Hayden-Wade et al., 2005; Zeller et al., 2006) and by losing weight adolescents

hoped to have better peer relationships. The participants also wished to attract a partner since all were single, and participate in social life without constraints set by their body size. This is not surprising given that youth (especially those that are overweight) express the importance of having the 'right' body, one that would not stand out among their peers (Booth et al., 2008). This does not necessarily mean wanting to look like a supermodel, but rather to 'fit in' and participate in social activities without fear of being ridiculed for being different (Lofrano-Prado et al., 2013; Murtagh et al., 2006). This finding is also consistent with results from the previous studies with adolescents having surgery (Childerhose et al., 2018; Doyle et al., 2018). Conversely, the one participant who did not wish to have surgery believed that they were a person worthy of a great relationship even with additional weight. Thus, their higher body esteem and self-confidence appeared to diminish what benefits they felt could be accrued with surgery. Another possible explanation is that the participant had lower internalized weight bias, which is a measure of the extent to which a person holds negative beliefs about themselves due to their body size. Internalized weight bias is prevalent in this population (Roberto et al., 2012) with one study finding a high mean of internalized weight bias among adolescents seeking weight loss regardless of sex and history of teasing (Puhl & Himmelstein, 2018).

Asking adolescents to evaluate their current state of health revealed the negative effect participants thought the excess weight had on their overall health status. In some cases, the presence of co-morbidities also impacted the score. However, many adolescents did not frame obesity as a disease because of the lack of treatment available and preferred to view it as a condition or disability. This observation is important in light of the ongoing push to recognize obesity as a disease (Sharma & Salas, 2018). Moreover, the distinction that many participants made between themselves and significantly impaired 'super obese' individuals' could be indicative of weight bias. In a follow-up study with adolescents who had undergone bariatric surgery, a sub-sample reported developing critical feelings towards other individuals living with obesity after achieving their target weight (Willcox et al., 2016). Therefore, weight bias and obesity stigma appears to affect youth not only in their self-perceptions but how they perceive others as well.

An unexpected finding was the fact that participants were reluctant to recommend surgery to other youth. While some agreed that older adolescents should be offered the option, two adolescents felt that being less than 18 years old was too young. The ambivalence over age is probably a reflection of the uniqueness of each individual situation and is largely

consistent with literature documenting the perceptions of healthcare professionals on adolescent bariatric surgery (Vanguri et al., 2014; Woolford et al., 2010).

Boundaries to this Inquiry and Future Directions

While the sample size of this study is small and limited to one geographical location, it is consistent with other qualitative studies in this area (Childerhose et al., 2018). Moreover, given the small population of adolescents having bariatric surgery in Canada, estimated at less than fifty individuals in the past ten years, this study represents over 15% of the total patient population. Not all participants who were approached agreed to participate; therefore, it is possible that those who declined have a different perspective on their experience than those that were involved in this study. All the participants were interviewed before their surgery (for those that went through the procedure) or within the week following surgery. Future research would be necessary to examine how their experience post-surgery impacts their perception of their initial decision

Conclusion

This study highlights that adolescents carefully integrate different factors into their decision-making process and the relative importance of such factors is unique to each person. Therefore, healthcare professionals must be willing to spend time with these patients to understand what is informing their decision and provide support when needed to ensure youth have appropriate understanding about the surgical procedure and post-operative life changes.

Table 4-1 Adolescent Interview Guide

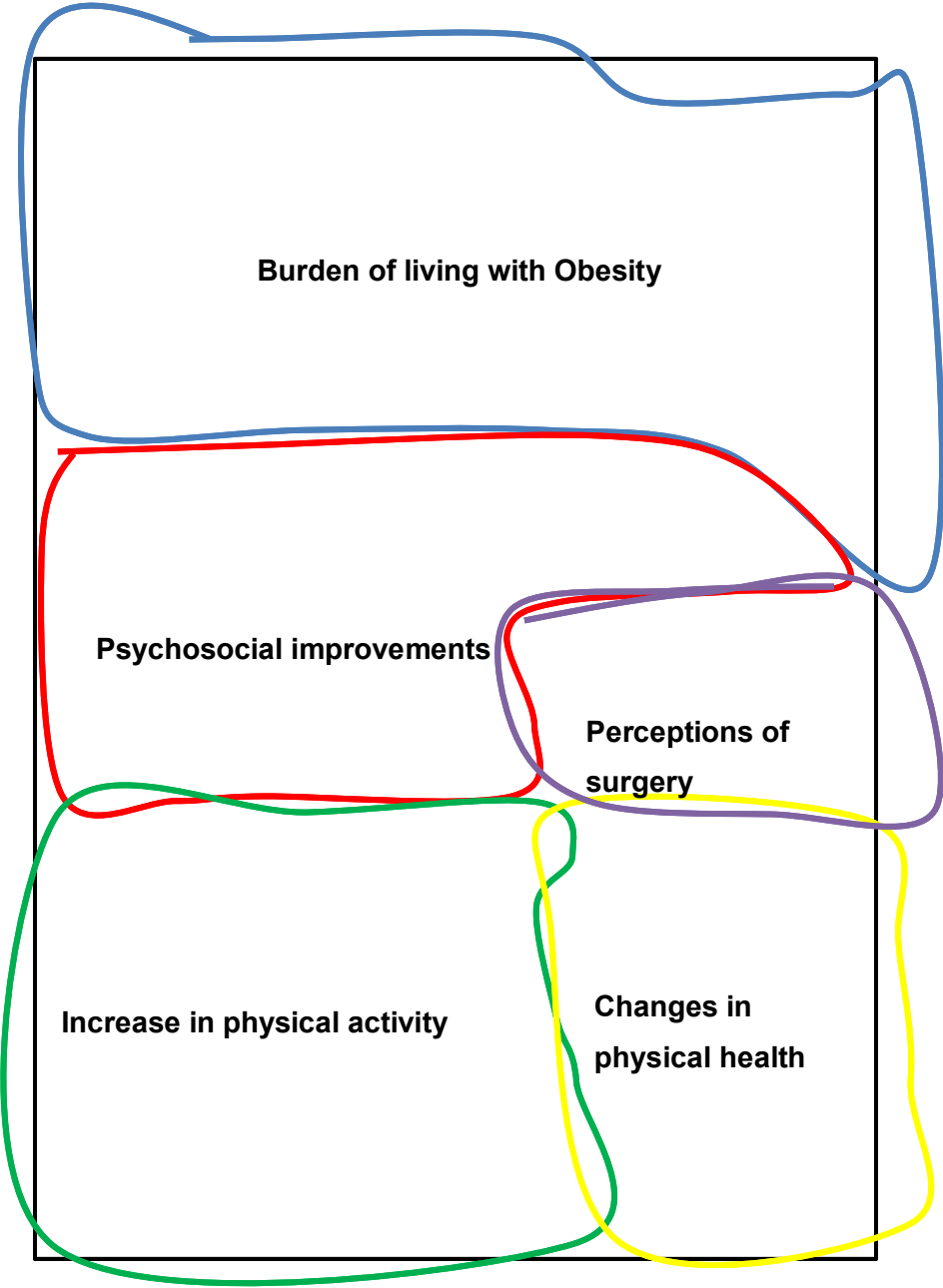
Guidelines/ Question	Probes & F/up Q
When did weight become an issue?	<ul style="list-style-type: none"> - How did you become aware? - What doctors did you see?
What is it like for you to be overweight?	<ul style="list-style-type: none"> - Main problems you encounter? - How do you deal with it? / How do other people deal with it?
How would you rate your current health status?	<ul style="list-style-type: none"> - What does it mean to be healthy? - What have been some challenges to becoming healthier? - Do you consider obesity to be a disease?
Where do you look for information about health and weight or who do you consult?	
When did you first learn about bariatric surgery?	<ul style="list-style-type: none"> - What was your impression about the surgery? - Do you know anyone who had bariatric surgery? - Do you think there should be a minimum age? - What are appropriate risks?
What process did you follow to decide whether or not to have the surgery?	<ul style="list-style-type: none"> - Did your decision change overtime? - What are your primary concerns? - What factors influenced your decision? - Would you recommend it to other youth like yourself?
What are your expectations as outcomes from having bariatric surgery?	<ul style="list-style-type: none"> - Do you have a specific goal weight? - How do your family/friends feel about it? - What type of outcomes would you find disappointing? - Do you have other health-related goals you hope to achieve?

Figure 4-1 Analytical Collage³



³ Translation of words from French to English: Endocrinologie = Endocrinology ; S.O.S Sante = S.O.S Health ; Intimidation = Bullying ; Mieux-vivre = Live Better; Les plaisirs de la vie = The pleasures of life ; Retrouvez votre forme = Get back in shape ; Coupe de pouce = boost/help

Figure 4-2 Analytical Collage by Theme



CHAPTER 5: A qualitative study examining pediatrician's perceptions of obesity and the practice implications

Targeted Journal: Pediatrics

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Abstract:

Background: Although a number of organisations now recognize obesity as a disease, there is ongoing disagreement about its status among healthcare providers and a lack of understanding of how individual perceptions inform healthcare delivery. Therefore, the objective of this qualitative study was to document the perceptions and reasoning of pediatricians on whether obesity is a disease and how this perception impacts their clinical practices.

Methods: Pediatricians (n=8) with varying degrees of experience in weight management were recruited through general advertisements to participate in a semi-structured interview, which was audio recorded and transcribed. Inductive thematic analysis was used to code the data.

Results: Participants practiced in urban settings, varied in years of experience (2-40 years) and patient caseloads with obesity (>10 to 100%). All pediatricians perceived health as being multi-dimensional and fluid, but there was disagreement on whether obesity was a disease. Participants who worked in a specialty setting were more likely to identify obesity as a disease versus 'a risky state of health'. Despite differences in perceptions, their approach to weight management was consistent, focusing on lifestyle assessment and changes for the families. However, participants reported that such approaches lacked effectiveness due to family, health professional and system-related challenges.

Conclusions: Findings from this study confirm ongoing disagreements about the nature of obesity; however, the differing perspectives tended to not impact their clinical management of weight. Rather, investigating the need for additional resources could potentially improve the care provided to families.

Keywords: Bariatric surgery, Obesity, Adolescents

Introduction

Pediatric obesity is a disease with serious health consequences (Dietz, 1998; Puhl & Latner, 2007), therefore pediatricians play an important prevention role through regular screening of their patients (Lau et al., 2007). While there is an increase in the number of pediatricians screening youth by regularly plotting body mass index (BMI) percentiles (Huang et al., 2009; Perrin, Skinner, & Steiner, 2012; Staiano et al., 2017), diagnosis of obesity is less common even when the BMI is calculated by the doctor (Thomas & Urrego, 2017). Pediatricians have also been tasked with providing health behavior change counseling to patients and families as part of prevention efforts (Lau et al., 2007), yet there is ongoing reluctance by health professionals to address weight (Pagnini, King, Booth, Wilkenfeld, & Booth, 2009).

In situations where weight is addressed by healthcare professionals, there is a perceived lack of self-efficacy in delivering weight management interventions. A systematic review found that physicians report a lack of competence for providing weight-related assessment and counseling (Van Gerwen, Franc, Rosman, Le Vaillant, & Pelletier-Fleury, 2009), which leads them to feeling frustration towards obesity management (Jelalian, Boergers, Alday, & Frank, 2003). These sentiments also contribute to physicians' beliefs that even if families are properly counseled, there will be little sustainable impact on the child's weight (Price, Desmond, Ruppert, & Stelzer, 1989; Story et al., 2002; Walker, Strong, Atchinson, Saunders, & Abbott, 2007).

In an effort to draw more resources towards obesity prevention, treatment and management (Puhl & Suh, 2015), the American Medical Association and the Canadian Medical Association recently recognized obesity as a disease (Frellick, June 19, 2013; Rich, October 3, 2015). Classifying obesity as a disease should also reduce weight stigma and bias that blames individuals for their weight status (Puhl & Suh, 2015). However, one study (Glauser, Roepke, Stevenin, Dubois, & Ahn, 2015) found that while 80% of primary care providers agreed that obesity was a disease, almost half of these participants similarly endorsed the notion that obesity was the result of a lack of self-control on the part of the patient. This finding is consistent with the prevalence of implicit fat bias found among providers and researchers who specialize in obesity management (Schwartz et al., 2003), which has been shown to ultimately lead to negative patient outcomes (Phelan et al., 2015). Given this ambivalence, it is important to further explore providers' (specifically pediatricians given their unique healthcare role) view of

obesity as a disease and the ways in which this perception informs their weight management practices.

Patients and Methods

Purposive sampling was used to recruit pediatricians who had clinical experience with weight management, were actively practicing in the Greater Montreal area (Canada), and fluent in French or English. Potential participants were approached through general email advertisements and by referral from other participants (snowball sampling). Eight pediatricians agreed to participate in the study (see Table 5-1). Two additional pediatricians initially expressed interest but later cited lack of time for not participating. Data was collected through individual interviews facilitated by BCF, either in-person (n=5) or by telephone (n=3) based on the participant's preference.

The interviews were semi-structured and prompts were used to deepen the discussion. The three guiding questions were: (1) how do you define health; (2) do you consider obesity to be a disease and why; and (3) how do you approach weight management in your practice. The interviews lasted between 30-45 minutes in length, were held in French or English, and were digitally audio recorded. Following each interview, summary notes were written capturing the main ideas and reflections by the interviewer (BCF). The interviews were transcribed by a certified transcriber. Data collection continued until data saturation was reached, defined as informational redundancy (Saunders et al., 2018), in the interviews.

The transcripts were imported into data analysis software (NVivo 12, QSR International) and coded (BCF). A modified version of inductive thematic analysis was used whereby each transcript was summarized into a descriptive outline and then compared to other participants (Boyatzis, 1998). Similar ideas, or points of difference, were identified and themes emerged from these findings. During the analysis, participant characteristics were also explored to identify any potential trends or patterns in reported experience. The emerging analysis and findings were discussed with the research team.

Ethics approval was granted by the human ethics committee at the CIUSSS du Nord-de-l'Île-de Montréal (#2015-1167).

Results

Participants practiced in urban settings, varied in years of experience (2-40 years) and patient caseloads with obesity (>10 to 100%). Table 4-2 provides a summary of the themes and illustrative participant quotes from interviews.

Theme #1: Health as being multi-dimensional and fluid

To understand their perceptions about obesity and disease, pediatricians were asked to define health. All pediatricians agreed that health was more than just the absence of disease. The majority distinguished between mental and physical health. Two pediatricians noted a spiritual dimension, while three pediatricians included social health as a component of overall health. Given the multiple dimensions identified by the pediatricians, being healthy was perceived as being fluid and a balance of each dimension.

Achieving developmental milestones was also offered as an additional definition by one of the participants, whilst another pediatrician believed it was important to factor in the patient's own perception of their health status.

Theme #2: Disagreement on whether obesity was a disease

When pediatricians were asked if they perceived obesity as a chronic disease, there was disagreement between participants. For half of the pediatricians, obesity was a "risky state of health" due to it being associated with increased risk of developing medical co-morbidities. Meanwhile, the remaining pediatricians viewed obesity as a disease because of the physical, mental, and social impacts it has on the patient. For one pediatrician, the multi-dimensional perception of health meant that even if obesity was viewed as a chronic disease, a patient living with obesity in the absence of medical comorbidities or complications was still considered healthy, i.e., obesity was not a disease.

Analysis using the participant demographics suggested that pediatricians who worked in a specialty setting (i.e., lipid clinic) irrespective of their overall patient case load with obesity, were more likely to view obesity as a chronic disease, as compared to those pediatricians who had a general practice.

Theme #3: Weight management interventions are similar regardless of viewing obesity as a disease

Despite the pediatricians having differing perceptions regarding obesity, they expressed an equal willingness to address weight in their practice. Their approach to weight management was similar with a focus on respectful communication, investigating potential causes of obesity, and feasible health-risk behavior change where possible.

Over half of the pediatricians emphasized the importance of respectful communication with patients. This included asking permission to discuss weight, avoiding words that could be perceived as harmful and demonstrating empathy. The majority of participants also endorsed the use of growth curves as a way to discuss weight and promote weight maintenance versus weight loss. Two pediatricians focused on aspects impacted by the patients' weight as a starting point to addressing obesity, like difficulty climbing stairs.

Investigating the underlying cause of the weight gain was mentioned by all participants. This included a health behavior assessment, and a quarter of pediatricians reported that requesting blood works and/or referring to specialists for an in-depth exploration of metabolic issues was also part of their weight management strategy.

In terms of intervention and counseling, all pediatricians alluded to feasible health behavior changes as their approach to weight management. This included promoting mindful eating, improving food quality, decreasing sedentary time, increasing physical activity levels, and setting monthly goals. When asked about referrals to other professionals, dietitians were the most often mentioned but always with the caveat that it would depend on the financial means of the parents to cover the costs if they did not have insurance, as most did not have access to this service within their respective clinic.

Theme #4: Perceived lack of effectiveness due to family, healthcare professional and system-related challenges

Despite their reported willingness to engage in weight management with families, the majority of pediatricians reported that their efforts were largely ineffective in impacting their patient's weight. Pediatricians identified family, healthcare professional and system-related challenges that contribute to this perception.

A perceived lack of prioritization on behalf of the families in combination with limited financial means rendered effective weight management challenging for pediatricians. Concurrently, the pediatricians recognized that weight is affected by more than just physiological factors which aligned with their views of health as being multi-dimensional. Unfortunately, this perception made their work difficult because they did not feel they had the resources to address those additional dimensions like socio-economic status and psychosocial issues.

Pediatricians were also critical about how effective health behavior change education was, such as teaching patients and family how to use food guide. Two pediatricians who had experience in a specialty clinic expressed that primary care providers lacked the weight management expertise for addressing weight in their practice. Meanwhile, a third pediatrician with similar specialty experience had a differing view, citing that it wasn't a lack of knowledge, but rather limited resources (e.g., dietitian not readily available free of charge) that was challenging for pediatricians. The remaining pediatricians did not mention a lack of knowledge in the area. The discussion on expertise and resource allocation prompted pediatricians to reflect on system-level issues, including the artificial divide of levels of care (primary, secondary, tertiary).

Three pediatricians believed that weight management should be addressed across the levels of care and not limited to one area, for example only in primary care. However, when probed to clarify the different roles and responsibilities, there was a lack of consensus among participants regarding tertiary care involvement, especially in the case of adolescents with severe obesity. Another pediatrician argued that while tertiary care needs to be involved, they felt that obesity was not viewed as a pediatric disease and thus the tertiary care centers had no interest in offering resources to address the issue ("no one looks after those patients"). In contrast, one pediatrician highlighted that by concentrating services in hospitals, it can limit access by patients and their families.

Discussion

This qualitative study with pediatricians found mixed perceptions about whether obesity was a disease, but their perception did not seem to impact their approach to weight management or their willingness to offer care. However, pediatricians generally felt that these

kinds of interventions were not very efficacious, largely due to family, healthcare professional and system-level barriers.

Half of pediatricians interviewed did not view obesity as a disease, a reflection of the current policy environment in Canada regarding weight management. For example, while the Canadian Medical Association has recognized obesity as a disease, Health Canada and individual provincial governments have not followed suit, resulting in a lack of consistent health messaging (Sharma & Salas, 2018). A literature review on obesity prevention policies and strategies in Canada found a prevailing narrative that framed obesity as a risk factor for co-morbidities and did not recognize obesity as a disease (Salas, Forhan, Caulfield, Sharma, & Raine, 2017), similar to half the group of pediatricians from our study.

Examining the differences between the two groups (obesity as a disease versus obesity as a risk factor), the pediatricians who viewed obesity as a disease also worked in a specialty setting where they were managing and treating complications due to excess weight. Given that a disease is defined as an abnormality in the function or structure of body systems (Tikkinen, Leinonen, Guyatt, Ebrahim, & Järvinen, 2012), a potential explanation is that the pediatricians who view obesity as a risk factor lack experience with the complications that directly stem from weight, thereby underestimating how obesity alone negatively impacts an individual's health.

Another consideration is the perception of what constitutes a disease. A Finnish study with healthcare professionals reported that a state of being was more likely to be viewed as a disease if participants felt that the individual did not have primary responsibility for the affliction and could be framed as a 'victim' (Tikkinen et al., 2012). Obesity, in particular, continues to be plagued by the notion that it is the individual's fault for their weight and weight stigma is prevalent in healthcare settings (Schwartz et al., 2003). In fact, the focus on an obesity epidemic can cause more harm to patients by promoting weight bias rather than focusing on improving overall health (Puhl & Suh, 2015). It has been shown that weight bias can lead to negative patient health outcomes, placing into question if focusing on an individual's weight is productive to achieving the desired health goals (Phelan et al., 2015).

In our sample we did not observe a difference in attitude or behaviour towards the cause or treatment of the obesity. The pediatricians who did not view obesity as a disease did not endorse this personal responsibility narrative by blaming the families for their child's weight, but that does not exclude the possibility that they may have implicit fat bias. While pediatricians did

perceive that families lacked motivation and prioritization for weight management, they concurrently noted that these were often the results of macro-level issues that limited family's level of engagement. The pediatricians recognized the complexity of obesity and the importance that factors like socioeconomic status play in the development of obesity (Davison & Birch, 2001).

The pediatricians' perspective was further supported by their conception of health as multi-dimensional, whereby factors like social welfare impacts healthiness. Therefore, they simultaneously faced two challenges: working with families who could not participate at the necessary intensity for successful weight management, and a lack of necessary resources to overcome the obstacles facing families. This rendered it difficult for pediatricians to intervene and ultimately led to the perception of treatment futility. The recurring sentiment regarding treatment ineffectiveness is not unique. Research shows that even when current 'gold standard' weight management counselling is delivered to families, physicians believe it is challenging to impact weight change (Price et al., 1989; Story et al., 2002; Walker et al., 2007). Shifting the focus from changes in weight to the adoption of healthier behaviors (e.g., diminishing consumption of sugar sweetened beverages) might help pediatricians feel more successful in the care they are delivering (Armstrong & Skinner, 2016). When combined with findings from a systematic review on primary care interventions showing modest changes in weight (Seburg, Olson-Bullis, Bredeson, Hayes, & Sherwood, 2015) the role of pediatricians beyond obesity prevention needs further exploration.

A four stage approach to obesity management was proposed by the American Academy of Pediatrics (Spear et al., 2007) from prevention to tertiary care intervention. The staged approach recommends that when primary care prevention is no longer sufficient and weight gain is ongoing, primary care providers are encouraged to refer families to additional support like dietitians for more structured weight management. If there are still difficulties then families should progress to comprehensive multi-disciplinary intervention and eventually tertiary care for medication and/or weight loss surgery (Brown & Perrin, 2018). By examining the findings through these four stages, pediatricians in our study highlight a number of gaps in the current healthcare system. Pediatricians mentioned that access to dietitians can be hard for families as they often do not have the means to pay for the service or it is not covered by their insurance plans. This means that stage two essentially falls back on pediatricians to do this work. The scarcity of comprehensive multi-disciplinary programs in Canada (Ball et al., 2011) also means

that as a child's weight continues to increase, there are limited options for primary care providers to refer their patients. Participants expressed that as the obesity becomes more severe, a team of specialized experts would be best suited for intervention but perceived that tertiary care did not view pediatric obesity as their responsibility, resulting in a significant gap in services. Thus, additional research is needed to best understand the optimal organization and role sharing across the levels of care to ensure families have access to health services best suited to their needs. For example, there is evidence to suggest that nutrition education without the inclusion of behavioural therapy to assist in making nutritional changes renders less optimal results (Epstein, Wing, Steranchak, Dickson, & Michelson, 1980). Behaviour change experts can also play a role in helping with other problematic eating behaviours like binge eating disorder (de Zwaan, 2001) and psychosocial issues like depression which has been shown to be prevalent in this population (Phillips et al., 2012). However, the role of behavior change experts was notably absent in the interviews with pediatricians.

Contrary to previous studies that reported reluctance on behalf of health professionals to address weight (Jones, Dixon, & Dixon, 2014; Mikhailovich & Morrison, 2007), this was not the case in this study. All pediatricians mentioned raising the issue even if it was not the principle reason for the appointment, and many recognized the need to communicate in a sensitive manner. As for screening and diagnosis, plotting height and weight on growth charts was commonly done by the participants as per the guidelines to view how a patient was progressing (Lau et al., 2007). However, it was unclear from the interviews whether or not they would associate a diagnosis of obesity for those patients who were above the 95th percentile, especially among pediatricians who viewed obesity as a disease. Delivering primary care interventions consisted largely of family and/or patient education centered on nutrition, physical activity, sedentary behaviors, and sleep. This is consistent with previous research with primary care providers which reported suggesting an exercise program and providing general advice and support to families on how to lose weight (Jelalian et al., 2003).

Our study did not find a perceived lack of self-efficacy by the pediatricians, unlike previous research (Van Gerwen et al., 2009). However, two pediatricians expressed need for improved training on obesity management for other pediatricians. These two participants also reported the highest patient case load of obesity, suggesting their more frequent experience with weight management may reveal an educational need for other health professionals.

There are several limitations to this study. First, self-selection bias needs to be recognized. The pediatricians who agreed to participate in this study may inherently see more importance to obesity management than those that did not take part. Second, although this sample included a variety of experience and work setting, all the pediatricians recruited worked in an urban setting. A larger sample that includes a mix of urban and rural providers may yield a different perspective as the burden to care for patients may be greater on providers who have limited access to additional resources and tertiary care centers are less readily available. Lastly, the sample was limited to pediatricians, but family doctors also play a role in caring for pediatric patients. Exploring their perceptions may yield a different outcome given their experience across the lifespan, thus observing how obesity evolves from childhood into adulthood.

Conclusion

Our study suggests that, irrespective of the perception pediatricians had on obesity as a disease, their approach to weight management was consistent. The pediatricians in our study identified that while their role is prevention and early intervention with youth who are increasingly struggling with excess weight, their ability to impact health outcomes are often limited by a number of perceived barriers. These barriers included a lack of family prioritization and financial means, limited resources, and a lack of program options outside of primary care for families that need more specialized weight management care. Therefore, increasing the availability and variety of services across multiple disciplines (nutrition, mental health, physical activity) that are available to families to address weight could potentially help alleviate the burden on pediatricians and be more tailored to the needs of families and the youth. However, the optimal format of these would need to be investigated further.

Table 5-1 Demographics of Pediatrician Participants

Sex	5 Female / 3 Male
Age	50.4 yrs old \pm 14.9 yrs <i>*one participant did not disclose their age</i>
Years of Experience	17.0 \pm 12.6 yrs
Work Location	8 Urban
Work Setting	4 Academic 2 Community 2 Community and Academic
Patient Caseload with Obesity	Range: <10% - 100%

Table 5-2 Themes and illustrative participant quotes from interviews

Theme 1 - Health as being multi-dimensional and fluid	
	<p>“a state of physical, mental, spiritual wellbeing.”</p> <p>“Well it’s probably one of those curves where there’s an ideal state where a bunch of different factors are intermingled and you can be healthy and have some issues in several different domains, it’s all balance.”</p>
Theme 2 - Disagreement on whether obesity was a disease	
Risky state of health	<p>“I tend to think of it more as a state that puts patients at risk for many complications and that puts them at risk for psychological suffering”</p>
As a disease	<p>“the physical, emotional, social consequences of living with severe obesity and/or obesity and also the challenges associated with treating this condition”</p>
Theme 3 - Weight management interventions are similar regardless of perception of obesity	
Communicating respectfully	<p>“We always ask ‘is it ok if we talk about this [weight]’, because it’s a sensitive issue”</p> <p>“I’m really conscious about the use of words and how they can be hurtful. It’s just a medical term, but I’m very conscious of the words around and try not to use the word fat and obese”</p>

	<p>“Suddenly with puberty they [patient] start to gain a substantial amount of weight. And then I’m getting worried, and then I will show them on the growth curve [...] ‘you see if you stay at the weight you are now, you don’t have to lose any weight, but you have to stop the weight gain and because you are still growing, [...] you are going to be fine. We just have to make sure that you do not continue to gain”</p> <p>“I try to look for specific concrete examples [...] telling someone who is living with obesity that the pains that they are feeling in their joints when they are trying to walk for a long distance or the shortness of breath that they have when they are climbing up the stairs can be directly linked to what they are carrying around extra is a gateway to having the bigger discussion”</p>
<p>Investigating potential causes of obesity</p>	<p>“I do cover with every patient you know basic nutritional assessments, physical activity patterns, sedentary behaviour assessment as well as sleep, so that’s for the causes”</p> <p>“We will do a blood test and we will look for liver and fat infiltration and cholesterol, triglycerides, thyroid”</p>
<p>Feasible health-risk behavior change where possible</p>	<p>“So just to make them aware when they are eating so that they can write it down, or they can for instance decide that they are only going to eat in a certain place at home, only in the kitchen and they sit down to eat, but no TV</p>

	<p>in the kitchen. [...] And then the other thing is regarding the type of food; it is one of the first things to try and attack is soft drinks because they can drink litres of soft drinks per day or juices [...] So it's a combination of motivation and then feasible steps"</p>
<p>Theme 4 - Perceived lack of effectiveness due to family, healthcare professional and system-related challenges</p>	
<p>Family: Complexity of family life</p>	<p>"I had one patient, he's a little boy, the family is so good ... and they tried. I think they came to see me because they have to pay a dietitian, right? A dietitian is not free on Medicare, so the plan was "come see me every month and show me that you are losing weight, and do a food diary and that" so they tried but the parents were separated and he was filling it out and she was filling it out and it wasn't realistic. And they didn't live close, they were travelling far to come here."</p>
<p>Family/professional: Lack of resources</p>	<p>"from a patient and family perspective, obviously for many of those families there is you know, socio-economic and psychosocial components to their disease, and so you know either they lack the financial resources to implement the changes we wish they would or their environment is just not conducive to a healthy lifestyle and so you know, that definitely is a big challenge that is difficult to address because they are very macro and we don't necessarily have the right tools to help patients navigate those"</p>

<p>Professional: Effectiveness of intervention</p>	<p>“saying to them ‘you should be exercising, [...] or you should be eating by these Health Canada guidelines’, it’s not very effective. And when you say ‘ok go see the nutritionist’ and the nutritionist sees them a couple of times, it’s not very effective”</p>
<p>System: Responsibility for clinical weight management</p>	<p>“I don’t think it can be broken down into tiers [primary versus secondary]. People have a perception that it needs to be in one place or another but I think it’s everybody’s responsibility”</p> <p>“It’s not primary care setting that can handle these cases. It’s not true [...] for me this is tertiary care, there’s no question. I don’t understand, if you look at the consequences that these patients are going to have if you don’t do something, it’s major, no? But all these consequences they are going to be tertiary care”</p>

**CHAPTER 6: Canadian pediatricians' perceptions on the acceptability of bariatric surgery
for adolescents living with severe obesity**

Targeted Journal: Pediatric Obesity

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Abstract:

Background: Adolescent bariatric surgery is a contentious issue, with studies to date demonstrating a majority of primary care providers against referral for surgery.

Objectives: This study explored pediatricians' perceptions on the use of bariatric surgery as a treatment option for adolescents living with severe obesity.

Methods: Pediatricians (n=8) recruited through general advertisement participated in semi-structured interviews. Participants worked in community and academic settings, had a range of professional experience (2-40 years) and patient caseloads with obesity (<10-100%). Interviews were audio recorded and transcribed. Inductive thematic analysis was used to identify emerging themes.

Results: Bariatric surgery would be considered acceptable when there was no medical reason for weight gain, ineffective behavioral treatment attempts, severe obesity, presence of medical and psychological co-morbidities, and further evaluation by an expert multidisciplinary team. To be eligible for surgery, the patients had to have: completed puberty; a supportive family environment; and participated in behavior lifestyle changes (with demonstrated adherence) prior to surgery.

Conclusions: The study demonstrates that these pediatricians were open to bariatric surgery, but the conditions for such a referral varied by individuals and they relied on a multidisciplinary team to make the final decision on the appropriateness of the patient to undergo surgery. By increasing the availability of behavioural weight management programs it would provide alternative options to surgery that are currently unavailable.

Keywords: Adolescent, bariatric surgery, obesity, weight management

Introduction

In Canada it is reported that 13% of youth between the ages of three and 19 years' old are living with obesity (Rodd & Sharma, 2016). Currently, lifestyle modification therapy is the primary treatment approach for youth with severe obesity. However clinically meaningful weight loss is rarely achieved nor sustained (Ryder et al., 2018) prompting the consideration of bariatric surgery as an additional treatment option for a select number of patients.

Research with healthcare providers has demonstrated skepticism towards adolescent bariatric surgery (Bailey et al., 2013; Iqbal et al., 2009; Vanguri et al., 2014; Woolford et al., 2010). In some cases, approximately half of healthcare providers would be unlikely and/or never refer an adolescent for bariatric surgery (Iqbal et al., 2009; Woolford et al., 2010). The underlying reasons cited include: unknown side-effects of the surgery; risks related to the operation; poor cognitive function of the youth; belief that non-operative approaches are a better choice (Iqbal et al., 2009); cost; potential complications; and believing it was not indicated in a pediatric population (Vanguri et al., 2014). Canadian healthcare providers reported there was a need for establishing long-term follow-up and a transition plan to adult care before a change in attitude towards these procedures emerges (Bailey et al., 2013).

In contrast, reasons to refer a patient for bariatric surgery included: significant weight-related medical comorbidities; lack of non-operative treatment effectiveness; need for sustainable weight loss; and psychosocial issues (Iqbal et al., 2009). In regards to pre-requisites for surgery, studies have shown that healthcare providers endorse the completion of a weight management program prior to considering surgery. However, there is a lack of consensus on the optimal length of weight management programs, with durations ranging from three to over 12 months (Penna et al., 2014; Vanguri et al., 2014; Woolford et al., 2010).

Unfortunately, the current literature is dated, especially considering the recent availability of new longitudinal data (Inge et al., 2016) and guidelines (Pratt et al., 2018) that may impact surgery perceptions. Also, given that pediatricians are the primary care provider for adolescents, a current limitation of the literature is the lack of focus exclusively on this group. Therefore, the purpose of this study was to understand pediatricians' perceptions and attitudes towards adolescent bariatric surgery and the conditions under which they would refer a patient for surgery.

Methods

To provide a rich description of pediatricians perspectives of bariatric surgery, qualitative description was used (Sandelowski, 2000). Purposive sampling was used to target pediatricians who could provide insight into the research questions (Richards & Morse, 2007). Pediatricians currently working in the province of Quebec (Canada) were recruited. Due to the provincial variations in the organization of health care in Canada, it was decided to focus only on one province. To be included in the study, pediatricians had to be fluent in either French or English, have experience with weight management, and be currently practicing.

Recruitment was done through a multipronged approach using emails and posters in a variety of academic and community settings. Interested participants were asked to contact the researchers to confirm their eligibility and an interview was scheduled.

The semi-structured interviews (guide in table 6-1) lasted approximately 45 minutes and were done in person (n=5) or by phone (n=3) by BCF. Prior to the start of the interview, participants reviewed and signed the consent form and completed a demographic survey. All interviews were digitally audio-recorded and transcribed verbatim by a certified transcriber. Any potentially identifying information was replaced in the transcripts and subsequently imported into data analysis software (NVivo 12, QSR International).

Modified inductive thematic analysis was used to analyze the transcripts (Boyatzis, 1998) by BCF. Each transcript was reviewed once to get a better sense of the content. During a second reading, parts of the transcript were assigned a descriptive code. Descriptive codes were reviewed throughout the process and renamed or merged as new data was analyzed. Once descriptive coding was complete, the codes were reviewed and emerging patterns and themes were identified. Constant comparison within and across participants was used to evolve the analysis. Interviewing and analysis were done concurrently in order to provide insights in successive interviews and continue to develop the emerging themes.

Debrief notes were written following each interview, and memos (Richards & Morse, 2007) were maintained to track any changes to the interview guides as well as thoughts and ideas of the researcher. Periodic discussion with the research team helped to further develop the analysis. Recruitment and analysis continued until data saturation was reached, defined as informational redundancy (Saunders et al., 2018). Thus, no new insights were being generated

and all the themes were well circumscribed. Rigour was ensured using five verification strategies detailed by Morse et al. (2002) that examine methodological coherence, purposeful sampling, iterative data collection and analysis, confirming new data as it emerges, and theory development.

Ethics approval was granted by the human ethics committee at the CIUSSS du Nord-de-l'Île-de Montréal (#2015-1167)

Results

Eight pediatricians participated in the study and participant details can be found in Table 6-2. Three pediatricians reported that they did not have any patients they would describe as severely obese.

The emerging themes were organized into two categories: (1) the acceptability of bariatric surgery; and (2) the eligibility criteria for patients.

Category #1 Acceptability of Bariatric Surgery for Adolescents

All of the pediatricians interviewed would consider referring an adolescent for bariatric surgery, although only two participants had previously referred a patient. Pediatricians would consider bariatric surgery for their adolescent patient when there was: (1) no medical reason for weight gain; (2) ineffective behavioral treatment attempts; (3) severe obesity; (4) presence of medical and psychological co-morbidities; and/or (5) further evaluation by an expert multi-disciplinary team was available.

Prior to considering bariatric surgery, pediatricians reported eliminating potential causes for the continued weight gain. As one participant noted, “our job is to prevent them [adolescents] from getting there [severe obesity] and if they are there, it’s to make sure, [...] we are not missing some medical, endocrinologic or syndromic reason why they are there and to look at lifestyle and to look for associated medical problems and psychological problems. [...] And then if it’s beyond our control with the patient suffering we will refer [for surgery]”.

Alongside this reasoning, all pediatricians agreed that bariatric surgery was to be considered as a last resort for patients experiencing a lack of treatment effectiveness with

previous weight management attempts. Pediatricians also mentioned that the patient had to be severely obese (with a BMI of $40\text{kg}/\text{m}^2$ being used to define the severity of obesity) to request bariatric surgery as a next step. For example, “If it’s a patient that I know, or even if it is the first visit, if they have told me that they have tried this and this and this and nothing is working and they are morbidly obese I guess it’s [surgery] an option”.

While BMI was an important indicator, the presence of medical and psychological co-morbidities made the situation more urgent and increased the likelihood of referring a patient. In fact, one pediatrician noted they felt more comfortable waiting until complications from the weight occurred instead of focusing on the adolescents’ body size since they would be considered a ‘metabolically healthy obese patient.’

The majority of participants highlighted their limited experience and knowledge with regards to bariatric surgery in adolescents, “I still don’t know a lot about it. So I know I’ve had training obviously in medical school, not really in residency because it was not available to our patients”. Therefore, the pediatricians were willing to consider bariatric surgery as part of a treatment plan, but most (7/8) participants stressed that a referral was for further evaluation by a team of experts and not directly to a surgeon for the procedure. For example, “You see I will not send a patient for bariatric surgery, I will send a patient to a severe obesity program, or bariatric program, hoping that they are going to do a whole bunch of things before they start to cut. [...] for sure you are not going there and the next day you will be operated on. That I can guarantee you. If I cannot guarantee that, I will not send them”.

In fact, pediatricians were unanimous in stating the importance of a multi-disciplinary team in evaluating and making the final determination if a patient should have bariatric surgery. The composition of that team was fairly consistent across participants with the inclusion of the physician, nurses, nutritionist, a mental health professional (family therapist, social worker, psychologist) and someone specialized in movement (physiotherapist, dance specialist, etc.). Including the family doctor or pediatrician into the team was also mentioned. Notably, the surgeon who would do the actual procedure was absent in many of the participants answers, with only two pediatricians mentioning the surgeon as a team member. Also, two pediatricians felt that an exercise specialist was less essential and perceived most physicians as having sufficient knowledge to provide the minimum level of physical activity information.

The strength of a multi-disciplinary team evaluation was described as follows, “I think having a multipronged assessment process is really important and then coming back as a multi-disciplinary team and having a discussion and finding out because there will be little things that were divulged to different team members, so trying to get a more truthful representation of families’ capacities and needs and desires, and their barriers is important to assess”.

Category #2 Patient Eligibility Criteria

Pediatricians identified four sub-themes that had to be considered to determine whether the patient was eligible for surgery: (1) age; (2) family environment; (3) participation in a behavior lifestyle intervention; and (4) demonstration of adherence to lifestyle changes.

The issue of the patients’ age was discussed with regards to puberty and decisional capacity. The majority of pediatricians cited that they expected the adolescent to have completed puberty before having surgery rather than focusing on a specific age. One participant expressed it as follows, “There is no age, it’s really based on the stages of puberty. [...] At the minimum the adolescent needs to be at Tanner stage 4 or 5”. Conversely, one pediatrician mentioned that there can be sex differences at which puberty can conclude, “You see the problem is that teenage boys have probably not reached their physical maturity until they are 16, 17, 18 and having a BMI of 40 or over. Yeah, those ones you probably have to intervene earlier, no? But it’s just, and for girls at the age of 14, there is nothing much changing anymore”. This participant stressed that in such situations it is not age or puberty that defines the intervention, but the medical need related to the severity of the obesity.

When it came to establishing decisional capacity, all pediatricians reported that age was not an obstacle. In fact, five pediatricians highlighted Quebec law regarding the ability of youth 14 years and older being legally able to consent to medical procedures with parental oversight, as explained by this participant, “I think it’s possible to have informed consent and to get the information if the patient is at a maturity level to understand that. And not only that, but after the age of 14 they have the legal ability to make that decision”.

The family environment was also deemed important by all pediatricians in order to support adolescents in behavior changes. For example, “a patient needs to have a supportive environment and a stable environment and especially for teenagers, that’s important”.

Pediatricians stressed that behavioral lifestyle intervention should precede the surgery, as explained by the following pediatrician, “I think an intensive program or an intensive attempt at healthy, active living I think is a general recommendation if we look at the literature for patients who are going to get bariatric surgery. [...] I think it would be reasonable to expect that something is done prior to the decision to do a surgery”. In fact, one pediatrician felt quite strongly that surgery without prior intervention would render the procedure useless. Yet, there was a lack of consensus on what would constitute an ‘attempt’ or ‘intervention’. The proposed duration of such interventions varied between six and 12 months, with one pediatrician specifying that anything shorter than six months in length would not result in improvements. Meanwhile another pediatrician specified a minimum of 25 hours of behavior lifestyle intervention in six months would be needed based on the recommendations of the United States Preventative Services Task Force guidelines. The ideal setting for this type of intervention was also a source of disagreement by participants. Due to the scarcity of resources in primary care, participants felt a tertiary program might be better suited, but one pediatrician noted that in this scenario, the access would be more limited.

Pediatricians reported that prior to being eligible for surgery, there had to be evidence of adherence to making lifestyle changes by the patient. When probed as to what kind of evidence they were referring to, they mentioned, “showing up to the appointments and making some of the efforts, both from the physical activity perspective and the nutritional behavior perspective that demonstrate the commitment and an ability to make some changes”.

Besides evaluating these different characteristics of the patient and their surroundings, pediatricians also raised potential contraindications to surgery. These included uncontrolled mental health conditions (e.g., depression) and serious developmental disorders that compromised patients’ ability to adhere to post-surgery guidelines.

Discussion

Contrary to previous research, our participants were open to considering bariatric surgery for their adolescent patient. This difference may stem from the fact that they considered a referral as a step for further evaluation by a specialized team and not a referral for obtaining the surgery directly. This would reflect Iqbal et al.’s (2009) conclusion that to overcome the current resistance to the idea, the focus should be on informing healthcare providers that a

referral for surgery is not a commitment to the procedure. Conversely, Woolford et al.'s (2010) concluded that the lack of referral was likely due to the lack of long term data available in this population. This was not the case in our study because our participants did cite a lack of knowledge on bariatric surgery, yet that did not influence how they perceived the procedure. Perhaps this might be due to an increase in the literature on adolescent bariatric surgery since 2010.

When examining the reasons when a referral might be warranted, the pediatricians in this study echoed many of the same reasons that were previously identified. In one study, participants were most likely to refer a patient with a BMI of 40kg/m² or a BMI of 35kg/m² with the presence of weight-related medical co-morbidities (Penna et al., 2014). Severe obesity and related co-morbidities were also drivers to refer in our study.

The treatment ineffectiveness of lifestyle interventions was another reason raised by the pediatricians. This reasoning does prompt consideration for the quality and availability of the treatment options for patients. Previous studies have shown that obesity treatment and management in Canada is lacking (Ball et al., 2011; Sharma & Salas, 2018) and that healthcare professionals find obesity management to be frustrating (Jelalian et al., 2003) and weight loss to be unsustainable (Price et al., 1989; Story et al., 2002; Walker et al., 2007). Given this reality, the pathway that leads youth to bariatric surgery can be construed as a 'failure' of the public health system by not offering these patients the best possible care to potentially prevent an invasive surgery.

An ongoing debate in the literature is to establish how young is too young to offer bariatric surgery (Beamish & Reinehr, 2017; Dan, Harnanan, Seetahal, Naraynsingh, & Teelucksingh, 2010; Penna et al., 2014). However, age often acts as a proxy for two other factors that are of concern in a youth population: decisional capacity and physical maturation. Our participants diminished the importance that age actually plays by referring to the Quebec legal standard of 14 years old as the age of consent and reported that bariatric surgery is not an exception to this. Consent or assent was deemed possible in most situations with patients, unless there was a cognitive impairment, which would be handled differently (bariatric surgery notwithstanding). Penna et al.'s (2014) reported that although participants found 16 years old as an acceptable age for surgery, 80% indicated that both parents and adolescents had to be engaged in providing informed consent. Similarly, the American Society for Metabolic and

Bariatric Surgery (ASMBS) guidelines recommend that bariatric surgery is only offered if both the parent and adolescent agree on bariatric surgery (Pratt et al., 2018). In fact, a qualitative study with adolescents living with obesity engaged in behavioral weight management found that most participants would like a greater involvement in decision-making (Kebbe et al., 2019). Greater consideration is needed on how to approach cases where adolescents have the capacity to make the decision to have surgery, but do not have the support from their caregivers.

As for physical maturation, the completion of puberty was cited by the majority as criteria prior to considering bariatric surgery. However, the ASMBS guidelines indicates that puberty is not negatively affected by bariatric surgery and there is no rationale for using pubertal stage to exclude potential candidates (Pratt et al., 2018). Waiting for puberty to finish might unnecessarily delay surgery in adolescents who could benefit from an early intervention.

Within the context of our study without access to adolescent bariatric surgery, a small number of patients are forced to wait until they are 18 years old to access the care they need. This may not be in the best interest of the patient because bariatric surgery results in better weight loss and increased likeliness of resolution of co-morbidities at lower BMI's (Pratt et al., 2018).

Surgical pre-requisites continue to include a behavior lifestyle component and a multidisciplinary approach, which is consistent with results from another Canadian study with healthcare professionals (Bailey et al., 2013). Our study provides greater details on who is expected to be on this team and the variations in how a program should be implemented. It also echoes the importance of a family-centered approach by stressing the importance of parental involvement and ensuring a stable home environment for the adolescents. Tied to the expectation of participation in a behavioral lifestyle program, is the demonstration of adherence to lifestyle changes by the adolescent. This requirement likely stems from the importance that youth follow the strict post-operative diet (Fullmer et al., 2012).

A limitation of this study is that most participants practiced in an urban center in Quebec where access to tertiary care is potentially easier than for patients living in rural areas. There was also a predominance of pediatricians working in an academic center, whereby their experiences might be different from community based pediatricians. Future studies should also extend to family physicians as they are in the unique position of seeing youth transition from

'adolescent' to 'adult' and thus may play a bigger role in determining when a patient might be ready for surgery. It would also be interesting to see if their perception varies from the pediatricians documented here. Extending this study to Ontario, Canada where the only other adolescent bariatric program exists would be useful to have a more complete national understanding of where the common educational needs are for pediatricians in relation to bariatric surgery.

In conclusion, examining the perceptions of pediatricians revealed that they have a generally favorable view of bariatric surgery for adolescents living with severe obesity especially when presenting with co-morbidities. However, they rely on a multidisciplinary team to make the final decision on the appropriateness of the patient for undergoing surgery. Moreover, participants identified a lack of behavioral weight management programs which creates a key gap in healthcare resulting in patients being referred from primary care to a bariatric program.

Table 6-1 Pediatrician Interview Guide

Questions	Probes & Follow-up Questions
How would you define health/ being healthy?	- What does it mean for someone to have ill or good health?
Do you consider obesity to be a disease?	<ul style="list-style-type: none"> - If yes, why? If no, how do you see it? - How do you communicate to patients and/or families about weight and health?
What is your experience with weight management in your practice?	<ul style="list-style-type: none"> - How do you manage weight in your practice? - What type of resources or programs are available to support your patients? - Barriers to optimal care? - Whose responsibility is it to manage adolescents living with severe obesity?
What do you think about the use of bariatric surgery as a treatment for adolescents living with severe obesity?	<ul style="list-style-type: none"> - Willing to refer a patient? - Under what conditions?
How should decisions be made about who qualifies for bariatric surgery?	<ul style="list-style-type: none"> - What should be the age limit for these procedures? - Should patients have tried conventional, multidisciplinary treatment before being eligible? - What does a multi-disciplinary treatment plan look like? - How is patients' motivation for pre- and post-operative treatment adherence determined? - How do you obtain informed consent in adolescents? - What other patient or family factors should be considered (SES, etc)?

- What are contraindications for surgery?

What do you feel are common misconceptions about bariatric surgery?

What aspects about bariatric surgery would like to know more information?

Table 6-2 Demographics of participants

Sex	5 Female / 3 Male
Age	50.4 yrs old \pm 14.9 yrs <i>*one participant did not disclose their age</i>
Years of Experience	17.0 \pm 12.6 yrs
Work Location	8 Urban
Work Setting	4 Academic 2 Community 2 Community and Academic
Patient Caseload with Obesity	Range: <10% - 100%

CHAPTER 7: Perspectives of Adolescent Bariatric Surgery by Adolescents, Pediatricians, Bariatric Surgeons and Healthcare Administrators

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Abstract:

Background/Objective: While the majority of weight management interventions target behaviour changes, there is a growing interest in bariatric surgery for adolescents living with obesity. The purpose of this study was to compare and contrast the perspective of multiple stakeholders with regards to adolescent bariatric surgery.

Subjects/Methods: Pediatricians (n=8), bariatric surgeons (n=5), healthcare administrators (n=4), and adolescents contemplating bariatric surgery (n=7) were recruited to participate in semi-structured interviews lasting 20 to 45 minutes. The Interviews were audio recorded and transcribed. Modified thematic analysis was used and to identify emerging themes within each participant group as well as points of agreement/differences across groups.

Results: Four emerging these were identified: (1) Bariatric surgery was acceptable for select youth patients; (2) difficulties in balancing risk and benefit in the pediatric population; (3) skipping to surgery without previous behavioral weight management; and (4) the necessity to optimize healthcare spending in this population. Findings from this study highlight perceptions of adolescent bariatric surgery were generally positive across all four stakeholder groups but differences did exist in terms of acceptable risks and benefits. Healthcare administrators and pediatricians identified systemic issues that may create barriers to the referral and implementation of bariatric programs for adolescents living with severe obesity.

Conclusions: When comparing the perceptions of all participants it was evident that although bariatric surgery was viewed as a viable option the current healthcare context may hastily refer patients to a bariatric program in the absence of having other options available. Improved healthcare services are necessary to properly equipping providers to best address the needs of adolescents and potentially reduce the number of patients who ultimately require surgery.

Keywords: Adolescent, bariatric surgery, obesity, weight management

Introduction

Adolescent bariatric surgery is an emerging area of research with important implications for the treatment and management of severe obesity in youth. A recent review of treatment options for youth living with severe obesity found that bariatric surgery was the only option that provided significant and sustainable weight loss (Ryder et al., 2018). The American pediatric guidelines recommend bariatric surgery as an option for adolescents when they have a Body Mass Index (BMI) $\geq 35 \text{ kg/m}^2$ or 120% of the 95th percentile with clinically significant co-morbid conditions; or BMI $\geq 40 \text{ kg/m}^2$ or 140% of the 95th percentile. Patients and their family also need to demonstrate the ability and motivation to adhere to pre- and post-operative guidelines (Pratt et al., 2018). However, there is an ongoing debate about performing bariatric surgery for adolescent weight management due to a number of factors, including lifelong micronutrient deficiency, safety, and long-term efficacy (Beamish & Reinehr, 2017).

The literature demonstrates that clinical decision-making is a multi-faceted and complex process where the healthcare provider's perception contributes to the decision taken (Smith, Higgs, & Ellis, 2008). In the case of adolescent bariatric surgery, two providers that are central to the clinical pathway are pediatricians and bariatric surgeons. For example, as primary care providers, pediatricians have a role in deciding whether to refer a patient to a bariatric program. Similarly, bariatric surgeons have to agree to perform the procedure in order for it to be available as a treatment option. Thus, their perceptions about bariatric surgery can ultimately influence the accessibility and availability of bariatric surgery for adolescents. These two healthcare provider groups must also work in collaboration with the adolescent patient, whose choice to select bariatric surgery among other options needs consideration. Finally, the context of these various decisions should not be disregarded as clinical decisions are made through a reciprocal and dynamic interaction with the environment (Smith et al., 2008). In order to understand the environment around weight management for severe obesity in adolescents, healthcare administrators can provide insight through their role in allocating funds to different programs and identifying how priorities are set.

The benefit of examining bariatric surgery through the lens of multiple-stakeholders is having the opportunity to more readily identify potential challenges and barriers to providing optimal care for adolescents with severe obesity, as well as areas where there is agreement across all groups. Therefore, the purpose of this study was to compare the perceptions of

adolescent bariatric surgery among multiple stakeholders (i.e., pediatricians, bariatric surgeons, adolescents, and healthcare administrators) and to understand the healthcare context in which these occur.

Methods

In order to best understand the decision-making process, four different stakeholder groups were identified: pediatricians; bariatric surgeons; adolescents who are eligible or who have had bariatric surgery; and healthcare administrators. The inclusion criteria can be found in table 6-1. Purposive and snowball sampling was used to recruit participants (Richards & Morse, 2007), which was done using general advertisements at local weight management clinics and relevant conferences, and through referral from other participants from May 2018 to April 2019. Interested individuals were directed to contact one of the team members (BCF) to obtain more information and schedule an interview. Healthcare administrators, pediatricians and bariatric surgeons were given the option to conduct the interview in person or via phone to best accommodate their schedules. Given that the adolescent participants also engaged in an arts project, the option to conduct the interview over the telephone was not possible. The interviews took place at a local clinic except one was held at a YMCA for easier accessibility.

Prior to the start of the interview the participants were given the informed consent to review and invited/encouraged to ask any questions. The interviews lasted 20-45 minutes in length, were digitally audio-recorded and subsequently transcribed verbatim. Although similar questions were asked, participant interview guides were adapted as function of stakeholder group.

Interview transcripts were imported into NVivo12 (QSR International), a qualitative data analysis software. Modified inductive thematic analysis was used to identify emerging patterns in the data (Boyatzis, 1998). This involves reducing each transcript into a content outline and using descriptive codes to further refine the information. By using constant comparison within and across each participant group, it allowed for the examination of commonalities and differences, which lead to the emergence of key themes regarding perceptions of bariatric surgery.

Ethics approval was granted by the human ethics committee at the CIUSSS du Nord-de-l'Île-de Montréal (#2015-1167).

Results

All participants who responded to the recruitment advertisement or were referred by another participant were eligible for the study and were included in the data collection. A total of 24 participants were interviewed for this study including seven adolescents, eight pediatricians, five bariatric surgeons and four healthcare administrators. The characteristics for each participant group can be found in table 6-2.

Four themes emerged from the data analysis: (1) bariatric surgery for select youth patients; (2) balancing risk and benefit in the pediatric population; (3) skipping to surgery; and (4) optimizing healthcare spending.

1- Bariatric Surgery for Select Youth Patients

There was agreement by all of the participants that there are patients who could benefit from bariatric surgery irrespective of their age when there is a perceived urgent medical need. As one healthcare administrator explained, “it’s like a medical emergency to do the surgery while they are adolescents”. The majority of participants described eligible patients as those who had a very high BMI and/or presented with weight-related co-morbidities. For example, a pediatrician explained, “...if the BMI is sky high, when we are in the range that is the criteria to get them into bariatric clinic, then the bariatric surgery should be an option”. Similarly, a bariatric surgeon noted, “...if their BMI is 32, but they are on 200 units of insulin and they have to basically sleep sitting up because of their sleep apnea and they have bad liver disease, I think that person is a great bariatric surgery candidate”.

Aside from medical emergency, other factors were considered, including the ability of youth to consent, which was often stated as being at least 14 years’ of age as defined by Quebec law. For example, a paediatrician noted, “I would say maybe 14 and over... that may change over time as I know more about it, but I think at this point that’s what I would say. [...] Because it’s the age also of consent [in the province of Quebec], [...] where a patient would get a say in the consent”. Inherent to their ability to provide consent is the demonstration that they understand the consequences of surgery. This was a perspective shared by adolescents as well as the other professional participants. As one bariatric surgeon explained, “I would be a little hesitant to go too young just because I’m not sure of their level of maturity and understanding of what the implications will be”.

A related issue is the perception that candidates must be post-pubertal. As explained by one of the participating pediatricians, “I think it probably would depend where they are in their puberty because things can change with puberty. [...] So I would think that you would want to let that happen first”. Finally, multiple participants across all four groups stated evidence of commitment to change [health behaviors] as documented by attendance to pre-operative clinical appointments. For example, “It’s difficult to predict 100% who is going to be committed, but I think seeing their attendance at all the meetings and appointments it is a good show”.

2- Balancing risk and benefits in the paediatric population

One of the concerns raised regarding adolescent bariatric surgery was balancing surgical risk with potential benefits, especially given the unknown long-term outcomes. Healthcare administrators in particular were more risk adverse because it was a pediatric population. For example, a health administrator expressed the concern as follows, “If you put a sleeve in a 60-year-old that’s one thing; you do a Roux-en-Y on a 14-year-old who’s got a whole lifetime ahead of him, that’s something else entirely. Is it even wise, or are we going to learn in 10 years ‘oh my god what a dumb idea this was’?”

Meanwhile, most bariatric surgeons interviewed highlighted the perceived surgical benefits even with the unknown long-term outcomes. For example, “We don’t have that data [long-term outcomes ...], but I think for the patients who are truly obese and they are younger than 18, even if they do need another operation when they are 30, the health benefits and psychological benefits potentially of being less heavy over the age group from 14 to 30 let’s say is going to be humongous”. This echoed similar viewpoints in the adolescents who opted for surgery, stating that their lives after surgery could be no worse than what they were experiencing right now. In speaking about the benefits of the surgery, an adolescent participant noted, “I could live a lot longer. I don’t see myself lasting much longer like this”.

As for the paediatricians, they deferred the decision for surgery to a team of experts, as they did not feel they had the capacity to make that kind of judgement. This was articulated as follows, “They [bariatric team] have a protocol, so they’ve decided what is safe. I think I would trust the specialist”.

3- Skipping to surgery

While participants saw a role for adolescent bariatric surgery, there were also implicit reservations in part due to current limitations in the healthcare system. The majority of participants across all stakeholder groups reported that they thought adolescents had to engage in a multi-disciplinary behavioural weight management program prior to being admissible for bariatric surgery. For example, a paediatrician stated, “I don’t think that less than 6 months of lifestyle behaviour is enough to see any kind of improvement, so at least 6 to 12 months of lifestyle behaviour attempted before referring to bariatric surgery”. This attempt at behavioural intervention was to ensure that surgery was absolutely necessary to achieve significant weight loss. However, an opposing view by some of the bariatric surgeon was that behaviour lifestyle intervention has been shown to be largely ineffective and therefore not ideal to have as a surgical pre-requisite. For example, “some places have requested that they have followed a supervised diet and so on. We know that those are not treatments that are effective, so why would we put it as a condition to undergo a treatment that is not effective in order to prove that they are a candidate?”

Concurrently, the bariatric surgeons, healthcare administrators, and paediatricians viewed the current approach to obesity prevention and management as less than ideal. Paediatricians expressed a lack of available and accessible resources to assist their patients with weight management. As stated by a paediatrician, “I don’t have a dietitian. I think there’s a dietitian at the [clinic] for kids under 5, but otherwise, there is a dietitian who works here part time, but she’s private and I don’t know how easy it is to get an appointment”. This was equally reflected in the healthcare administrators’ results, whereby they recognized that the system is not currently offering the services needed for this chronic condition. “We have programs for youth, but when it comes to physical health and obesity there really is a very, very large gap”. This gap in healthcare described by paediatricians and healthcare administrators was reflected in the experiences by adolescents who shared previous behavioural weight management attempts that were of poor quality and largely self or parent directed. One adolescent mentions “in secondary 5 I tried to do a water fast. It did not really work because like I was successful for approximately three days on just water, but it was not that easy. Plus it gave me a headache.” They felt tired of failing and believed bariatric surgery was their last chance. They felt that “it shouldn’t be your first choice to do it. You should try other things before [...] if there’s nothing

else I'd say it's best to do it as a final resort". Thus patients find themselves deciding on surgery without necessarily having been through a quality weight management program.

When taken together, there was a general perception among the professionals that offering bariatric surgery in the current context means potentially skipping a key step in the pathway that could prevent the need for surgery, as expressed in the following statement, "so to push for surgery for everybody because nothing else works, but the only reason nothing else works is because we are not doing it right-then no, you are going to have a hard time convincing me to just give up on this and go straight to that".

4- Optimising healthcare spending

A key narrative related to the availability of behavioural weight management programs was how to optimise healthcare spending. Healthcare administrators reported being challenged by operating in a single payer system where each dollar spent should ideally contribute to increasing accessibility according to government priorities. In the absence of obesity prevention and management programs, they argued that perhaps funding such initiatives would be financially more efficient than an adolescent bariatric program.

These participants noted that bariatric care is very resource intensive and benefits a small number of patients, for example "you know it's [bariatric surgery] complex, it takes a complete team, and it won't be many individuals [patients] per year, but it will be very expensive anyways per person because these are very complex cases when you end up doing surgery with adolescents." A proposed solution would be to centralise bariatric surgery in one location: "We thought it was probably better to refer those youth to a centre that would consolidate all of the demands in Quebec". Another consideration was the source of the funds and whether it should be included in the budget of chronic disease management, family and youth, or a special government mandate "because the chronic disease program in the adult is one budget and a direction that is different from the pediatric program and there was a lot of discussion as to where the money should come from for childhood obesity", as explained by a healthcare administrator. Therefore, the nature of obesity management made for difficult decision-making regarding allocation and spending of money. This was a topic that was not addressed by the other participant groups.

Discussion

Our study found agreement among all stakeholder groups that adolescent bariatric surgery was considered acceptable in patients that were perceived as being medically urgent. This was defined as either a high BMI and/or weight-related co-morbidities. Other considerations that were mentioned were the ability to consent for the surgery, demonstrating an understanding of the surgical implications, having completed puberty, and evidence of commitment to behavioural weight management. This finding demonstrates a shift in acceptance of adolescent bariatric surgery from previous research, where a significant percentage of healthcare providers were resistant to the idea (Iqbal et al., 2009; Woolford et al., 2010). This may be due to the increasing evidence reporting positive outcomes in adolescent patients at five years post-surgery (Inge et al., 2019) and findings that the procedure is safe in accredited centres (Altieri et al., 2018).

The description of patients who should be eligible for surgery in our study is consistent with another study where participants cite a BMI over 40kg/m² or a BMI of 35kg/m² with the presence of co-morbidities as being a minimum criteria (Penna et al., 2014). Interestingly, when comparing the proposed eligibility criteria reported in our study to the recent American Society for Metabolic and Bariatric Surgery guidelines, they are largely congruent except for the ability of the patient to consent and completion of puberty. While patients should ideally be in a position to provide assent or consent, the guidelines do not list this as a contraindication. Similarly, the guidelines state that the current evidence suggests bariatric surgery has no reported adverse effects on puberty, and thus it is not necessary to wait until patients are post-pubertal (Pratt et al., 2018). Both of these criteria appear to be an effort on the part of the professionals to protect the vulnerable pediatric patient.

Indeed, our study found that the relative importance attributed to the lack of long-term data on adolescent bariatric surgery was different between the stakeholder groups. Bariatric surgeons and adolescents opted to focus on the positive short-term outcomes and perceived these as outweighing the potential negative side-effects of surgery or denying surgery until the adolescent becomes an adult. In previous research, bariatric surgeons have expressed greater acceptance of using bariatric surgery as a treatment option in comparison to other healthcare providers (Bailey et al., 2013). As for the adolescents, focusing on the benefits of the surgery

while minimizing the associated risks has also been documented in the literature (Doyle et al., 2018) and is unsurprising given their final decision to undergo the procedure.

Comparatively, paediatricians preferred to defer the final decision to more 'expert' healthcare providers, while healthcare administrators were the most risk adverse and conservative in their perceptions. When it comes to healthcare decisions in pediatrics, the principal intent is to act in the best interests of the child (Ross, 2019). As a vulnerable population, there is considerable effort made to ensure that treatment decisions are carefully evaluated and that the anticipated benefits outweigh the potential risks (Ross, 2019). However, even when there is substantial research demonstrating the safety and efficacy of a treatment option, changes in perceptions and behaviours of healthcare providers do not automatically follow. Using another chronic disease as an example, there is ongoing perception among certain healthcare providers that inhaled corticosteroids for the management of asthma could have a negative impact in children and thus not prescribed (Cabana 2000) despite evidence showing the drugs' safety (Pedersen, 2006). Therefore, the hesitancy towards bariatric surgery based on the lack of long-term evidence may signal some deeper, implicit beliefs about pediatric weight management that may not be resolved simply with 'more research'. When it comes to obesity management, there is evidence that demonstrates how implicit negative attitudes towards individuals living with obesity can impact the care that is provided to the patient. This could happen by not using patient-centered communication, beliefs that the patient will be less adherent, or attributing other symptoms to obesity and not referring the patient for further tests (Phelan et al., 2015).

While the participants in our study perceived adolescent bariatric surgery as largely acceptable, there was reluctance by paediatricians and healthcare administrators to move in that direction because of the existing gaps in obesity prevention and management programs. Indeed, the scarcity of Canadian comprehensive multi-disciplinary programs has been previously documented (Ball et al., 2011), which means the burden of obesity management falls principally on primary care providers like paediatricians. However, these healthcare providers find that the lack of resources is an important barrier to optimal care (Story et al., 2002). Qualitative research with adolescents similarly noted the perception that there was a gap in treatment for their age group (Reece, Bissell, & Copeland, 2016). The implication is that funnelling youth towards bariatric surgery may be hasty given the healthcare context. While the adolescent participants did not note a lack of services available to assist them in weight

management, their description of previous behavioral weight management attempts, which were mostly of poor quality and not supported by any evidence, like doing a water fast, appears to support the assertion of the pediatricians and healthcare administrators interviewed.

Another key finding from this study that was raised primarily by the healthcare administrators is the limitation of provincial public health care systems, where finite resources are obstacles to meeting the multiple needs of obesity prevention and management. Since bariatric surgery is resource intensive and recommended for only a small portion of patients living with obesity, it may not be preferred to allocate the funds to such an approach instead of more accessible, behavioural programs targeting a larger audience. If long-term savings is important, economic modeling of cost-effectiveness of bariatric surgery in the US context has found that it becomes cost-effective at 5 years post-surgery in comparison to no intervention (Klebanoff et al., 2017). In adults, it was found that when comparing bariatric surgery with behaviour lifestyle intervention, patients from the former group had lower drug costs at seven years post-surgery until 20 years post-surgery (Neovius et al., 2012). Therefore, while the investment in adolescent bariatric surgery might seem high for the anticipated volume of patients, the potential for long-term savings that could be re-invested in expanding quality behaviour lifestyle interventions may serve as a rationale for selecting this pathway. In fact, these two management approaches should not be seen as exclusive to each other. As it was previously argued, if society is ready to support irreversible surgery for adolescents and to invest money into this procedure, we must also be demanding high quality programs that teach adolescents living with obesity the necessary skills and knowledge to be successful (Barlow, 2004).

Since snowball sampling was used to increase the number of participants in this study, one of the limitations of the research is that the majority of participants may have belonged to group of individuals that shared a similar interest in obesity or were familiar with adolescent bariatric surgery. This may explain the positive perceptions of bariatric surgery found in our study and like all qualitative research, may not be generalised to other contexts. However, this research presents an opportunity for future studies to examine whether the findings are applicable more broadly in the Canadian context, and target additional participant groups including parents and family doctors. Another avenue for research is examining whether intervening during adolescence versus young adulthood has superior impact on health

outcomes and provides increased long-term healthcare savings to justify the procedure in adolescents.

In conclusion, this study found that perceptions of adolescent bariatric surgery were generally positive across all four stakeholder groups. However, differences did exist in terms of perceived acceptable risks and benefits, with adolescents and bariatric surgeons being more likely to endorse the advantages. Healthcare administrators and paediatricians identified systemic issues that may create barriers to the referral and implementation of bariatric programs for adolescents living with severe obesity. When comparing the perceptions of all participants it was evident that although bariatric surgery was viewed as a viable option the current healthcare context may hastily refer patients to a bariatric program in the absence of having other options available.

Table 7-1 Participant Inclusion Criteria

Participant	Inclusion Criteria
Bariatric Surgeons	<ul style="list-style-type: none">- Fluent in English or French- At least one year experience performing Bariatric surgery in adults and/or children
Administrators	<ul style="list-style-type: none">- Fluent in English or French- ≥ 1 year experience with administrative and budgetary responsibility for some form of weight management care in a formal public structure (e.g., a hospital).- Practice based in Quebec
Pediatricians	<ul style="list-style-type: none">- Fluent in English or French- ≥ 1 year experience and currently practicing- Practice based in Quebec
Youth	<ul style="list-style-type: none">- Fluent in English or French- Up to 21 years old- Involved in weight management for ≥ 1 year- BMI $\geq 95^{\text{th}}$ percentile for age and sex

Table 7-2 Participant demographics

	Pediatricians (n=8)	Bariatric Surgeons (n=5)	Hospital Administrators (n=4)	Adolescents (n=7)
Age (years)	50.4 [31-76]	47.2 [36-60]	44.0 [37-55]	15.7 [14-17]
Sex				
Male	3	5	2	4
Female	5	0	2	3
Body Mass Index (kg/m²)	-	-	-	50.3 [42.0-70.1]
Years of Experience in Current Role	17.0 [2-40]	13.2 [5-21]	5.25 [3-10]	-
Practice Setting				
Urban	8	5	4	-
Sub-urban	0	0	0	-
Rural	0	0	0	-

CHAPTER 8: Conclusion

Summary of Findings and Thesis Implications

The purpose of this thesis was to provide insights into the treatment and management of youth living with severe obesity within Quebec with a focus on adolescent bariatric surgery. Multiple stakeholders were included to gain a better understanding on how individual perceptions contribute to clinical and administrative decisions regarding the management of severe obesity.

Comparison of interviews with paediatricians, bariatric surgeons, healthcare administrators, and adolescents living with severe obesity revealed that there was general agreement that adolescent bariatric surgery is acceptable for medically urgent cases regardless of age. Although our sample was limited to one geographical area, this was a departure from previous studies that showed healthcare professionals as being more reluctant to the idea (Iqbal et al., 2009; Woolford et al., 2010). However, there were some divergent views across the groups. Namely, surgeons and adolescents expressed a more positive outlook on the surgical outcomes, while healthcare administrators were more concerned with the long-term risks and complications. Another disagreement was identified in the surgeon group regarding whether adolescents should undergo a behavioural weight management intervention prior to being considered a candidate for surgery. The high support for demanding a behaviour lifestyle intervention prior to surgery across all four stakeholder groups is not surprising given that such a requirement is consistently reported in the literature as being part of the pathway to surgery (Penna et al., 2014; Woolford et al., 2010).

Despite the fact that only four healthcare administrators participated in the study, they offered an additional dimension to understanding obesity management beyond the clinic by focusing on how decisions are made regarding the availability of different healthcare services. Healthcare administrators expressed reluctance in allocating funds for pediatric bariatric surgery given that it would benefit a small patient population, while noting that there was already a lack of behavioural weight management programs needing to be addressed. This healthcare challenge was reflected in different ways within the paediatrician and adolescent groups.

Paediatricians discussed having limited access to additional public resources like mental health professionals and nutritionists. Therefore, the majority of weight management

interventions were done by themselves and if/when they were unsuccessful they would refer to a surgical program. Adolescents described their attempts at weight management as being poorly informed, transient, and self or parent directed initiatives. Only a small minority had been in an organized program or had worked with professionals other than their family doctor. By comparing the experiences of healthcare administrators, paediatricians, and adolescents, it is clear that bariatric surgery emerges as an acceptable solution for severe obesity in part because there is no alternative option available in the Quebec healthcare context. There is evidence to suggest a gap exists between primary care management and tertiary surgical intervention.

The implications of this are two-fold. First, it highlights the need to improve the availability and accessibility of behavioural weight management programs for families. Prior to reaching the point of needing surgical intervention, patients could benefit from working with behaviour change experts alongside exercise, nutrition, and mental health team members. Having an integrative program specialized in weight management can be an important bridge between primary and tertiary care. Additionally, embedding these programs in the community would help ensure accessibility beyond urban centers and facilitate the integration with other social services that families could benefit from. However, the fact that obesity continues to not be seen as a disease creates an additional challenge to addressing the scarcity of programs for adolescents and adults (Sharma & Salas, 2018). Indeed, the interviews with paediatricians revealed that half of participants viewed it as a risk factor rather than a disease. Although this thesis demonstrated it did not impact the care being delivered by the paediatricians, this view of obesity does implicitly minimise the important impact that excess weight has on adolescents and may be indicative of weight bias among the health professionals.

Findings from the adolescent interviews revealed that although the patients were young, many spent the majority of their life living with obesity and experienced the physical and mental toll of the disease. Spurred by unsuccessful previous weight management attempts, bariatric surgery becomes their sole opportunity for successful weight loss. This is consistent with the health belief model (Champion & Skinner, 2008) which seeks to explain individual change and maintenance of health-related behaviours by examining individual beliefs through multiple constructs. For example in this thesis, adolescents felt that obesity had a significant effect on their physical and mental health, and believed that their condition was only going to get worse. This aligns with perceived severity and susceptibility in the model, whereby the more significant

the health problem is perceived to be and the risk of developing more health conditions, the more likely a person is to take an action. Similarly, when looking at the additional factors for wanting surgery, the potential benefits figured prominently in the interviews with adolescents. From resolution of co-morbidities to improved peer-relationships, these anticipated changes outweighed the potential risk which partially explains their decision to have surgery. Finally, a critical difference between the group of adolescents who wanted surgery and the one who did not was a lack of self-efficacy to lose weight in the former group. Thus when all of the constructs within the individual beliefs are examined, the health belief model is consistent with what was found in the study. However modifying factors such as age, gender, and ethnicity were not explored to see how those impacted the individual beliefs.

Interestingly the factors that are considered and their relative importance varied by individuals. Clinically, this has important implications for healthcare professionals that work with adolescent bariatric surgery patients. Healthcare professionals would be remiss to assume that adolescents have the same goals as they do and that all adolescents have similar rationales. If healthcare professionals consider how adolescents come to make their decisions, they will be better equipped to handle adolescents' satisfaction with the post-surgery outcomes.

Strengths and Limitations

A key strength of this thesis is taking a multi-stakeholder approach. This is the first study to include adolescents who are considering bariatric surgery alongside healthcare professionals. Additionally, the inclusion of healthcare administrators provided insight on how the healthcare system operates and makes decisions, providing deeper context in understanding the individual participant experiences. The advantage of using a multi-stakeholder approach was the ability to identify potential challenges and barriers to providing optimal care for adolescents with severe obesity as well as areas where there is agreement across all groups.

Another strength of this study is the inclusion of an arts-based component in the data collection with adolescents. The creation of body maps allowed the adolescents to take ownership of how their experiences were represented and they were able to highlight the most meaningful aspects through the selection of symbols and words. While some of the adolescents were very forthcoming in the interviews, others opened up more freely when sharing the different elements they had chosen on their maps. This provided richer and more in-depth data.

The thesis also had several limitations. First, all professional participants who were recruited worked in an urban setting where access to hospitals and other tertiary care centres were readily available. As such, it is unclear how healthcare professionals working in more rural settings would view obesity management and the impact on deciding to refer a patient knowing that it would require overcoming geographical distance between the participant's home and the surgical team. Moreover, given that snowball sampling was used to augment the number of participants, those that agreed to the interviews were likely from a similar group of individuals with a specific interest in obesity management. This may explain the generally favourable view towards adolescent bariatric surgery.

Within the adolescent sample, there was only one adolescent who opted to not have surgery. Therefore, it is hard to glean any significant differences between those that desire surgery and those that decide against it.

Another limitation is the selection of the different stakeholder groups. The inclusion of parents could have provided additional insight into the family dynamic when it comes to deciding on bariatric surgery even if the final decision remains with the adolescent. Additionally, paediatricians are not the only group that care for adolescents and the inclusion of family physicians may provide a different perspective.

Future Directions

Based on the findings from this study, there are a number of future areas of research that should be explored. A first step would be to replicate the study with healthcare professionals and administrators Canada-wide to provide a larger sample size and identify how provincial variations in healthcare organisation can impact perceptions of paediatric obesity management.

Moreover, given the qualitative nature of this study, it is not possible to generalise the findings to a broader group of healthcare professionals. Therefore, the Canadian data could be used to develop a survey that would be disseminated to a larger participant sample across Canada. It would be particularly interesting to compare the perceptions regarding adolescent bariatric surgery between Quebec and Ontario given that they both have established programs. Similarly, comparing these two provinces with the rest of Canada will also be telling in how attitudes may shift based on availability of services. Another benefit of deploying a survey is to

include a more diverse group of healthcare professionals. Incorporating the perspectives of family physicians is of high importance as they are often included in caring for adolescents in the absence of paediatricians. Additionally, they provide a unique perspective as they care for patients throughout the lifecycle and can observe how childhood obesity may evolve over time in a patient. Other groups of interest would be mental health professionals, nutritionists, and exercise specialists as they each play a critical role in the management of obesity and may have differing perspectives based on their professional training.

This study interviewed adolescents at the beginning of their bariatric journey. Therefore, a key future study would be to follow these individuals across the 12 to 18 months post-surgery to examine how their perceptions might have changed and whether they feel differently about their decision to go ahead with the surgery. In particular, their expectations pre-surgery and their satisfaction post-surgery regarding weight loss, changes in eating habits, and body shape, would help inform how future adolescent patients are prepared for surgery and how they manage their expected outcomes.

A potential gap in the current study is the absence of parents as part of the stakeholder groups. While adolescents increasingly demonstrate autonomy, parents do continue to play a role even if diminishing in importance (Boutelle et al., 2012). A future study should target this group to better understand how parents frame their role in supporting their adolescent during the surgical process and what type of resources they might need to facilitate this task.

While not the primary focus of this study, healthcare administrators did allude to the complexity of budget allocation and whether obesity should fall under the budget of family health (primary care) or chronic disease management (tertiary care), which prompts a future discussion about how best to transition adolescent bariatric patients from a pediatric centre to an adult clinic. Given the contrast in the medical approach from protecting vulnerable youth to expecting independent adults, this delicate time period requires careful attention to ensure that patients are not lost in the transition process.

Concluding Remarks

This thesis examined how different stakeholders perceived adolescent bariatric surgery. Although there was a generally positive perception regarding bariatric surgery for adolescents it was evident that this perception was inherent to a healthcare context that offered surgery as the

only alternative to behavioural weight management conducted in primary care. Thus, there is a need to expand services for pediatric obesity in order best meet the needs of this population.

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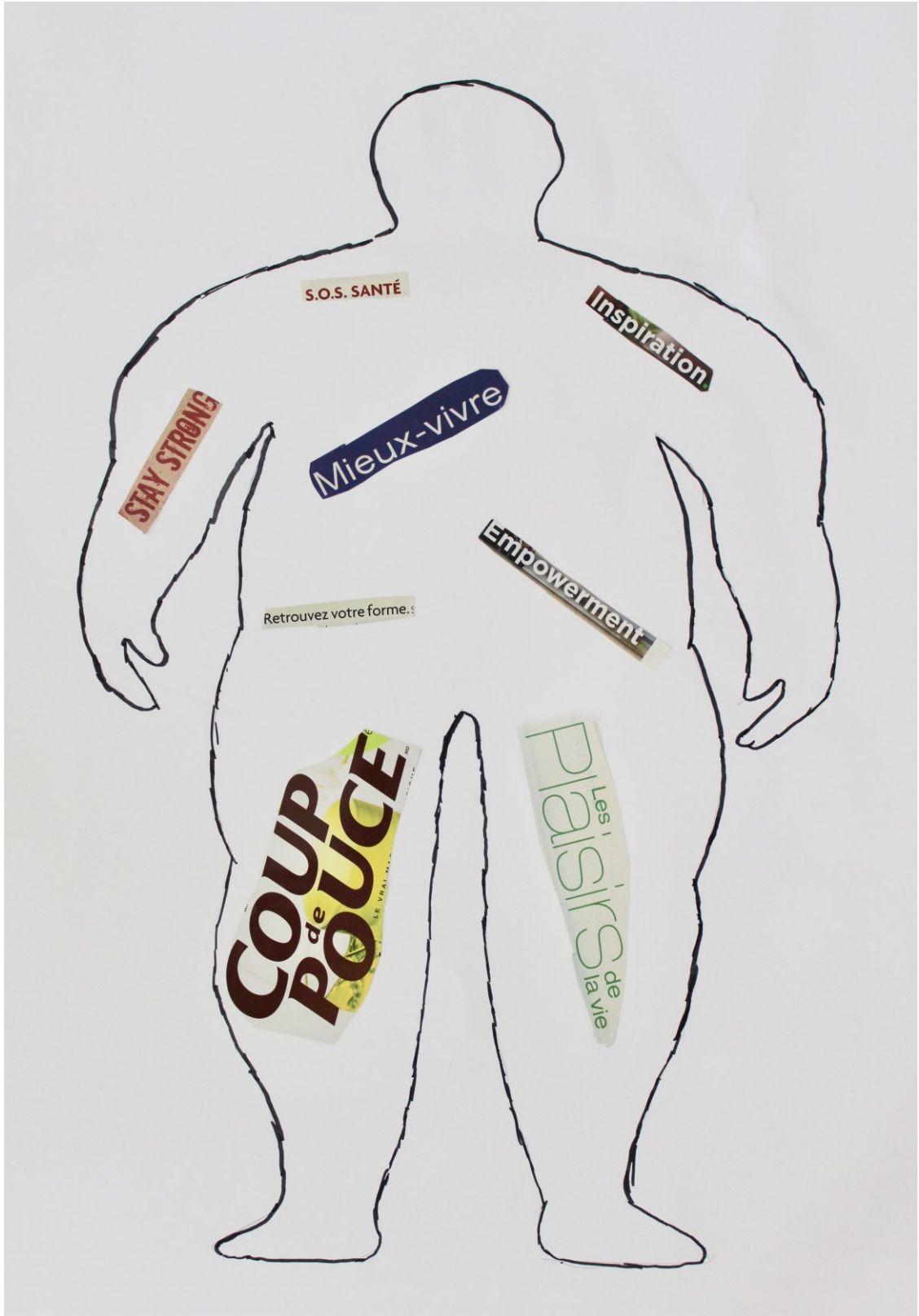
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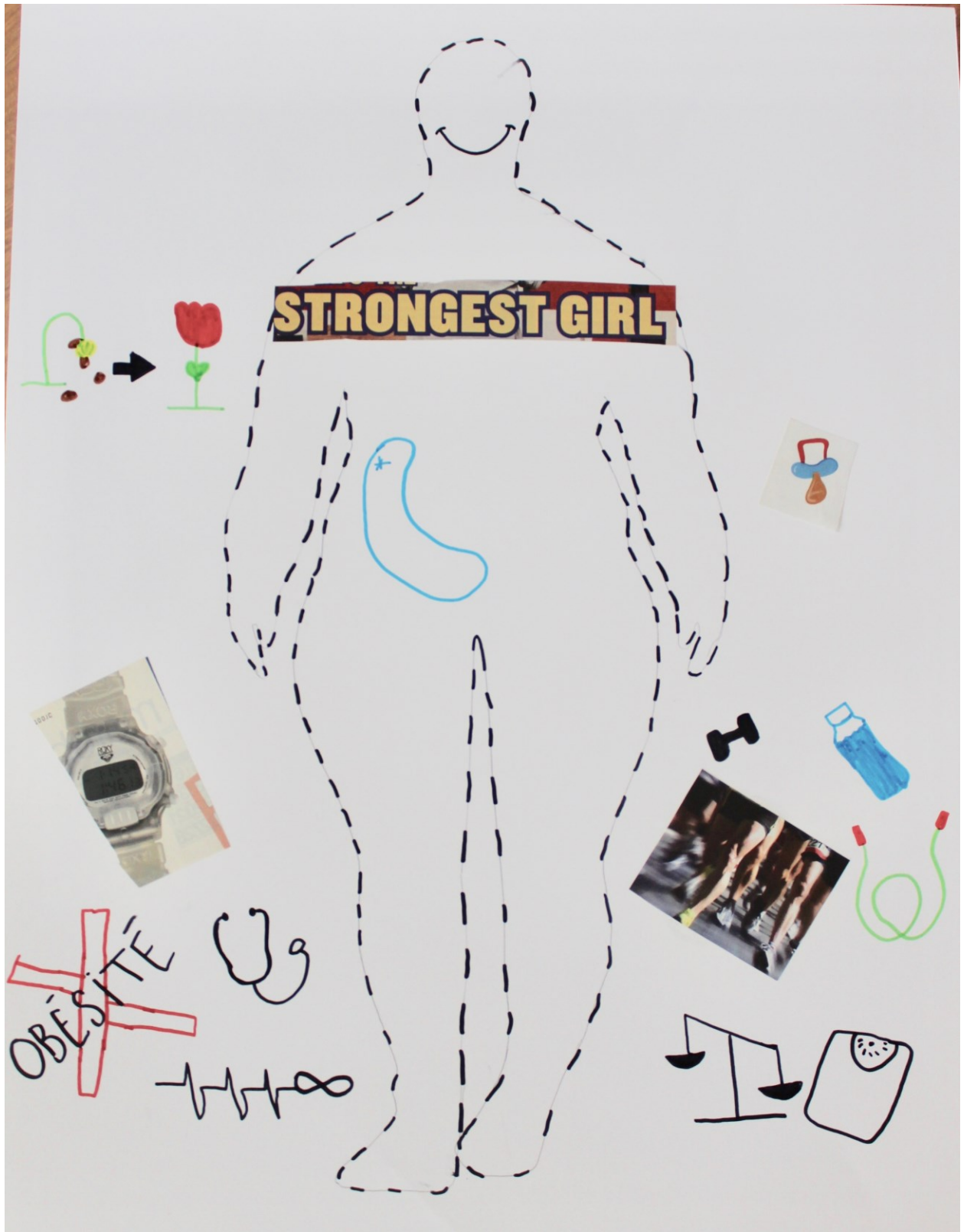
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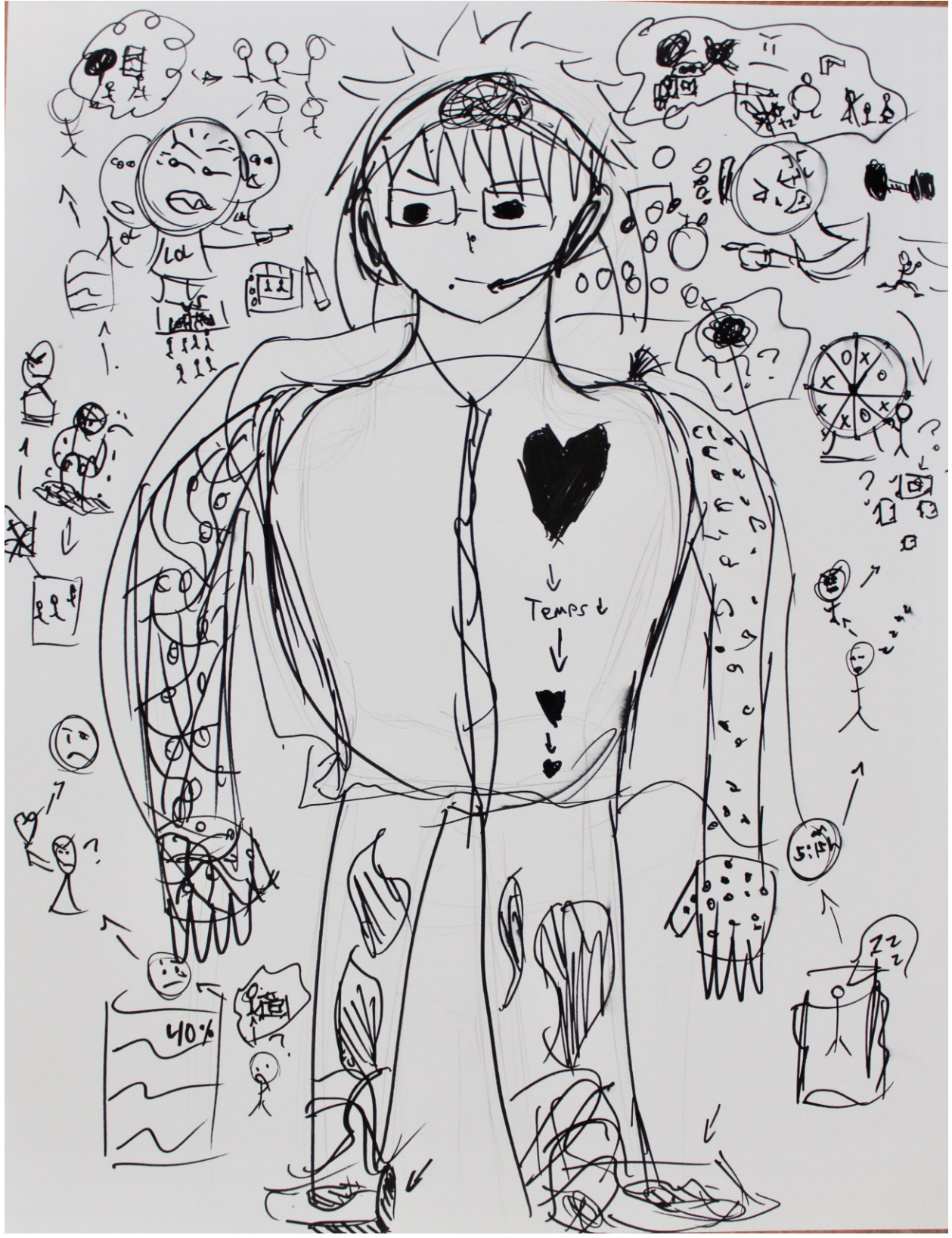
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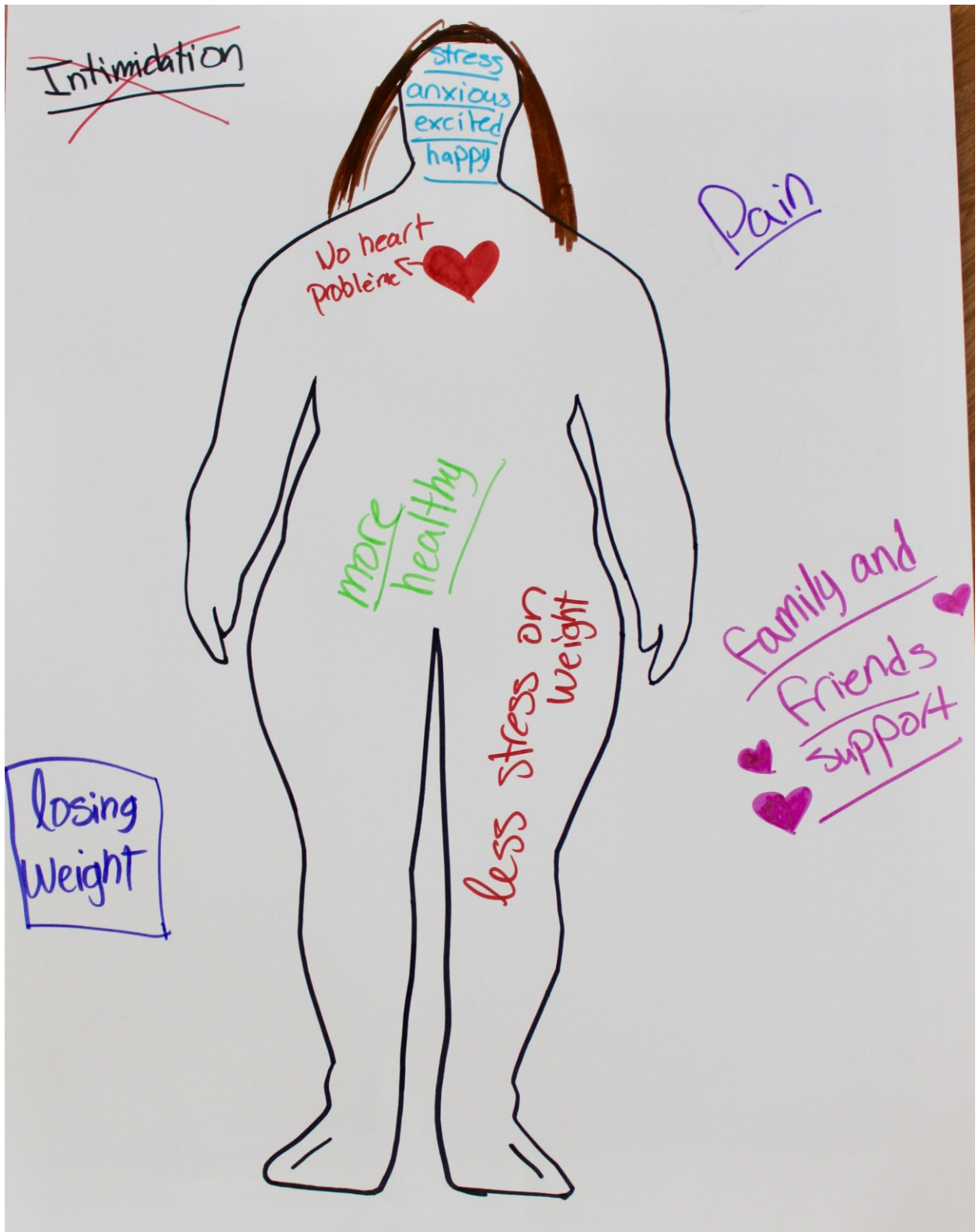
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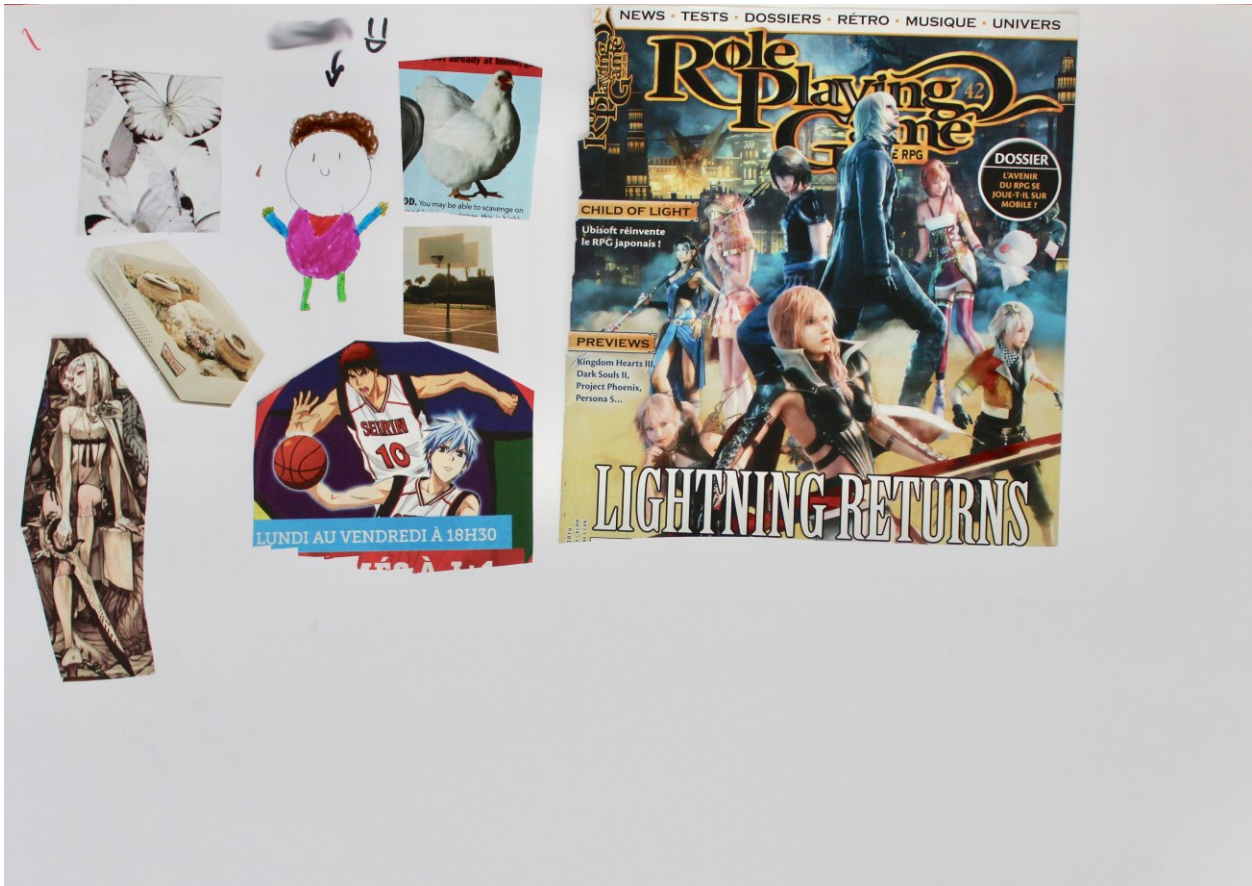
APPENDIX 1: Body Maps from Main Study with Adolescent











Nutritioniste

Endocrinologie

