Experiences of Families With Children Attending a Clinic-Based Weight Management Program

BY

Karyn Roberts

BSN Madonna University, Livonia MI 1995

MSN Grand Canyon University, Phoenix AZ 2012

THESIS

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Defense Committee:

Catherine Vincent, Chair and Advisor
Agatha Gallo
Crystal Patil
Mary Dawn Koenig
Helen Binns, Ann and Robert H Lurie Children's Hospital and Feinberg School of Medicine, Chicago

To my husband, Dave, whose patience, love, and support allowed me to complete this marathon; my children Abigail, Joel and Caleb, who remind me daily why the children I strive to serve are our greatest resource; my parents who inspired me to believe there were no limits if you work hard and put other's first.

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SUMMARY

Childhood obesity rates have increased from 5% in the 1970's to 18.5% today for children aged 2-19 years old. This represents 270% increase in less than 50 years. A recent study projected 57% of today's children will be obese by the time they are 35 years of age. Childhood obesity is the leading chronic illness in the United States and children with obesity have been shown to suffer negative effects on their metabolic, cardiovascular, pulmonary, and psychological health. As with other chronic illnesses, significant disparities exist among children of color and lower socioeconomic status.

Current CDC measures of child body mass index (BMI) are not sufficient in tracking children who suffer from severe obesity, the fastest growing category in childhood obesity. Classifying children accurately in relation to their obesity is important to consider as current research has shown that children with severe obesity suffer the most sequelae from their condition as compared to children who are overweight or with Class 1 obesity. More accurate measures of BMI now exist to better predict adiposity and help identify children with severe obesity—Class 2 and Class 3—defined as BMI $\geq 120^{th}$ percent of the 95^{th} BMI percentile (BMIp95).

Treatment of childhood obesity has shown limited long-term success in reducing BMI and maintaining health even with intensive interventions. Though some interventions show statistically significant reductions in BMI these reductions are often not clinically significant in improving or reversing the physiologic sequelae children with obesity experience. Best practice interventions are focused on multicomponent family-based care addressing behavioral changes in diet, physical activity, decrease in screen time, and improved sleep patterns, however, little data exist to describe how families and children with severe obesity manage their condition daily.

Obesity is a complex disease and current research lacks insight into potential moderators and mediators affecting how families of children with obesity manage day to day.

This dissertation is composed of two publishable manuscripts aimed at understanding the experiences of families of children with obesity who are being treated in a clinic-based setting. Families of children with obesity who are either referred to or seek specialty care may have different needs than families in program-based interventions which tend to be more intensive and short term. The first manuscript in this dissertation is a scoping review of families with children in clinic-based obesity treatment. Twelve articles met inclusion criteria for this review and results described the differences and similarities in care providers and resources, barriers and facilitators to treatment, and gaps in current literature. Barriers and facilitators to treatment focused on structural components specific to the clinic setting and treatment, financial, patient and families, and personal expectations, motivation and behaviors. Limitations noted were related to the lack of data from family members other than mothers, and lack of consistent BMI-related measures identifying children with severe obesity.

The second manuscript is original research. I conducted a qualitative study aimed at: 1) documenting the experiences of families and children with severe obesity who attend a clinic-based treatment program, 2) exploring how families and children manage the treatment of severe obesity on a day to day basis, 3) evaluating the applicability of the family management styles framework (FMSF) to families and children with severe obesity. I conducted individual interviews with 17 parents and 14 children in participant homes or another location chosen by the parent. Children were between 12-17 years of age, were severely obese (BMI $\geq 120^{th}$ percent of the 95^{th} BMI percentile), attend a pediatric weight-management clinic and have had an initial visit and at minimum one follow up clinic visit, spoke English or Spanish and had no

developmental delay. In total 15 families were represented in the data. Interviews were recorded, transcribed, coded, and analyzed using directed content analysis using a modified FMSF.

To the best of my knowledge, this study is the first to apply the FMSF to obesity and one of only a handful to apply the FMSF to the perspectives of children. Results supported the application of the FMSF to children with severe obesity. Both parents and children described the day to day management as challenging and impacted parent-child and sibling relationships. Both described the need for sustained support and coaching in meeting daily physical activity requirements, and related stories of weight-based stigma they experienced. Further, parents and children's' views were mostly aligned except in their view of how family attitudes and actions did or did not support the child with obesity and the existence and effectiveness of daily routines. The results suggest the need for interventions to address the need for increased social support for children with severe obesity aimed at reducing weight-based stigma and physical activity recommendations tailored to individual children's' needs.

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A Scoping Review of Families with Children in Clinic-Based Obesity Treatment

Childhood obesity is a complex chronic disease affecting families with increasing prevalence both in the United States (US) and globally. Currently, 18.5% of US children ages to 19 years are obese (Hales, Carroll, Fryar, & Ogden, 2017; Skinner, Ravanbakht, Skelton, Perrin, & Armstrong, 2018). Obesity disproportionately affects children of lower socioeconomic status and of color (Hales et al., 2017; Lee, Andrew, Gebremariam, Lumeng, & Lee, 2014; Skinner et al., 2018). Of all Hispanic youth 45.9% are overweight or obese, followed by African American (37.8%), White (29.9%), and Asian (23.2%) (Hales et al., 2017; Skinner et al., 2018). The economic cost of childhood obesity is high and increases with age. Total projected direct medical costs over the lifetime for the current number of only 10-year-olds with obesity is approximately $14 billion above projected medical costs for their normal weight peers (Finkelstein, Graham, & Malhotra, 2014). There is a need for effective interventions for children with obesity and their families.

Child obesity treatment strategies include a focus on family-wide diet, physical activity and behavior change (Janicke et al., 2014; Katzmarzyk et al., 2014). Reviews of obesity intervention trials report very modest body mass index (BMI) improvement, (Peirson et al., 2015; van Hoek, Feskens, Bouwman, & Janse, 2014) however, only a few studies report on >1 year outcomes (Al-Khudairy et al., 2017). There is an increasing awareness that successful childhood obesity treatment must be directed at the family and identify and address limitations to behavior change imposed by genetic and prenatal risks, mental health issues, and social determinants of health (e.g., living environment, education, resources).

Child obesity program care delivery is quite varied, ranging from individualized patient and family care provided by a multidisciplinary team at episodic visits to participation in

structured group programs with pre-determined content and visit frequency (Al-Khudairy et al., 2017; Oude Luttikhuis et al., 2009). Families who seek medical care for their child with obesity in clinic-based treatment settings as opposed to program-based interventions may have differing needs and challenges. Additionally, the treatment structure may limit the ability to identify and address the barriers to behavior change. Clinic-based treatment for this review is defined as care provided in an outpatient or tertiary care clinic with at least one primary care provider, (MD, Advanced Practice Nurse [APN], or Registered Dietician [RD]). The primary goal of the clinic being to treat children with obesity as a diagnosis and who either currently experience or are at risk of sequelae as a direct result of the child's obesity diagnosis.

Data are limited describing families of children with obesity in individualized, clinic-based treatment and how they manage their child's condition daily. Few studies exist which describe families and children in program-based obesity treatment and focus on reasons for attendance/nonattendance, barriers/facilitators to program adherence, and satisfaction with program components (Kelleher, Harrington, Shiely, Perry, & McHugh, 2017; Sallinen, Schaffer, & Woolford, 2013). Program-based obesity treatment is typically more intensive (i.e., meeting more than once per week), delivered over a short period of time (i.e., over 3- 6 months), and have a defined start and stop time (Golley, Magarey, Baur, Steinbeck, & Daniels, 2007; Janicke et al., 2014; Taveras et al., 2017). Though these interventions may include a clinic visit, the typical design includes group meetings, social work visits, nutrition classes and an exercise component. Results of current interventional research provide little data or understanding of why outcomes are poor and short lived. Describing and understanding the perspectives of families with children in clinic-based obesity treatment can inform research and practice and potentially improve long term outcomes for children with obesity.

This review aims to explore the scope of evidence reported by families of children with obesity who have received out-patient clinic-based obesity treatment. Specifically, the review aims to answer the following question; What is known about existing studies in clinic-based child obesity treatment as reported by families and children?

Methods

Scoping Review

A scoping review was conducted, using the framework described by Arksey and O'Malley (2005). The review process employs an iterative process to comprehensively identify and review relevant literature, identify key concepts, and identify gaps in existing research (Arksey & O'Malley, 2005; Levac, Colquhoun, & O'Brien, 2010). We employed Arksey and O'Malley's (2005) five-step process for scoping reviews: a) identification of the research question, b) identification of relevant studies, c) study selection, d) charting the data, and e) collating, summarizing and reporting the results.

Identification of Relevant Studies

A systematic search strategy was conducted in February 2018 to identify relevant studies in the following databases PubMed, CINAHL, Scopus, PsycINFO, Cochrane Reviews, and Embase and resulted in 2,011 records. There were no date limits placed on the search. Search strategies were database specific using the Boolean terms 'AND' and 'OR' as appropriate, and a combination of the following key words or MeSH terms: evaluation, pediatric, obesity, child, parents, experiences, family, treatment, intervention, and therapy. An ancestral search of reference lists from seminal papers resulted in 26 additional records. To ensure no recent studies were missed, an updated search with date limits of 2017-2019 was conducted in January of 2019. This search resulted in no additional studies.

Study Selection

Articles were identified, screened, and selected for further review in three stages: a) titles and citations, b) abstracts, and c) full text or article. Figure 1 details study selection and exclusion criteria at each stage in the process. Inclusion and exclusion criteria were identified a priori. Studies were included if investigators reported parent, family, or child perspectives of being involved in clinic-based obesity treatment, and barriers or facilitators to success in obesity treatment from the parent/family/child perspective, including reasons for failure to return to clinic and satisfaction to care. There was no age limit placed on the child involved in treatment. Studies were excluded if they were not in English, did not focus on families and children in clinic-based treatment, and did not identify concepts related to barriers and facilitators to treatment. Twelve articles qualified for final inclusion in this scoping review.

Charting the Data

Data were extracted from the included articles and placed into tables to facilitate analysis. Participant characteristics across studies are summarized in Table I and includes; sample size, child age (range and mean), child sex, child BMI-related measures and comorbidities, adult/other participant relationship to the child, and race/ethnicity of participants. The study design, providers and setting, measures, and results are presented in Table II. Table III and Table IV report study concepts identified to be barriers and facilitators to treatment respectively.

Collating, Summarizing, and Reporting the Results

Participant Characteristics

Participants across studies were mixed. Table I summarizes the characteristics of participants. Parents or caregivers were sampled in the majority of studies (Barlow & Ohlemeyer, 2006; Campbell, Benton, & Werk, 2011; Hampl et al., 2013; Sallinen Gaffka, Frank,

Hampl, Santos, & Rhodes, 2013; Stewart, Chapple, Hughes, Poustie, & Reilly, 2008), followed by a combination of parents/caregivers and the child (Banks, Cramer, Deborah, Shield, & Katrina, 2014; Owen, Sharp, Shield, & Turner, 2009; Rhodes et al., 2017; Skelton, Martin, & Irby, 2016), only children (Murtagh, Dixey, & Rudolf, 2006; Sousa, Gaspar, Fonseca, & Gaspar, 2017), and siblings of children in treatment were sampled in one study (Bishop, Irby, & Skelton, 2015).

Sample size in each study was dependent on study design and aims. Ages of children included in studies ranged from 1-20 years old, with five studies failing to report mean age (Banks et al., 2014; Bishop et al., 2015; Murtagh et al., 2006; Owen et al., 2009; Stewart et al., 2008). Parent/caregiver participants were mainly mothers as opposed to fathers or 'other' caregivers (Banks et al., 2014; Bishop et al., 2015; Campbell et al., 2011; Hampl et al., 2013; Owen et al., 2009; Sallinen Gaffka et al., 2013; Skelton et al., 2016; Stewart et al., 2008), with no data provided on the characteristics of parents of caregivers in three studies (Barlow & Ohlemeyer, 2006; Murtagh et al., 2006; Sousa et al., 2017). Sampling also included a caregiver other than a parent (i.e., grandparent or 'other') (Banks et al., 2014; Campbell et al., 2011; Owen et al., 2009; Stewart et al., 2008) and a sibling (Bishop et al., 2015). In all studies but one (Murtagh et al., 2006), the majority of children with obesity were female, however, Bishop and colleagues did not describe the sex of participants (Bishop et al., 2015).

Race/ethnicity of study participants was not included in five studies (Banks et al., 2014; Murtagh et al., 2006; Owen et al., 2009; Sousa et al., 2017; Stewart et al., 2008), with White or non-Hispanic White being the dominant race in the majority of studies reporting these data (Barlow & Ohlemeyer, 2006; Bishop et al., 2015; Campbell et al., 2011; Rhodes et al., 2017; Skelton et al., 2016), followed by Black (Hampl et al., 2013; Sallinen Gaffka et al., 2013). BMI

of children in treatment was reported in all except two studies (Owen et al., 2009; Stewart et al., 2008). Investigators used inconsistent measures when reporting BMI in the majority of studies (N = 10) (Banks et al., 2014; Barlow & Ohlemeyer, 2006; Bishop et al., 2015; Campbell et al., 2011; Hampl et al., 2013; Murtagh et al., 2006; Rhodes et al., 2017; Sallinen Gaffka et al., 2013; Skelton et al., 2016; Sousa et al., 2017). Variations of measures used were BMI percentile data based on the CDC and/or WHO growth charts (Banks et al., 2014; Campbell et al., 2011; Sallinen Gaffka et al., 2013), BMI along with BMI z-score (Hampl et al., 2013; Rhodes et al., 2017; Skelton et al., 2016; Sousa et al., 2017), only BMI z-score (Barlow & Ohlemeyer, 2006; Murtagh et al., 2006), and the mean and raw BMI score in addition to percentile (Bishop et al., 2015). Data describing comorbidities of children were not included in the majority of studies (Banks et al., 2014; Hampl et al., 2013; Murtagh et al., 2006; Owen et al., 2009; Rhodes et al., 2017; Sallinen Gaffka et al., 2013; Sousa et al., 2017; Stewart et al., 2008), while children in the remaining studies had at least one comorbidity related to their obesity (Barlow & Ohlemeyer, 2006; Bishop et al., 2015; Campbell et al., 2011; Skelton et al., 2016).

Study Characteristics

Studies included were a mix of qualitative (Banks et al., 2014; Bishop et al., 2015; Murtagh et al., 2006; Owen et al., 2009; Sallinen Gaffka et al., 2013; Skelton et al., 2016; Stewart et al., 2008), quantitative studies (Rhodes et al., 2017; Sousa et al., 2017), and mixed methods (Barlow & Ohlemeyer, 2006; Campbell et al., 2011; Hampl et al., 2013). Table II shows details regarding individual study measures and results. Seven studies were conducted in the US (Barlow & Ohlemeyer, 2006; Bishop et al., 2015; Campbell et al., 2011; Hampl et al., 2013; Rhodes et al., 2017; Sallinen Gaffka et al., 2013; Skelton et al., 2016) 3 in England (Banks et al., 2014; Murtagh et al., 2006; Owen et al., 2009), and one each in Scotland (Stewart et al., 2008)

and Portugal.(Sousa et al., 2017). Eleven of the studies were conducted in a tertiary care clinic in large urban settings (Banks et al., 2014; Barlow & Ohlemeyer, 2006; Bishop et al., 2015; Campbell et al., 2011; Hampl et al., 2013; Owen et al., 2009; Rhodes et al., 2017; Sallinen Gaffka et al., 2013; Skelton et al., 2016; Sousa et al., 2017; Stewart et al., 2008), while Murtagh and colleagues conducted their study in a community-based clinic (Murtagh et al., 2006).

All children were seen in an outpatient clinic setting for treatment, however the provider delivering the care varied. Provider specialty was not reported in three studies (Hampl et al., 2013; Murtagh et al., 2006; Rhodes et al., 2017). Five clinics included a MD, RD, and a psychologist or behavioral health counselor as part of multidisciplinary care (Barlow & Ohlemeyer, 2006; Bishop et al., 2015; Campbell et al., 2011; Sallinen Gaffka et al., 2013; Skelton et al., 2016). In addition to a MD, RD and psychologist, two of the clinics also provided a physical therapist (PT) or exercise specialist (ES) (Owen et al., 2009; Sousa et al., 2017). Three clinics were staffed by a MD, RD, and PT or ES (Hampl et al., 2013; Murtagh et al., 2006; Rhodes et al., 2017). One clinic had a medical provider APN or MD and a RD (Banks et al., 2014). One clinic had a lone provider who was a RD (Stewart et al., 2008). None of the clinics reported having nursing as a component of their models of care, with the exception of an APN as a provider in one study (Banks et al., 2014).

Barriers and Facilitators to Treatment

A summative content analysis approach was used to identify key concepts during the collating and summarizing of the data from the studies (Hsieh & Shannon, 2005). In summative content analysis the key words/concepts are derived from both the interest of the researcher and review of pertinent literature (Hsieh & Shannon, 2005). Barriers and facilitators were identified during the review process as salient as they impact adherence, attrition and outcomes of

interventions. Barriers and facilitators to treatment outcomes were synthesized into the following categories by the authors after analyzing data reported in each study. The categories 1) structural; 2) financial; 3) patient and family; and 4) personal behaviors, motivation and expectations, and are summarized in Tables 3 and 4.

Barriers: Structural. Structural barriers refer to: clinic location; accessibility to the treatment site; clinic hours and scheduling; cultural appropriateness of treatment; and content and acceptability of both the intervention and the clinicians who deliver the intervention. The most common structural barriers reported were: dissatisfaction with the program content itself or the expressed concern that the clinic did not meet expectations in terms of service delivery (Banks et al., 2014; Barlow & Ohlemeyer, 2006; Hampl et al., 2013; Owen et al., 2009; Sallinen Gaffka et al., 2013), location of clinic and the distance to travel or problems with transportation (Barlow & Ohlemeyer, 2006; Bishop et al., 2015; Hampl et al., 2013; Sallinen Gaffka et al., 2013), scheduling conflicts (i.e., inconvenient clinic hours with work and school) (Barlow & Ohlemeyer, 2006; Hampl et al., 2013; Sallinen Gaffka et al., 2013); length of visits (i.e., too long or short) and visit frequency (i.e., too often or too few) (Barlow & Ohlemeyer, 2006; Bishop et al., 2015; Sallinen Gaffka et al., 2013); negative experiences with providers (Murtagh et al., 2006; Owen et al., 2009; Stewart et al., 2008); and the lack of psychological support (Banks et al., 2014; Owen et al., 2009). Barriers specific to clinic recommendations were unrealistic food guidelines (Murtagh et al., 2006); lack of specific diet advice including structured meal plans and recipes (Banks et al., 2014; Owen et al., 2009); and the program not offering rewards.(Hampl et al., 2013)

Barriers: Financial and patient and family. Financial barriers identified were either no insurance coverage or services needing to be paid for out of pocket (Barlow & Ohlemeyer, 2006;

Hampl et al., 2013; Sallinen Gaffka et al., 2013); excessive costs related to exercise advice, either due to pay for play sports or gym memberships (Banks et al., 2014; Owen et al., 2009; Sallinen Gaffka et al., 2013); parents missing work to attend visits, (Bishop et al., 2015; Skelton et al., 2016) and cost to purchasing healthy food (Campbell et al., 2011; Owen et al., 2009). Barriers identified related to patient and family were children missing school and parents balancing work and other demands (Banks et al., 2014; Barlow & Ohlemeyer, 2006; Bishop et al., 2015; Campbell et al., 2011); parents feeling guilty in restricting their child's food intake (Owen et al., 2009); and undermining behavior change efforts by either the other parent or other family members (Stewart et al., 2008).

Barriers: Personal behaviors, motivation and expectations. Barriers identified related to personal behaviors, motivation, and expectations specific to children were: children were either not involved in the decision to attend treatment, or were not ready to make behavior changes (Banks et al., 2014; Barlow & Ohlemeyer, 2006); low self-esteem and low self-confidence (Murtagh et al., 2006); and low self-efficacy (Owen et al., 2009). Parents described their personal motivation as a barrier to success for their children (Barlow & Ohlemeyer, 2006; Bishop et al., 2015; Owen et al., 2009; Sousa et al., 2017). Parents reported the lack of motivation to make recommended changes in their or their child's diet (Campbell et al., 2011; Hampl et al., 2013) and parents were not ready to make necessary lifestyle changes (Barlow & Ohlemeyer, 2006). Parents endorsed inherent difficulties in making dietary changes as well as changing eating behaviors like eating less and eating slower (Bishop et al., 2015). Parents also identified difficulties in adhering to the program specifics (Sousa et al., 2017) and either did not implement specific changes or could not identify ways they might change their lifestyle long term (Owen et al., 2009). Mismatched parental expectations and clinic expectations regarding

treatment and care provided were also barriers (Banks et al., 2014; Barlow & Ohlemeyer, 2006; Hampl et al., 2013).

Facilitators: Structural. Structural facilitators were sometimes the direct opposite of the barriers identified. For example, specific meal plans, additional clinic locations and more frequent appointments, and financial support for parking and transportation costs. Participants in 7 studies reported the following as facilitators to success. Tailoring advice regarding diet and exercise for the individual child and family, taking into account the child's age/development and the parents ability to accommodate recommendations; and giving detailed plans to follow by providers (who were seen as the one's with the knowledge and expertise) (Banks et al., 2014; Bishop et al., 2015; Campbell et al., 2011; Owen et al., 2009; Rhodes et al., 2017; Sallinen Gaffka et al., 2013; Skelton et al., 2016). Participants reported they desired to have motivational techniques and continual support by providers even after treatment was complete (Campbell et al., 2011; Murtagh et al., 2006; Owen et al., 2009; Sousa et al., 2017; Stewart et al., 2008), and more frequent appointments (Owen et al., 2009; Sallinen Gaffka et al., 2013). Participants suggested group support and/or classes where children and/or families could interact would help facilitate success (Sallinen Gaffka et al., 2013; Skelton et al., 2016). Families wanted providers to be more supportive and relaxed as well as more culturally sensitive (Owen et al., 2009; Sallinen Gaffka et al., 2013) and would have liked an orientation to the clinic and general information prior to starting treatment (Skelton et al., 2016). Parents reported that having some type of reward during treatment would also be beneficial but were not specific on what that reward would be (Sallinen Gaffka et al., 2013). Finally, families wanted additional or extended clinic hours along with additional locations closer to where families lived (Skelton et al., 2016).

Facilitators: Finances and patient and family. Facilitators related to finances were providing financial assistance with both transportation and parking (Sallinen Gaffka et al., 2013; Skelton et al., 2016), and assistance and resources related to exercise recommendations (i.e., gym memberships) (Skelton et al., 2016). The most common facilitators to success related to patient and family were increased family cohesion and connectedness (Bishop et al., 2015; Rhodes et al., 2017; Skelton et al., 2016; Sousa et al., 2017; Stewart et al., 2008), and support—unconditional and ongoing—of the whole family (i.e., significant other, nuclear family and extended family) (Campbell et al., 2011; Murtagh et al., 2006; Rhodes et al., 2017; Stewart et al., 2008). Participants also valued having an additional voice outside of the family to give legitimacy to the family role in new behaviors (Banks et al., 2014).

Facilitators: Personal behaviors, motivation and expectations. Facilitators related to personal behaviors for the child were: the increase in the child's self-esteem and self-efficacy from seeing weight loss, autonomy and support in making healthy choices, and making behavior changes in exercise and diet (Bishop et al., 2015; Campbell et al., 2011; Murtagh et al., 2006; Stewart et al., 2008). Additional facilitators were adherence to specific program recommendations related to physical activity and diet changes by children and families (Owen et al., 2009; Skelton et al., 2016; Sousa et al., 2017). Facilitators important for setting expectations and staying motivated were: having children actively involved in the decision to attend treatment (Banks et al., 2014), goal setting for realistic weight loss that also reflected specific numeric goals and at a more rapid pace (Rhodes et al., 2017; Skelton et al., 2016), and the desire to fit in socially (Murtagh et al., 2006).

Discussion

Our review of the literature identified 12 studies that have a key component of obesity program evaluation, namely data collected from the family and patient perspectives. To our knowledge this is the first scoping review to explore the scope of evidence about what is known about existing studies in clinic-based child obesity treatment as reported by families and children. Participants across studies were primarily mothers. BMI-related measures used across studies were inconsistent and there were no studies that specifically focused on youth with severe obesity. Families reported experiencing a lack of tailored recommendations in the treatment setting which reflected their individual family needs and available resources. Barriers and facilitators to success reported by families were often the direct opposite of one another.

Perspective of Families and Children in Treatment

Maternal perspectives dominated the findings throughout this review, and though children in treatment were included in some of the studies, these data were sparse. Data from fathers is also minimal, as is data from siblings or other family members in the household. Understanding the perspectives of other family members (i.e., fathers, siblings, etc.) are important to pursue as best practice recommendations for treatment of children with obesity is targeted at comprehensive behavioral family lifestyle interventions (Janicke et al., 2014; Whitlock, O'Connor, Williams, Beil, & Lutz, 2010). Studies examining father's involvement in children with other chronic illnesses have supported greater paternal involvement to be associated with more favorable treatment adherence and quality of life among children (Wysocki & Gavin, 2006). Improved engagement and understanding how fathers influence health behaviors in the home and/or support treatment recommendations for children has been identified as an important area for future study (Allport et al., 2018). Fathers' experiences are

salient to understand when tailoring lifestyle change treatment recommendations to families' available physical and psychosocial resources. Treatment recommendations may be facilitated through increased paternal engagement in family lifestyle change.

Barriers and Facilitators: Structural

Structural barriers identified which are specific to the clinic setting supported previous work identifying barriers to interventions for obesity in other treatment settings (i.e., short-term programs and community based interventions) (Cason-Wilkerson, Goldberg, Albright, Allison, & Haemer, 2015). Structural barriers included both facility-related issues (location, distance, visit frequency) and dissatisfaction with the program itself and with providers (advice not as expected, low levels of provider support). Providing a way to access support from providers between visits is something that has been identified in non-clinic settings as a facilitator to success (Grow et al., 2013; Jensen et al., 2014; Lyles et al., 2012). A barrier identified across several studies is that families struggled with understanding and implementing advice given by providers which they considered too general for both diet and physical activity recommendations. Tailoring of interventions needs to consider individual family's financial resources, and family and patient logistics and interpersonal dynamics. Implementing a process for pre visit orientation to the clinic for parents and children may help to assess and clarify parent/child expectations, motivations and behaviors.

Barriers and Facilitators: Financial

Financial barriers identified included cost to implement dietary and exercise recommendations, as well as costs related to transportation and parking. Other studies have noted that families have reported struggling to afford making recommended changes to diet and exercise given during program-based interventions as well (Cason-Wilkerson et al., 2015).

Providing specific resources families can access that are free or low cost and available in their community or online for both food and exercise options may facilitate success by reducing barriers. Optional free access to an exercise specialist may increase motivation and adherence to physical activity. An exercise specialist can evaluate the child's current fitness and create a specific home exercise program which matches child/family interest and resources along with periodic scheduled fitness testing to monitor progress.

Barriers and Facilitators: Patient and Family

In this review, families reported time constraints due to work, school and other obligations which impact the energy and time families and children can devote to making lifestyle changes. Time constraints can influence parental availability to shop for and prepare healthy meals, participate in physical activity and attend clinic appointments (Cason-Wilkerson et al., 2015). Unsupportive nuclear or extended family members was a consistent barrier. Undermining the efforts of the child and caregiver in charge of seeing that treatment guidelines are followed is a theme supported in community-based and program interventions (Cason-Wilkerson et al., 2015; Grow et al., 2013; Rhee et al., 2016). Studies in our review reported that not supporting the need for the child to be in treatment, not removing all unhealthy food from the home and/or allowing other family members to consume unhealthy food in front of the child are barriers to successful outcomes (Campbell et al., 2011; Stewart et al., 2008). Ways to better include family members do not present at the visit is an important area requiring further examination.

Barriers and Facilitators: Expectations, Motivation, and Behaviors

A theme noted by both parents and children was the program was 'not what we were looking for' (Barlow & Ohlemeyer, 2006; Hampl et al., 2013). The concept of expectations is

closely related to patient and family satisfaction. Previous research has demonstrated significant correlations between parent/child expectations of treatment and satisfaction (Alm et al., 2008; Skelton & Beech, 2011). Clarifying treatment expectations with all stakeholders (i.e., parents, child, family and provider) may help raise parent and child satisfaction.

Satisfaction is also closely tied to parent and child motivation to make lifestyle changes. Motivational Interviewing is a nascent research domain being applied with some success with parents and children with obesity as an adjunct to treatment (Bean et al., 2018; Borrello, Pietrabissa, Ceccarini, Manzoni, & Castelnuovo, 2015). If an older child does not have a good understanding of how their weight affects their overall health and are not motivated to improve their health, it is likely to be a significant barrier to success (Jensen et al., 2014; Sallinen et al., 2013). Parents who fail to comprehend the serious sequelae their child is at risk for, either present or imminent, may be unmotivated to make changes in the home environment. Children will be less motivated if they are not involved in the initial decision to engage in treatment.

Gaps

Gaps identified in this review were related to the paucity of data from the family members other than the mother, specifically fathers and siblings' perspectives and lack of consistent BMI-related measures identifying children with severe obesity. Data describing how fathers, siblings and other family members experience treatment recommendations for children with obesity are lacking. Bishop and colleagues (2015) interviewed 4 fathers and 4 siblings—siblings reported that food and exercise choices of the child in treatment influenced siblings and changed food purchased by their parents. Fathers reported a desire to attend clinic-visits but were often unable due to work. Fathers reported getting information from their partners and were able to give concrete examples of behavior changes being made at home (Bishop et al., 2015). Fathers

and mothers often differ in their parenting styles, involvement, and opinions about lifestyle behaviors for multiple reasons, (i.e., parental work schedules, cultural expectations, gender norms related to parental roles and responsibilities, and views on how family finances are used, etc.) (Allport et al., 2018; Wysocki & Gavin, 2006). Successful treatment requires family-wide support, participation, and lifestyle change over time (Anderson, 2018; Katzmarzyk et al., 2014), therefore, consideration of how families experience treatment recommendation and function on a daily basis is essential. Data from fathers, siblings and other family members may be needed to identify additional strategies to improve interventions and reduce barriers to success.

BMI-related measures to evaluate child weight outcomes across studies were varied, which prevented comparing results across studies and the identification of children with severe obesity. Use of more current measures, specifically use of BMIp95, are needed. Careful analysis of epidemiologic and clinical data have resulted in the BMIp95 (Flegal et al., 2009; Freedman et al., 2017; Kelly & Daniels, 2017). BMIp95 accounts for and more accurately identifies children with extreme BMI's. Current CDC growth charts at the 99^{th} percentile in reality encompass a wide range of BMI's and have a maximum BMI value of 36 kg/m^2 (Gulati, Kaplan, & Daniels, 2012). Similarly, BMI *z*-scores generated from the CDC growth charts are poor predictors of adiposity, particularly for children with severe obesity (Freedman et al., 2017), and can be misleading, potentially causing inaccurate conclusions to be drawn both in clinical practice and research findings (Kelly & Daniels, 2017).

Agreement on a common measure to identify and track children with obesity both clinically and in research is needed, particularly for those youth with severe obesity. Severe obesity is the fastest growing subcategory for both children and adolescents and is defined as a body mass index (BMI) $\geq 120^{th}$ percent of the 95^{th} BMI percentile (BMIp95) for age and sex

(Freedman et al., 2017). Six percent of all US youth have severe obesity (Skinner et al., 2018). Children and adolescents with severe obesity are at high risk of being severely obese when they reach adulthood (Freedman, Mei, Srinivasan, Berenson, & Dietz, 2007) and may exhibit serious obesity comorbidities in their young adult years, or even earlier (Freedman et al., 2007; Skinner, Perrin, Moss, & Skelton, 2015). Comorbidities include increased cardiometabolic risks, such as dyslipidemia, elevated blood glucose, hypertension, insulin resistance, and nonalcoholic fatty liver disease (Kelly et al., 2013; Reilly & Kelly, 2011; Skinner et al., 2015). These sequelae increase health care costs over a lifetime, decrease productivity, and shorten lifespan (Brotman et al., 2012; Reilly & Kelly, 2011; Skinner et al., 2015; Ward et al., 2017).

Limitations

Though care was taken to systematically search multiple databases, it is possible pertinent studies have been missed. Overall, the literature reporting on families of children with obesity in clinic-based treatment from the family/child perspective is limited. This review did not assess the quality of included studies, consistent with scoping methodology, therefore it is difficult to determine if particular studies provide robust findings (Arksey & O'Malley, 2005). Comparing participant results across studies was limited due to the differing study designs and the lack of standard reporting BMI-related measures. Utilizing the extended growth charts for children with obesity (Flegal & Ogden, 2011; Flegal et al., 2009; Gulati et al., 2012) would facilitate comparisons among future studies and help more accurately identify children with severe obesity, which in turn will ensure children are receiving best practice care.

Recommendations for Research

Concepts warranting further research identified in this study are attrition, adherence, obesity related quality of life, motivation of the child themselves both individually and in the

context of the family, self-efficacy and confidence, and parental and child communication as it relates to motivation and encouragement of children to reach their goals. The use of technology as an adjunct to improving adherence and patient outcomes in clinic-based treatment warrants further study.

Further qualitative research is needed to provide context and understanding of why children with obesity and their families currently in treatment experience barriers and facilitators to successful outcomes identified in the quantitative arena. Qualitative research may uncover concepts, variables, and barriers and/or facilitators not yet identified. Replicating well designed qualitative studies in various age groups, regions of the country, and ethnic minority populations may provide needed insight to inform current interventions and design future interventions.

Clinical Recommendations

Careful assessment of patient/family motivation and expectations of treatment, prior to beginning treatment may increase engagement and adherence to treatment recommendations. Providers and parents may prioritize health and sequelae of the obesity diagnosis rather than weight status. Children, particularly adolescents, describe their motivation for seeking treatment is largely to lose weight and be more socially accepted rather than for health reasons (Murtagh et al., 2006; Sallinen Gaffka et al., 2013; Skelton et al., 2016; Sousa et al., 2017). Therefore, providers and parents need to consider developmentally appropriate care when engaging the child in treatment, setting goals and providing ongoing support.

Families reported needing specific diet and exercise recommendations that are tailored to their individual family structures, schedules and available resources. General recommendations regarding diet and exercise, though providing content, are not sufficient and may prove overwhelming to families. Tailoring interventions to the specific child and family by ensuring

providers consider available financial resources, child and parental time constraints, and developmental stage of both child and family is crucial when making recommendation in the clinical setting (Barlow & Ohlemeyer, 2006; Bishop et al., 2015; Hampl et al., 2013; Owen et al., 2009; Sallinen Gaffka et al., 2013; Skelton et al., 2016). Assessing individual family preferences in regard to providing detailed shopping lists, specific meal plans and recipes, and exercise regimens to follow on a day to day basis may give some concrete actions to follow and help facilitate lifestyle changes.

Technology adjuncts can be used to both tailor interventions and increase provider support between clinic visits. Increasing support by providers between visits was identified as a potential facilitator of success in this review (Hampl et al., 2013; Owen et al., 2009; Skelton et al., 2016). Sharing this responsibility among the various disciplines can reduce provider workload and engaging nursing in this domain will allow providers to focus on the medical needs of the children and families.

Group care for children with obesity and their families is something to consider. The Centering® Model of Group Healthcare is an evidence-based model of group health care that effectively addresses the complex social determinants of health and has been used to deliver prenatal care, well infant care, and other chronic conditions (Centering® Healthcare Institue, 2019). The Centering® model has been shown effect in delivering care and improving outcomes particularly in high risk groups (Trotman et al., 2015). It would be beneficial to see if structuring visits for children with obesity and their families using a centering model would help to address some of the barriers to success identified in this review by building into clinic visits additional provider and peer support, community building, and interactive learning for families.

Considerations to implementing this model are language, culture and difficulties with reimbursement in some instances.

Conclusion

This scoping review was the first to examine the experiences of families of children with obesity in clinic-based treatment. Mothers' perspectives dominated the data and data from children in treatment or other family members were sparse. Gaps identified by this review were lack of uniform BMI-related measures appropriate for the evaluation and identification of children with severe obesity, and lack of data describing the experiences of fathers, siblings, or other family members. Future research should concentrate on identifying missing variables which impact successful treatment outcomes through more rigorous qualitative studies. Research targeted at children with severe obesity is needed as their risk of experiencing sequelae from their obesity is significantly increased. Clinical practice recommendations which may improve adherence to treatment and weight-based outcomes include assessing expectations and motivations prior to treatment; providing tailored recommendations considering individual family structures, schedules and available resources; strategically designed technology applications as an adjunct to treatment and group care. Identifying ways for clinics to utilize nursing in their care model may help narrow barriers identified and facilitate successful outcomes. Our review highlighted the need for more robust family centered research which will identify and explore factors impacting adherence to treatment recommendations which may lead to improved weight-related outcomes for children with obesity and their families.

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Table I.

Summary of Participant Characteristics

First author, year, country	Sample Size (*N*)	Child Age range (years)	Child Mean Age (years)	Child Sex (*N*)	Child BMI and Comorbidities	Parent/Family	Race/Ethnicity
Banks, et al., 2014 UK	32 Families	5-16	NDR	M = 13 F = 20	≥ 98th centile Patient excluded if not managed by PCP = NDR	[1]Mo = 21 Mo/C =8 Fa/C = 1 GP/C = 1 Mo/Fa = 3	NDR
Barlow, et al., 2006 US	43 Families	1- 17	11.9	M = 14 F = 29	z-score mean/SD 2.52/ ± .39 30 patients had a comorbidity (69.8%)	NDR	*Child* [2]W = 28; 65.2% AA = 13; 30.2% O = 2; 4.7%
Bishop, et. al., 2015 US	23 Families	7 and older	NDR	NDR	X = 37.8 ± 7.98 X > 99th percentile At least one weight related comorbidity	C = 23 Mo = 21 Fa = 4 Sibling = 4	*All Participants (Parents and Child)* W = 50% AA = 32% BR = 14% H = 5%
Campbell, et al., 2011 US	193 Parents	3-17	11.3	F = 105 M = 88	X = 99.1th percentile SD ± 1.03 At least one weight related comorbidity • Insulin resistance- 78.4% • Cardiovascular conditions - 57.8%	Mo = 83.9% Fa =9.3% Other = 6.7%	*Parents* Non-H= 105; 54% W = 71, 37% AA = 34, 18% H = 67, 37% W = 61, 32% AA = 6, 3% O = 25, 13%

First author, year, country	Sample Size (*N*)	Child Age range (years)	Child Mean Age (years)	Child Sex (*N*)	Child BMI and Comorbidities	Parent/Family	Race/Ethnicity
					• Sleep disturbances – 42.7% Two comorbidities- 15% • Three- 16.8% • Four or more- 56.2% Multiple comorbidities- 88%		
Hampl, et al., 2013 US	147 Parents	2-18	10.8	M = 58 F = 82 Missing = 7	Percentile X = 99.2 SD ± 1.9 z-score X = 2.4 SD ± 0.5	Mo = 87%	*Child* W = 52; 34.7% B = 53, 36.1% O = 12, 8.2% Missing = 22, 14.9%
Murtagh, et al., 2006 UK	20 Children	8-14	NDR	Children M = 14 F = 6	NDR	NDR	NDR
Owen, et al., 2009 UK	32 P = 21 C = 11	7-18	NDR	F = 6 M = 5	NDR	Mo = 17 Fa = 4 GP = 1	NDR
Rhodes, et al., 2017 US	405 P = 405 C = 160	2-18	11.7 (3.6)	F= 246 M = 160	Percentile X = 98.6 SD ± 3.1 z-score X ± 2.43 SD 0.47 NDR	P = 405 C = 160	*Families* H = 6, 15.6% W non-H = 185, 45.7% B non-H = 92, 22.7% A non-H = 4, 1% O = 16, 4% Missing = 45, 11.1%

First author, year, country	Sample Size (*N*)	Child Age range (years)	Child Mean Age (years)	Child Sex (*N*)	Child BMI and Comorbidities	Parent/Family	Race/Ethnicity
Sallinen Gaffka, et al., 2013 US	147 Parents	2-18	10.8 (3.3)	F = 56% M = 44%	Percentile X = 99.2 SD ± 1.9 NDR	Mo = 87%	*Parents* B = 36% W = 35% H = 6% O = 8% Missing = 15%
Skelton, et al., 2016 US	87 Parent/child dyads	7-18	11.8 (2.51)	C = 30 F = 65%	BMI X = 34 SD ± 8.35 z-score X = 2.36 SD ± 0.355 At least one weight related	P = 57 F = 93%	*Child* H = 1% Non-H AA = 40% Non-h W = 54% A = 1% AI = 1% O = 3% *Parent* H = 2.4% Non-H AA = 38.8% Non-h W = 57.7% A = 1% AI = 1% O = 3%
Sousa, et al., 2017 Portugal	94 Children	12-18	14.17 (1.51)	F = 48 M = 46	z-score X = 2.065 SD ± 0.377 Percentile X = 97.32 SD ± 2.193 NDR	NDR	NDR
Stewart, et al., 2008 UK	17 Parents	5-11	NDR	F = 9 M = 8	NDR	Mo = 14 Fa = 2 GP = 1	NDR

NDR = No data reported

M = Male F= Female

[1]Mo= mother, C = child, Fa = Father, P = parent, GP = grandparent

[2] W = White, H = Hispanic, AA = African American, O = other, BR = biracial, Non-H = Non-Hispanic, Non-W = Non-white, A = Asian, AI = American Indian

Table II.

Study Design, Measures, and Results

First author, year country	Design	Setting and Providers	Study Measures	Results
Banks, et al., 2014 UK	Qualitative	One tertiary care clinic or two primary care - based obesity clinics in Bristol, England Primary clinics [1]APN, RD Tertiary clinic MD, RD	**Parents and Children Report*** Semi-structured interviews • Parents of children interviewed together who attended at least 3 appointments and provided final outcome measures during 12-month treatment Number of questions= NDR Topics: • clinic expectations • experience of clinic and practitioner advice • lifestyle and diet changes made after advice • practical aspects of clinic elements missing from clinic	Main factors that promote or discourage engagement with obesity services • Building engagement • Maintaining engagement • Disengaging
Barlow et al., 2006 US	Mixed methods	Tertiary care clinic in St. Louis, MO MD, RD, Psych	**Parent Report** 9 item questionnaire developed by PI completed via mail or phone Validity/Reliability= NDR Topics • Lack of insurance coverage • Scheduling conflicts • Dissatisfaction with frequency of visits • Distance from home • Concerns about missed school • Lack of readiness to make lifestyle changes • This program is not what we are looking for	Parent reasons for nonreturn • Program did not meet expectations 37.2%, $N = 16$ • Child would miss too much school 27.9%, $N = 12$ • Too far from home 23.3%, $N = 10$ • Scheduling conflicts 20.9%, $N = 9$ • Insurance does not cover obesity care 20.9%, $N = 9$ • Child is not ready to make changes 16.3%, $N = 7$ • Visits are not frequent enough 11.6%, $N = 5$ • Visits are too frequent 7.0%, $N = 3$ • Family is not ready to make changes 4.7%, $N = 2$ • Return for a 3rd visit was associated with the highest BMI quartile (z-score > 2.9) $p = 0.02$ • OR =3.6 for return of those in highest BMI quartile (CI = 1.1-11.6, 95th%), $p = 0.01$ • White families more likely to report the program was too far $p = 0.02$ and program did not meet expectations $p = 0.03$ • Two parent families more likely to report program did not meet expectations $p = 0.02$
Bishop, et. al., 2015 US	Qualitative	Tertiary care clinic	**Parent and Child Report** Semi-structured interviews Active in treatment families conducted in person:	Themes • Family perceptions and attitudes toward program • Barriers to family participation • Reasons for attrition

First author, year country	Design	Setting and Providers	Study Measures	Results
		MD, RD, Psych, PT	• Parent and child interviewed separately Inactive in treatment via phone Questions covered 4 domains • Family and child experience • Family behavior changes • Family participation • Challenges	• Family preferences for addressing health behaviors
Campbell, et al., 2011 US	Mixed methods Cross-sectional retrospective study	Tertiary care clinic in Orlando, FL MD, RD, Psych	**Parent Report** 30 item questionnaire combination of Likert type questions and qualitative short answer to explore perception of Importance, Readiness, and Confidence to effect change in 4 lifestyle domains Likert scale 1-5 1 = NOT, important, ready, concerned or confident 5 = VERY important, ready, concerned, confident • General questions about child's weight • Eating habits • Physical activity habits • Next steps Validity/Reliability: NDR	• Level of concern and importance of child's weight rated as "high"77.1% with a "5"; *M* = 4.7; *SD* = 0.7 • Importance: to change eating- 78% with a "5" *M* = 4.7; *SD* = 0.7 • Importance: to change physical activity-76.6% with a "5" *M* = 4.7; *SD* =0.8 • Readiness: to change child's eating 80.5% with a "5"; *M* = 4.8; *SD* = 0.7 • Readiness: to change child's physical activity 69.8% with a "5"; *M* = 4.6; *SD* = 0.8 • Confidence: to change eating overall 50.7% with a "5"; *M* = 4.1; *SD* = 1.1 • Confidence: to change physical activity overall 53.7% with a "5"; *M* = 4.3; *SD* = 1.0 Ready to change eating habits: • χ^2 [1, *N* = 193] = 12.399; p < .001 • Confident group - 94.2%; *N* = 104 • Not confident group - 75.3%; *N* = 89 Ready to change physical activity habits: • χ^2 [1, *N* = 193] = 21.577; p < .001 • Confident - 87.3%; *N*= 110 • Not confident group - 56.6%; *N* = 83
Hampl, et al., 2013 US	Mixed methods Nonexperimental descriptive study Qualitative data-not reported	Tertiary care clinics-provided 56% of data Programs-44% Multisite study-13 participating sites from Children's	**Parent Report** Author developed semi structured survey measuring 48 factors which may contribute to attrition in 10 domains using 3-point Likert scale of how influential in the decision to leave (1= no/low influence, 2 = moderate influence, 3 = high influence; also, options of 'don't know' and 'not applicable')	Domains as having moderate to high influence on attrition in order of importance • Scheduling- 59.8%, *N* = 88 • Implementation barriers-53.7%, *N* = 79 • Transportation problems-51.7%, *N* = 76 • Motivation-39.4%, *N* = 58 • Mismatched expectations-36.8%, *N* = 54 • Child physical/emotional health-34.7%, *N* = 51

First author, year country	Design	Setting and Providers	Study Measures	Results
		Hospital Association in US Providers-NDR	Validity/reliability = NDR Domains • Transportation • Program characteristics • Scheduling • Finances • Barriers to implementation • Mismatch of expectations • Communication with providers • Parent physical/emotional health • Child physical/emotional health • Motivation	• Parent physical/emotional health-34%, *N* = 50 • Finances-33.4%, *N* = 49 • Program characteristics-32.7%, *N* = 48 • Communication-30.6%, *N* = 45 Mismatched expectations having a moderate or high influence on the decision not to return • Private insurance: 62.5% vs all other insurance 33.3%, *p* = .003 • Race/ethnicity: White 64.1% vs Non-White 36.7%, *p* = .008 • Program or clinic type: clinic 52.5% vs program 32.7%, *p* = .04 • Rewards for participation: rewards not offered 60.9% vs offered 22.2%, *p* < .0001 Patients referred from a physician transportation had a moderate/high influence on their decision not to return compared to self-referrals * 63.4% vs 42.4%, *p* = .03 Clinic patients indicated finances had a moderate/high influence on their decision not to return * 51/5% vs 29/8%, *p* = .005
Murtagh, et al., 2006 UK	Qualitative	Community based clinics sponsored by National Health Service in Leeds, England Providers- NDR	**Child report** • Open ended questions individual interviews and 3 focus groups (6-8 children) Number of questions = NDR Topics • When they first became aware of their weight problem • What instigated the process of behavior change? • The presence of barriers to behavioral change • Whether attempts to lose weight had been made previously • Why they felt the need to lose weight • What helps them lose weight • What makes it difficult to lose weight	Themes • Reasons to change: • Cues for action • Barriers to action • Continued compliance • Barriers to compliance
Owen, et al., 2009	Qualitative	Tertiary care clinic in Bristol, England	**Parent and Child Report** In-depth in person semi-structured interviews with parent and child separately	Themes • Role of the clinic-successful families • Role of clinic-unsuccessful families

First author, year country	Design	Setting and Providers	Study Measures	Results
UK		MD, RD, ES	Interview guide: Parent/Child • Questions about child referral • Descriptions and feelings about appointments • Suggestions for improvement • Reasons for on attendance Parent only questions • Clinic accessibility • Thoughts on hospital setting Compared themes between unsuccessful/did not attend (DNA) and successful families • Successful reduction in BMI in SDS = 0.69 DNA -attended one or more appointment but no follow-up	• Approach used by the provider team- successful and unsuccessful • Advice given and changes made by families in relation to diet- successful • Advice given and changes made by families in relation to diet- unsuccessful • Advice given and changes made by families in relation to exercise- successful • Advice given and changes made by families in relation to exercise- unsuccessful
Rhodes, et al., 2017 US	Quantitative Prospective, nonrandomized, uncontrolled single arm pilot trial	Tertiary care clinic and Programs Multisite study- 12 sites from Children's Hospital Association, in US Providers-NDR	**Parent and Child Report** Paper survey developed by authors in 4 main categories baseline "What do you want?' and follow-up "What do you need?" 3 months ± 2 weeks in person on paper if possible, if not follow-up then via mail or phone • Healthier food/drinks • Physical activity/exercise • Family support/behavior • Weight management goals Items were based on acquiring knowledge, behavioral skills, and role of family support Cronbach's $\alpha \geq 0.8$ in all subcategories of the too internal consistency Parents (Cronbach's αs .08 - .96) adolescents (Cronbach's αs .08 - .92) Concordance of parent/adolescent expectations = difference between parent and adolescent dyad survey responses in each category	• Overall attrition rate = 42.2% • More discordant parent/adolescent treatment expectations the higher the odds of attrition at 3 months (for one-unit difference on the Likert scale OR 1.36, 95% CI 1.04-1.78, $p = 0.02$) • Adolescents showed greater interest in getting families involved in healthy eating and exercise decreased odds of attrition (for one-unit difference on the Likert scale OR 0.75, 95% CI 0.57-0.98, $p = 0.04$) • Compared to dropouts' adolescents who did not drop out greater desire for help at baseline to get family "onboard" with Healthy eating changes (2.44 vs 1.83, $p = .02$) Physically Active (2.48 vs 1.80, $p = .01$) • Attrition was associated with adolescent weight-loss goals above the desired median for the group (50% above the median vs. 28% below the median, $p = 0.02$)
Sallinen Gaffka,	Qualitative	Tertiary care clinics and programs	**Parent Report** Semi structured phone interview developed by 2 of the authors	Most common themes to reduce attrition • Components of the program: 23% though they may be general tailor treatment options to each child/family

First author, year country	Design	Setting and Providers	Study Measures	Results
et al., 2013 US		Multisite -13 sites with National Association of Children's Hospitals	Designed to assess for parent perspectives about what programs/clinics could do to increase retention included 3 open ended questions	• Logistical: 21% of parents reported extended or weekend hours and more accessible locations • Treatment delivery: 19% no consistent responses as some desired individual while others desired group care that was grouped by age • Financial assistance with transportation, exercise and/or rewards:18%
Skelton, et al., 2016 US	Qualitative	MD, RD, Psych Tertiary care clinic North Carolina, US MD, RD, Psych, PT, ES	**Parent and Child Report** • Semi-structured phone interviews developed by authors using tenets of patient-centered care • Pilot tested interviews via cognitive interviewing • Reviewed for face validity by expert clinicians	• Attrition rate: 63%; reasons given were lack of weight loss, desire for more structured in treatment and lack of adolescent-specific program • Children who dropped out had higher BMI z-scores by t-test (2.45 vs. 2.21, $p < 0.01$) Main themes • Overall positive experience with the program • Logistical challenges of participation • Improved health • Discrepancies between child and parent experience and perception • Importance of structure and expectations of weight loss

Sousa, et al., 2017 Portugal	Quantitative Cross-sectional correlation study	Tertiary care clinic in Portugal
		
		MD, RD, ES
			Child Report
			• Adherence to Weight Control Questionnaire- AWCQ- measures Treatment Adherence to Weight Control-29 items with four subscales: SEA (Self-efficacy and Adherence Behaviors); PPI (Parental and Provider Influence): FSI (Friends and School Influence) and PB (Perceived Benefits) (reliability 0.908) and Risk of Non-Adherence to Weight Control-7 items (reliability 0.770)
			• Impact of Weight on Quality of Life-IWQOL self-report instrument 27 items, 4 factors (physical comfort, body esteem, social life, family relations) (Internal consistency 0.73-0.93/ total scale 0.934)
			• Clinical files for demographic, anthropometric, and behavioral variables
				• Larger the self-efficacy/adherence behavior index, the higher the body esteem ($r_s = 0.282$, $p < 0.01$) and obesity-related quality of life index ($r_s = 0.275$, $p < 0.01$).
				• Influence of parents and providers on adherence to weight control is associated to an increasing rate of physical comfort ($r_s = 0.253$, $P < 0.05$); social life ($r_s = 0.237$, $p < 0.05$); family relations ($r_s = 0.326$, $p < 0.01$); and obesity-related quality of life index ($r_s = 0.236$, $p < 0.05$)
				• Overall higher indices of adherence to weight control are associated to several higher indices of IWQOL (coefficients between 0.225 and 0.289, $p < 0.05$)
				• Obesity-related quality of life scores (IWQOL) (range 1-100) 79.795 (*SD* = 18.972)
				  • Subscales
				  • Family relations 93.81 (*SD* = 16.365)
				  • Social Life 83.154 (*SD* = 22.013)
				  • Physical comfort 82.491 (*SD* = 20.959)
				  • Body Esteem 66.357 (*SD* = 28.036)

First author, year country	Design	Setting and Providers	Study Measures	Results
			(weekly physical activity, screen time, previous treatment length).	

Stewart, et al., 2008 UK	Qualitative	Tertiary care clinics- 2; in Scotland
		
		RD
			Parent Report
			In-depth interviews- no data on how the interview guide was developed
				• 7 children of parents interviewed met their treatment goal of reduction in BMI
				Themes identified
				• Aware parents- of child's weigh problem
				  • Seekers those aware parents seeking help
				  • Avoiders parents unable or unwilling to discuss concerns
				• Unaware parents- described their child's weight as normal for age
				  • Deniers- parents who did not see a problem
				• During treatment:
				  • Need for support from both nuclear and extended family
				  • Extended family less supportive and often sabotaged efforts
				  • Parents felt the need to justify lifestyle changes to family
				• Post treatment
				  • Need for continued support after formal treatment completed
				  • Noted improvement in child's self-esteem and confidence
				  • Parents did not prioritize weight loss at the end of treatment

[*] Bold faced font indicates who is providing the data

[1]APN = Advanced Practice Nurse, RD = Registered Dietician, FC = Family counselor, Psych = psychologist or counselor, PT = Physical therapist, ES = Exercise specialist

Table III.

Barriers to Treatment

First author, year country	Structural	Financial	Patient and Family	Personal Behaviors, Motivation, and Expectations
Banks, et al., 2014 UK	**Disengaging* • Clinic did not meet expectations in terms of services • Expected medical or pharmacy approach • No psychological practitioner which was desired by parents • Clinic was not age appropriate in their approach • Did not provide structured meal planning	*Disengaging* • Structured plan for exercise was too expensive to implement	*Building Engagement* • Children not involved in decision to attend *Disengaging* • Stigma of missing school for clinic visits particularly with adolescents among peers	*Building Engagement* • Family expectations did not match experience
Barlow et al., 2006 US	• Dissatisfaction with the program • Distance/too far • Scheduling conflicts • Visits not frequent enough • Visits too frequent • Distance from home • Scheduling conflicts • Dissatisfaction with visit frequency	• Insurance not covering obesity care • Lack of insurance	• Concerns about missing too much school	• Readiness to make changes • Family not ready to make change • Child not ready to make changes • Program not what expected
Bishop, et. al., 2015 US	*Barriers to family participation* • Time commitment for visit was great *Reason for attrition* • Distance to clinic • Finding reliable transportation	*Barriers to family participation and Reason for attrition* • Parental work schedule, (i.e., shift work)	*Barriers to family participation* • Scheduling conflicts due to siblings' activities and parents work obligations	*Barriers to family participation* • Inherent difficulties of diet changes • Difficulty changing eating behaviors, (i.e., how fast and how much)
Campbell, et al., 2011 US	NDR	• Financial concerns to buy healthy food	• Hectic schedule of child and difficulty balancing demands • Parent work schedule creates difficulty in making healthy choices and monitoring child's food and activity	• Reported lack of motivation • Worry of social stigma (child and family) of obesity as an obstacle to making change (being seen exercising)

First author, year country	Structural	Financial	Patient and Family	Personal Behaviors, Motivation, and Expectations
Hampl, et al., 2013 US	• Scheduling • Transportation problems, distance to clinic • Mismatched expectations between family and clinic • Program recommendations were overwhelming to families and unrealistic given their resources • Program recommendations were too general • Communication between visits was not sufficient for families	• Program costs • Lack of insurance • Insurance did not cover obesity care • Cost of transportation	• Implementation barriers-recommendations were not practical and took too much time • Child physical/emotional health, children were stressed by program requirements • Parent physical/emotional health	• Parent/family motivation • Mismatched expectations between parent, child and clinic
Murtagh, et al., 2006 UK	*Barriers to action* • Negative experiences with dieting and dietitians • Unrealistic strict food guidelines	*Barriers to compliance* • Expensive 'healthy' foods • Expensive sports activities	*Barriers to action* • Blaming parents for not addressing their weight problem sooner	*Barriers to action* • Difficulty making lifestyle changes needed *Barriers to compliance* • Low self esteem • Low self confidence • Perceived that barriers were beyond their control (actions of peers, voices of authority, physical inability, access to sports facilities and place of residence) • Wanted weight loss to be faster as they wanted more immediate results
Owen, et al., 2009 UK	*Role of the clinic* • Expected clinic and staff to keep child in control (low self-efficacy) • Did not see RD or PT at first appointment • Wanted psychological support to help with parenting issues and child's emotional needs *Dietary advice received, and changes made by families* • Parents wanted more specific diet advice, plans and recipes Approach used by the team • Provider was too harsh	*Dietary advice received, and changes made by families* • Lack of resources to follow advice *Exercise advice received, and changes made by families* • Exercise advice was impractical due to expense of exercise facilities or lack of facilities	Dietary advice received, and changes made by families • Parental guilt with restricting diets feared they were damaging their child psychologically *Exercise advice received, and changes made by families* • Felt the exercise requirements/time were impractical and they already did adequate exercise	*Dietary advice received, and changes made by families* • Did not implement any specific changes *Exercise advice received, and changes made by families* • Unable identify ways to change their lifestyle long term

First author, year country	Structural	Financial	Patient and Family	Personal Behaviors, Motivation, and Expectations
Rhodes, et al., 2017 US	NDR	NDR	• Disagreement on the importance of familial involvement between adolescent and parent	• Unrealistic weight loss goals which can predict attrition rates
Sallinen Gaffka, et al., 2013 US	• Scheduling not flexible • Location-distance to travel • Unmet expectations • Too much information at first visit	• Exercise resources offered by clinic were expensive • Cost of treatment was prohibitive, or insurance did not cover • Transportation costs • Cost of healthy foods	NDR	NDR
Skelton, et al., 2016 US	• Time commitment for the program was to intensive • Clinic hours were not flexible • Clinic was too far	• Missed work time by parents	• Stress in the family apart from the treatment • Difficult for the whole family to participate • Missed school time for child	• Dissatisfied with the program, (i.e. they did not lose weight, more treatment structure, lack of adolescent -specific program)
Sousa, et al., 2017 Portugal	• Not assessing motivation • Not considering obesity related quality of life • Lack of provider support	NDR	• Lack of parental involvement and support	• Non-adherence to program specifics
Stewart, et al., 2008 UK	• Negative experience with the providers	NDR	Problems with the parent's significant other • Offering children junk food • Undermining the parent who initiated lifestyle changes • Extended family and friends not supportive and actively undermining healthy behaviors-particularly grandparents	NDR

** Italicized text are themes identified in the study results*

Table IV.

Facilitators to Treatment

First author, year country	Structural	Financial	Patient and Family	Personal Behaviors, Motivation, and Expectations
Banks, et al., 2014 UK	**Maintaining engagement* • One on one specialty advice given based on knowledge, experience and personal circumstances of children and families • Tailoring exercise advice to the child's age, gender, social environment and interests and parents' ability to accommodate the recommendations	NDR	*Maintaining engagement* • Parents valued having another voice (clinic) to lend legitimacy to the family role around diet and exercise	*Building engagement* • Child was involved in the decision to attend
Bishop, et. al., 2015 US	*Family preferences for addressing health behaviors* • Examples of exercise options	NDR	*Family preferences for addressing health behaviors* • Clear roles and responsibilities for food provider and preparer • Mores structure at home *Family perceptions and attitudes toward treatment program* • Increased family cohesion due to program recommendations	*Family preferences for addressing health behaviors* • Autonomy for children to choose among healthy options in food and exercise
Campbell, et al., 2011 US	• Motivational interviewing techniques • Clinic partnering with child and family to work through child resistance to treatment • Targeted goal setting with detailed plan • Unconditional support of care providers	NDR	• Unconditional support of the whole family	• Seeing weight loss will be motivating to continue to make healthy choices • Assistance to help improving self-esteem of child

First author, year country	Structural	Financial	Patient and Family	Personal Behaviors, Motivation, and Expectations
Murtagh, et al., 2006 UK	*Continued compliance* • Continual support and motivation by providers to remain motivated	NDR	*Cues for action* • External influence of role model to change behavior, typically intervention by their mother *Continued compliance* • Continual support and motivation by family to remain motivated	*Reasons to change* • Bullying • Desire to fit in • Health and physical ability Continued compliance by • Increased self-efficacy
Owen, et al., 2009 UK	*Role of the clinic* • Ongoing support by clinic by keeping families mindful of weight as an issue and motivated • Children preferred hearing advice from a professional • More frequent appointments *Approach used by the team* • Supportive and relaxed provider *Dietary advice received, and changes made by families* • Structured advice given about diet *Exercise advice received, and changes made by families* • Motivational PT	NDR	NDR	*Dietary advice received, and changes made by families* • Motivated by weight loss • Families made changes in diet based on advice *Exercise advice received, and changes made by families* • Increased exercise intensity
Rhodes, et al., 2017 US	• Tailoring treatment to meet family needs based on initial expectations and realistic goals	NDR	• Having entire family on board with eating healthier and being physically active	• Setting realistic goals for weight loss
Sallinen Gaffka, et al., 2013 US	• More tailored treatments • Offer more information in advance so participants know what to expect • Group activities • Rewards	• Transportation assistance • Exercise resource assistance	NDR	NDR

First author, year country	Structural	Financial	Patient and Family	Personal Behaviors, Motivation, and Expectations
	• Increase staff and cultural sensitivity • Parent encouragement • More interaction with staff and family • More frequent appointments	• Financial assistance		
Skelton, et al., 2016 US	• Staff support and "having someone to talk to" about weight/health • Classes/group support • Holistic/multidisciplinary approach • Extended clinic hours • Orientation to clinic and information PRIOR to starting • Specific weight loss goals • Specific guidelines for behavior change • Additional locations in the communities • Adolescent-specific content	• Assistance with transportation • Assistance with parking	• Children valued the increased family time in meal planning, goal setting and family meals (NEW INSIGHT) • Improved health behaviors • Improved confidence	• Specific guidelines on meal plans and goal setting • Specific guidelines on how to lose weight more rapidly
Sousa, et al., 2017 Portugal	• Assess and consider obesity related quality of life • Assess motivation • Sustained provider support and influence	NDR	• Parental involvement and support • Strong family relationships	• Adherence to lifestyle change and treatment program • Personal motivation by adolescent
Stewart, et al., 2008 UK	• Continued support from providers once 'treatment' was complete	NDR	Support needed from significant other • Actively reinforcing agreed lifestyle changes • Supporting the decision to seek treatment • Support from extended family.	• Increased self-esteem through the knowledge gained at the clinic

** Italicized text are themes identified in the study results*

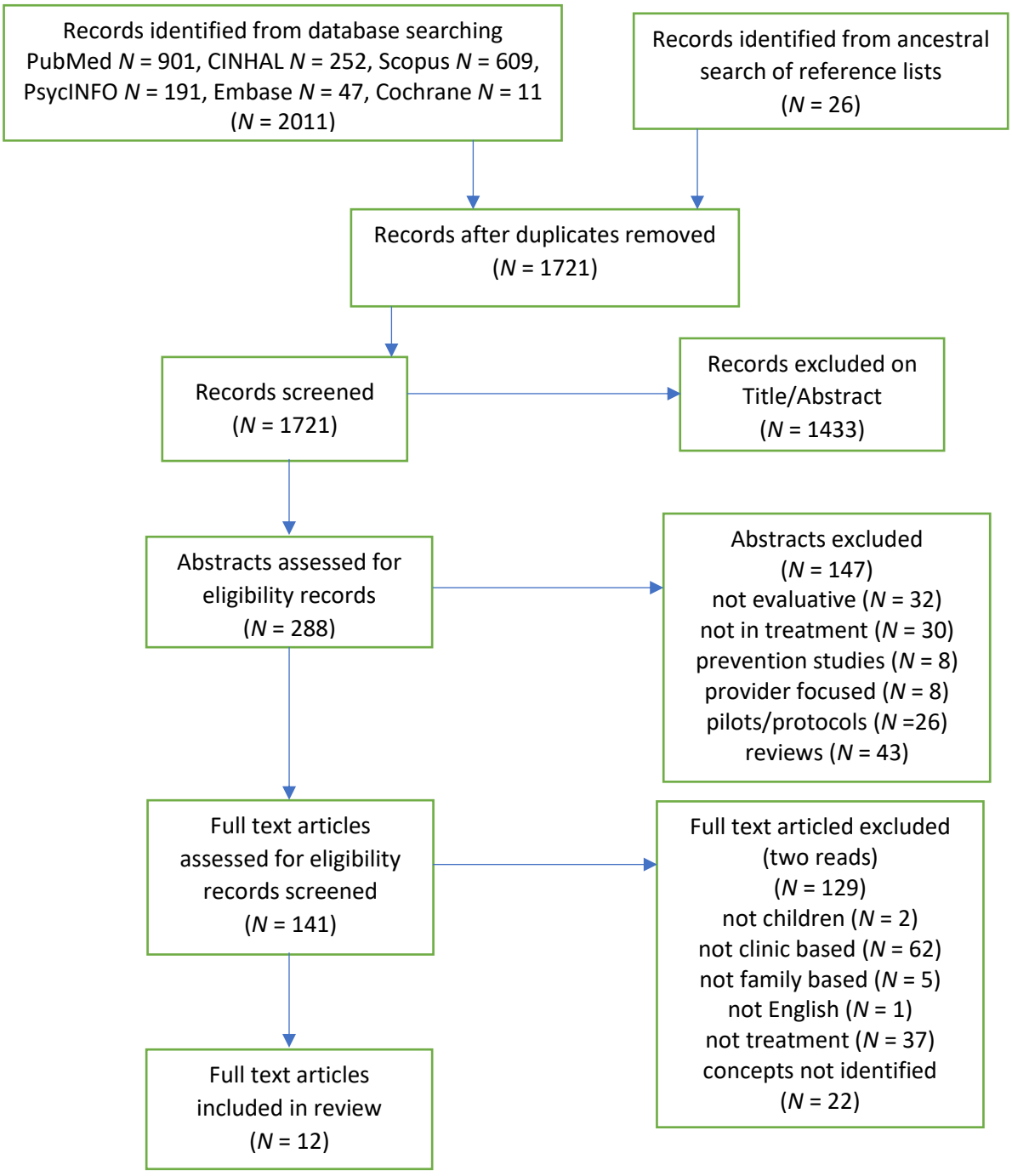

Figure 1. Flowsheet for article selection

Experiences of Families with Children Attending a Clinic-Based Weight Management Program: A Qualitative Study

Childhood obesity is one of the most prevalent chronic illnesses in children in the United States (U.S.) (Perrin, Gnanasekaran, & Delahaye, 2012) with 18.5% of US children ages 2 to 19 being obese (Hales, Carroll, Fryar, & Ogden, 2017; Skinner, Ravanbakht, Skelton, Perrin, & Armstrong, 2018). *Childhood obesity* is defined as body mass index (BMI) $\geq 95^{th}$ percentile on The Centers for Disease Control and Prevention (CDC) age and sex-specific growth references (Ogden et al., 2016). Health disparities in childhood obesity exist with prevalence rates highest in children of lower socioeconomic status and of color. Hispanic youth have the highest rates of obesity (25.8%), followed by Non-Hispanic Black (22%), Non-Hispanic White (14.1%), and Non-Hispanic Asian (11.0%) (Hales et al., 2017; Lee, Andrew, Gebremariam, Lumeng, & Lee, 2014; Skinner et al., 2018). It is imperative in both research and practice to identify and treat children who are severely obese as they are at increased risk for cardiometabolic sequelae from their obesity in both childhood and beyond (Chung, Onuzuruike, & Magge, 2018; Freedman, Mei, Srinivasan, Berenson, & Dietz, 2007; Kelly et al., 2013; Reilly & Kelly, 2011; Skinner, Perrin, Moss, & Skelton, 2015; Ward et al., 2017). Cardiometabolic sequelae in children with severe obesity include dyslipidemia, elevated blood glucose, hypertension, insulin resistance and nonalcoholic fatty liver disease (Kelly et al., 2013; Reilly & Kelly, 2011; Skinner et al., 2015). The prevalence of metabolic syndrome in children with severe obesity has been reported to be three times higher than for children with a moderate level of obesity (Rank et al., 2013). These sequelae increase health care costs over a lifetime, decrease productivity, and shorten lifespan (Brotman et al., 2012; Reilly & Kelly, 2011; Skinner et al., 2015; Ward et al., 2017).

Limitations in the current CDC growth charts in identifying children with severe obesity have been identified. A new outcome metric, the BMIp95, has been developed as a better measure to use across ages for obesity outcomes as it more accurately predicts adiposity than BMI z-scores and allows for the classification of children with severe obesity (Freedman et al., 2017; Kelly & Daniels, 2017). Severe obesity is the fastest growing subcategory for both children and adolescents and is defined as a BMI $\geq 120^{th}$ percent of the 95^{th} BMI percentile (BMIp95) for age and sex (Freedman et al., 2017). Currently 6% of U.S. youth have severe obesity (Skinner et al., 2018). Adolescents aged 12 to 19 years have the highest rates of severe obesity compared to other age groups (Skinner et al., 2018).

The majority of children with severe obesity will become obese adults unless they receive intensive intervention (Freedman et al., 2007; Ward et al., 2017). Multicomponent family focused treatment that includes diet, physical activity, and behavior change currently is considered best practice for children with severe obesity (Al-Khudairy et al., 2017; Mead et al., 2017). Intervention strategies for children with severe obesity include inpatient treatment, bariatric surgery, and medications. These interventions are combined with lifestyle behavior change—which address the determinants of childhood obesity, such as having parent who is overweight, consumption of sugar-sweetened beverages, physical inactivity, increased screen time, low socioeconomic status, and limited access to fresh fruits and vegetables (Boutelle, Cafri, & Crow, 2012; Gordon-Larsen, Nelson, Page, & Popkin, 2006; Wang & Beydoun, 2007). These interventions have limited success and available data show minimally significant improvements in BMI even with intensive lifestyle interventions (Peirson et al., 2015; van Hoek, Feskens, Bouwman, & Janse, 2014). The success of behavioral interventions is limited to stabilizing children's BMI, which is unlikely to achieve metabolically beneficial effects (i.e., decreased

lipids, insulin, glucose and hypertension) (Al-Khudairy et al., 2017; Hampl et al., 2016; Mead et al., 2017; Taveras et al., 2015). Enhanced efforts to identify strategies and deliver effective interventions to children with severe obesity and their families is needed (Ogden et al., 2016; Skinner, Perrin, & Skelton, 2016). More insight is needed into the moderators and mediators of excessive weight gain in children and adolescents (Skinner et al., 2018). Little data exist which explains how families and children with severe obesity manage the condition on a day-to-day basis.

Theoretical Framework

The family management styles framework (FMSF) was developed to understand identifying key aspects of the family and family member experience and functioning in childhood chronic conditions through the perspective of parents or custodial caregiver (Knafl, Breitmayer, Gallo, & Zoeller, 1996; Knafl, Deatrick, & Havill, 2012; Knafl & Deatrick, 2003). The three main components of the FMSF, 1) definition of the situation, 2) management behaviors, and 3) perceived consequences are concepts which influence how family experiences within the context of childhood chronic conditions and are informed by contextual influences: social networks, care providers and systems, and resources (Knafl et al., 1996; Knafl et al., 2012). Components of the FMSF are interrelated and influence the child with the condition and family members, resulting in a unique family management style (Figure 2). In addition to the three components, the FMSF has eight dimensions; child identity, view of condition, management mindset, parental mutuality, parenting philosophy, management approach, family focus and future expectations.

Definition of the situation addresses the child's capabilities within the demands and limits of the condition. Management mindset reflects the ease or difficulty in implementing and

managing the child's treatment. Parental mutuality reflects how partnered parents have shared or discrepant views of their child, the condition, and their approach to condition management (Knafl et al., 2012). Management behaviors includes parenting philosophy and management approach. Parenting philosophy focuses on the goals, priorities, values and beliefs that guide their overall approach and development of routines and specific strategies for condition management in everyday life (Knafl et al., 2012). Perceived consequences includes family focus and future expectations. How the condition management is incorporated into family life, impacts the child and family, and implications for their child and the family's future define these dimensions (Knafl et al., 2012).

The original intent of the FMSF was to examine family management styles from the parental perspective and did not include the perspectives of the child. Recent studies have built on the FMSF and have developed specific definitions related to the dimensions that are applicable to children (Beacham & Deatrick, 2015, 2019; Wollenhaupt, Rodgers, & Sawin, 2012). A recent concept analysis by Jang and Whittemore (2015) analyzed the applicability of the FMSF for childhood obesity and modified the FMSF based on the literature. Their framework adds the component perceived barriers and the additional dimensions of parental perception of their child's weight status, parenting style, and parental knowledge about physical/psychological consequences. The modified framework from Jang and Whittemore (2015) along with a more recent review of the literature resulted in an adapted FMSF (Figure 3), which informed the development of the interview guide, the codebook and methods for data analysis for this current study.

To date, the FMSF has not been used to examine how families of children with obesity or severe obesity understand their child's condition and incorporate management into their daily

lives. No published studies have examined the perspectives of children with severe obesity in relation to understanding their condition and how they manage day to day. Therefore, the aims of this study are to: 1) document the experiences of parents and children with severe obesity who attend a clinic-based obesity treatment program; 2) explore how parents and children manage the treatment of severe obesity on a day to day basis; 3) evaluate the applicability of the FMSF to families and children with severe obesity.

Methods

Design

In this qualitative descriptive study, data were collected through one-time semi-structured interviews with parents and 12 to 17-year-old children and field observations in the clinic and participant homes. When little research has been conducted in an area of interest, qualitative descriptive methods are suitable for identification of the problem, hypothesis generation, theory formation, and concept development (Neergaard, Olesen, Andersen, & Sondergaard, 2009; Sandelowski, 2000). Qualitative description remains close to the data, producing a description of the informant's experiences in a language of their own (Sandelowski, 2000; Sullivan-Bolyai, Bova, & Harper, 2005). Field observations during clinic visits and in-home interviews, provided context and ethnographic data of the setting and culture of the clinic and participant homes, and was used to triangulate data during analysis.

Subjects and Setting

Participants were recruited in person and via phone by the primary investigator (PI) from children and parents or custodial caregiver who attend clinic-based obesity treatment through a regional children's hospital. The tertiary clinic has two outpatient settings, one urban and one suburban in the Midwest of the US. Clinic visits are individual, including time with a healthcare

provider (physician or advanced practice nurse), and registered dietician. A social worker is available for additional support as needed.

Purposeful sampling identified potential participants of at least one parent or custodial caregiver (hereafter parent will be used) and the child. Inclusion criteria consisted of children age 12 to 17 years who are severely obese (BMI ≥120th percent of the 95th percentile), have had an initial clinic visit and at minimum one follow-up visit, no developmental delays, and could complete the interview in English or Spanish. Final sample size of 15 families resulted in 12 parent/child dyads, two parent/child triads and one parent only.

Measures

To address the aims of the study, interview guides for the parent and child were developed, grounded in the current literature, and the major components and dimensions of the FMSF. Pilot testing of the interview guides were conducted with parents and children during clinic visits and feedback was obtained. Sample interview questions are found in Table V.

Data Collection

Institutional Review Board (IRB) approval and authorization agreement was obtained from Ann & Robert H. Lurie Children's Hospital (Protocol # 2018-2244) and the University of Illinois at Chicago. Parental permission and informed consent was obtained from parents and assent obtained from children prior to interviews. The PI conducted interviews between February and September 2019. Interviews were conducted in the home of the participants (n =10) or at a private location chose by the participants (n = 5). Interviews were conducted with children and parents separately and lasted between 24 to 53 minutes (M = 40.2) for parents and 19 to 47 minutes (M = 30.5) for children. Each parent and child interviewed was compensated with a $20

gift card for their participation. Interviews were conducted by the PI and/or the PI and the Spanish interpreter (neither involved in the care of the children) and were audio recorded.

Field notes were collected during general observations in the both clinic sites, as well as shortly after completing interviews. These data provided context, ethnographic data, and reflexivity by the PI. Data collected during clinic observations included: interactions during clinic visits between providers and families and children; physical space at the clinic; body language and physical characteristics of providers, staff, families, and children. Data collected after interviews included the PI's impressions of the parent/child congruency in responses, body language, receptivity to questions and physical observations of the home.

Data Analysis

Taped interviews were transcribed verbatim and entered into Dedoose Version 8.2.14, web application for managing, analyzing, and presenting qualitative and mixed method research data (2019) for coding and analysis) Los Angeles, CA: SocioCultural Research Consultants, LLC www.dedoose.com. The PI transcribed initial interviews (n = 6). The remainder of interviews were transcribed using a transcription service and checked by the PI for accuracy prior to analysis. Demographic data via paper survey from both parent and child and pertinent medical record data through chart review were collected after interviews were completed, analyzed descriptively, and are summarized in Tables VI and VII.

Rigor was maintained throughout data collection and analysis to ensure accuracy of the data, dependability, trustworthiness, credibility of study results, and occurred by giving careful attention to interview quality through constant comparison of the aims for each interview question, using a second data coder, and persistent observation to ensure analysis accurately reflect the participant's experience (Creswell, 2014; Hsieh & Shannon, 2005; Patton, 2015).

Directed content analysis was used to analyze the data collected through the interviews (Hsieh & Shannon, 2005). The intent of this approach is to extend or validate conceptually a theoretical framework, by identifying key concepts as initial coding categories (Hsieh & Shannon, 2005). Directed content analyses are based on an a priori framework that guide the creation of interview guide and analytic codes (Hsieh & Shannon, 2005).

The initial code list was developed using the definitions of the main components and dimensions within the FMSF, the additional dimensions suggested from a recent concept analysis (Jang & Whittemore, 2015) and the PIs review of the pediatric obesity literature. Code definitions were also added to reflect the perspective of children. Codes which were new to the FMSF were organized under the appropriate component or dimension based upon review of code definitions and consensus discussions between the PI and A. Gallo, one of the co-developers of the FMSF. The PI and a second coder analyzed transcripts independently and then met to discuss results and come to consensus on final code applications.

Matrices were developed and organized according to the major components and the original dimensions of the FMSF, and the additional component and dimensions identified by Jang and Whittemore (2015) and the PI for this study after final code applications. Parent and child interview data were reviewed and entered into the matrices independent of one another. Parent and child interview data were analyzed separately to identify parental subthemes and child subthemes, summarized, and compared between parent and child responses for congruence or discordance. Table VIII shows and example of the content analysis process.

Results

A total of 15 families were represented in this study. Seventeen parents and 14 children between 12 to 17 years old were individually interviewed in this study. There were at total of 12

dyads (parent/child), two triads (mother, father and child) and one parent only interview. Demographic and descriptive statistics are presented in Table VI and VII. The analysis supported the use of the FMSF in families of children with severe obesity to reflect both parent and child views. Three additional dimensions have been identified in this study; perceived barriers, perceived facilitators, and knowledge of the consequences of obesity. The PI and AG discussed where the additional dimensions fit theoretically into the adapted FMSF after preliminary coding and consensus was reached. The dimensions of perceived barriers and perceived facilitators were then placed into the component definition of the situation, while the added dimension of knowledge of obesity were placed into the perceived consequences component.

Definition of the Situation

Six dimensions describe the family's definition of the situation: child identity, management mindset, parental mutuality, view of condition, perceived barriers and perceived facilitators. To better reflect the experiences of families of children with obesity, the definition of view of condition was expanded to include the parent/child perceptions of the child's weight status and journey to seeking care.

Child identity. Parents described their children in a variety of ways, but common themes were noted. Many parents observed that their child had always been "bigger" or "chubbier" compared to other children their age. As one mother of a 15-year-old girl indicated, "But it's been a struggle since she was five? And she's just, her growth chart's been off the record, weight and height." (P04) Parents often noticed that their children were not as active or athletic, not liking sports, or not being able keep up with other children. A father of a 12-year-old boy noted, "We realized his activity level wasn't the same as all of his friends. He doesn't have the same interests. It's just the way he is. And his lack of motivation… And he's not athletic." (P02)

Parents also described their children as having a long way to go in regard to weight loss and overall thought that the advice and support at the clinic was what was helping them, and their child 'stay in check' with diet and exercise recommendations as it provided accountability for the family. A father of a 15-year-old boy stated, "From our point of view without the clinic he would probably right now, probably weigh double." (P03)

Children's view of themselves mirrored themes of the parents. They described themselves as "bigger" or "chubbier" than peers from a young age, though a few children had not thought about weight until a medical provider had brought up concerns about possible sequelae and/or suggested they seek treatment at the weight management clinic. Some children described themselves and no liking sports or exercise, though others described themselves as active and enjoying being active. Children discussed their personal desire and perceived ability to lose weight and accomplish their goals for weight loss. One12 year old boy noted, "Now I really want to lose weight, so I'm eating it [vegetables] and she's [mom] helping me." (C11) While another 12-year-old boy shared, "Uh, sometimes I really, I don't feel, I don't really feel. I don't feel really uh, self-confident about it [his weight]. I mainly just accept it and I know I have to do something about it and change it. So, yeah that's-that's what I do." (C06)

Management mindset. Children and parents described how they viewed their treatment plan related to diet, exercise and medications. The two major themes identified by both parents and children were related to ease or difficulty in following treatment recommendations related to dietary changes, exercise recommendations and in some cases medication management. Both parents and children frequently described how exercising was a particular struggle and how difficult it was to achieve the recommended frequency and intensity. A mom of a 13-year-old girl noted, "I think that was the hardest piece and I feel like we're still looking. We're still trying

to make adjustments and things like that. Like the exercise piece." (P12) While a 15-year-old girl shared, "Exercise because I think that's what I struggle with most because of time and just how everything is set up for me." (C04)

Family mutuality. The dimension of family mutuality is modified from the parental mutuality in the original FMSF. Parents described concordant and discrepant views of how the family viewed the child, their obesity, parenting philosophy, and approach to obesity management. Two themes were identified: parents were either 'on the same page' or not, and parents were strict or lenient in maintaining diet recommendations. Some parents reported conflict and tensions with the other parent in relation to these discrepant views. A married mom of a 13-year-old girl shared, "So, my husband was resistant to it [diet changes] and I would still say is not on board. And he was still doing the things that I said we shouldn't be doing. So, it's a point of a contention, it's a bit of friction. And at the same time, like I don't want to be fighting with him about this. But like this is the health of our child. Like you need to knock it off. So, I would say, 'Sue, like you have to tell him that you don't want it anymore [unhealthy food].' Because he thinks I'm just being kind of bossy and overbearing." (P12) Other family members, both in and outside of the household, were described as supportive or unsupportive of the parents' attempts to implement changes in their child's diet and in some cases reflected extended family members' beliefs about the cause and seriousness of the child's obesity which opposed the parents' belief. A mom who is divorced from the father of a 15-year-old girl noted, "Her dad is not [supportive]. Her side of the family, her dad and his side of the family are not supportive at all. They make fun of it. They say, 'It's not a condition. What is PCOS? What is that? It's nothing.' (P04)

Some children described family mutuality and to how their parents were often at odds with one another in relation to what they thought the child should and should not be doing, particularly in relation to diet. In two families this conflict was intensified due to divorce and both children discussed the stress this caused them. A 15-year-old girl whose parents are divorced noted, “My real dad. He just doesn't like me doing this. He likes me how I am type of thing. He's like, ‘You don't need to change for no one.’ (C04) Children shared how they felt when the actions of parents, siblings or extended family were at times contradictory to supporting diet recommendations. Most distressing was when siblings, parents or other family members would either bring home or be allowed to have certain foods the children were ‘not allowed’ to have. A 16-year-old girl with two siblings who are normal weight shared, “I’ve been calling them temptations that my sister has in her room, even though it's her room and her stuff, I get that, but she always eats it.” (C08) Children also described how their family was all working together to make changes and how this was encouraging to them and did not make them feel singled out or excluded. A 12-year-old boy whose family shares a home with grandparents stated, “We all eat the same food. There's not, ‘You get this, and you get that.’ My grandma and grandpa, they know that I'm supposed to be eating healthy; so, if I'm with them, they know that it's healthy food. They're really supportive, too. Whatever I eat, they eat.” (C11)

View of the condition- parent/child perception of the child’s weight status. Several parents described a period where their child had a rapid weight gain in a short amount of time and they either did not understand where this came from, (i.e., the reported not noting any particular changes in diet or activity that would account for this gain), or they did not notice it until ‘it was too late’ and then reported being surprised and overwhelmed or unsure what to do next. A mom of a 16 year old girl stated, “Just looking at the pictures of her growing up, she was

such a tiny little thing growing up and then, you just kind of notice that she's just getting a little bigger and a little more overweight and we didn't really notice it too much, until I felt like it was almost too late. 'Okay, How do I do this?' Yeah. I felt like I let things get way out of control." (P08) Most parents had concerns about their child's weight prior to any referrals from providers, though two mothers reported they had not thought much about their child's weight it until they were referred to the clinic due to abnormal blood tests performed by their pediatrician. The mom of a 13-year-old girl noted, "Yeah, it's when the pediatrician brought it up. We hadn't really put much thought into it." (P13)

Most children described not being concerned or thinking about their weight prior to it being addressed by a parent, doctor or both. The majority of children described initially being upset and confused about coming to the weight management clinic, not understanding why weight was an issue. A 16-year-old girl stated, "The pediatrician was concerned about the weight. When I was younger, and they were talking about it (the weight) I was like 'what are you guys talking about?'" (C08) However, most of these children described understanding the significance of excess weight in relation to overall health after the initial clinic visits. Some children described wanting to get help from the clinic and were encouraged to find out there was a place that could help. A 15-year-old girl who was requesting her mother find help for her obesity shared, "I mean obviously you can't, poof, lose 50 pounds but be proactive about it, I guess you could say. Actually, come up with a plan. So, I wasn't expecting her (the doctor at the clinic) to be like, 'Okay we have this, this, and this.' But I was *hoping* that she was, and she did. So that was awesome." (C04)

Perceived barriers. Barriers to adopting health behaviors to manage obesity described by parents and children were related to food environment, lack of time and control, physical

environment, established lifestyle preferences, and medications. Themes identified related to the food environment were the cost and accessibility to healthy food options. Lack of time and control to manage health behaviors related to exercise was endorsed by children and parents. Parents endorsed shopping and preparing healthy food options and monitoring their child's health behaviors as requiring much time and control. The physical environment barriers reported by parents and children were focused on access to places where children could exercise outside of competitive sports or, age restrictions at gyms or health clubs, and reported confusion on how to exercise to meet recommended guidelines. A mom of a 15-year-old girl who noted challenges in accessing gyms or available spaces for physical activity outside of school commented, "I wish there was help for kids. I don't want to say free help, but like some kind of discounted help. Not even a gym, but almost like a trainer…Because they don't know what to do (exercise wise). They don't know what to do." (P04) Descriptions by parents or children relating to established lifestyle preferences focused on preferred foods, which included culturally preferred diets as well as the preference for sugary food and beverages and dislike of exercise. One 12-year-old boy who verbalized opposition to attending the clinic noted, "I'm a kid and I want sugar constantly." (C02) While another 13-year-old girl commented, "It's like when you're Hispanic culture, there's a lot of carbs, like rice, protein, a lot of those things, and it's tough to stay away from it." (C14) Barriers to medication compliance were related to side effects, not understanding the purpose of the medication and forgetting to take medications as scheduled. A 12-year-old boy whose mother has given him the sole responsibility to take his medications shared, "Recently it's really hard to remember to take them. I think it's because we just got back from a trip and that I put them in my room and then I'm supposed to eat them before breakfast. But now if they're in my room and then I go down and they're not there, I'm just like oh, I forget about it." (C10)

Perceived facilitators. Parents and children described two main facilitators to adopting health behaviors to manage obesity—support and structure. Specifically, parents and children described support from providers, family and peers as being important to sustaining healthy behaviors. They described structure related to diet and exercise components wanting more specific lists and plans for foods to buy, meals to prepare and an exercise component from the clinic which would be accessible and structured for their children. A mom of a 12-year-old boy with four normal weight siblings suggested, "I would think more of a structured thing (exercise). Where he could relate with kids that are going through what he's going through. I think that would not only help him, you know physically, but I think mentally. You know realizing he's not the only one. He may be the only one in his class (at school), but he's always got that friend that he could see later, that knows what he's going through. And that he can, you know work on physically. And somebody that, who is, has a challenge physically that he has, and they push each other. Like that would be great." (P06) Children also described how having positive self-motivation and mindset in how they viewed themselves and their abilities as something important to help them achieve their goals. A 16-year-old girl with a history of depressive symptoms noted, "The most important thing for me is to have a good mindset because my mindset is always all over the place. I need to have a set mindset of what I want to do, what I need to do to lose weight." (C08)

Management Behaviors

Parenting philosophy. The dimensions of parenting philosophy and management approach comprise the management behaviors component of the FMSF. The parenting philosophy dimension was described by parents; however, children's views did not necessarily describe their parents' beliefs and priorities guiding obesity management. Parental philosophy of

obesity management fell into two themes: the child needs to do this themselves or we need to help them do this. Some parents described initially feeling like the child was the one who was completely in control of their behavior though they took an active role is trying to reinforce recommendations for management. A mom of a 16-year-old girl of two normal weight siblings noted “Right and it was one of those things where we were always like she has to do it for herself, but we really pushed her a lot. You shouldn't be eating this. You shouldn't be doing that. I realize we were just taking a real bad approach here.” (P08) Parents who described their support of the child in unconditional terms took a more cooperative approach to management. A mom of a 12-year-old boy who quit her job to be more available to her three young children stated, “I am here to support him and do whatever he needs to help.” (P11)

Management approach. Parents and children described their approach to obesity management in terms of specific dietary changes, exercise and medication recommendations. Dietary changes discussed were reducing intake of added sugars, for example no more than 6 grams of added sugar for any food consumed and reading labels to look for this information. Exercise recommendations described by parents and children were less specific. Few parents or children gave any guidelines for daily physical recommendations (i.e., 60 minutes per day for children) and made generic comments like “I have gym everyday” or “we walk the dog everyday”. Few parents and children were able to identify specific routines or strategies they used on a day to day basis to follow obesity management recommendations. A 13-year-old girl with a history of depression and anxiety commented, “We don't really have a plan that they (the clinic) set. They're kind of just do these things kind of every day. And then like maybe it'll work. (C12) Those parents who did describe specific strategies noted meal preparation, keeping set mealtimes, bedtime, and exercise routines such as taking daily walks together or with the dog.

The single mom of a 12-year-old boy with 2 siblings, one who also attends the clinic shared, “We’ve discovered that if we, sometimes as a team, put together just individual containers of a meal, pop it in the microwave and then eat it you’re good.” (P05)

Perceived Consequences

Three dimensions describe the perceived consequences: family focus, future expectations, and knowledge of the consequences of obesity. **Family focus** is defined as how management of the condition has been incorporated into family life and in these data specifically address the themes related to how the obesity of the child impacted the child and the family.

Impact on child. Themes described by parents as to how obesity has impacted the child fell into physiological and psychological components. Parents described some of the physical sequelae children suffered, (i.e. insulin resistance, increased triglycerides, low vitamin D levels, requiring medication, clinic visits, and blood work). Many parents also described their child suffering from anxiety, depression and experiencing negative reactions from peers. A mom of a 15-year-old girl with diagnosed polycystic ovarian syndrome noted, “She's been struggling with depression about her weight and about her image and everything. But it's been a struggle since she was five?” (P04) Children described the impact of their obesity in mostly psychological terms related to the distress they felt in having to receive medical care specifically for their weight as well as the difficulty experienced in trying to lose weight. A 15-year-old girl with polycystic ovarian syndrome shared, *“*I just feel like sometimes you get judged because of your weight and it’s hard. I don't think they understand it's hard to go to someone about your weight because you're so insecure about it. And to have them say your weight out loud and all that stuff. And they talk about it like it's nothing. But to you it's everything**.** (C04)

A prevalent theme which emerged from the data was related reasons children and parents gave for their or their child's obesity and the impact it had on the child or parent. In both instances there was the assigning of blame either to self or by others (i.e., partners, peers, parents, or healthcare providers). A 12-year-old boy whose parents divorced three years ago prior to his weight gain shared without any prompting, "And it is my fault (long pause and patient looks down) for the weight gain." (C05) Descriptions of being bullied or weight-based bias/stigma reactions by others toward the child because of their obesity was also prevalent. Parents described incidents with healthcare providers, spouses, and peers which caused them to blame themselves for their or their child's weight. Children described similar experiences of self-blame or internalized weight bias. Parents and children described both specific incidents and ongoing bullying they have experienced which have caused depression, anxiety and guilt. A mom of a 12-year-old boy with a history of anxiety shared, "All they did was make fun of him. He didn't wanna go back. (to the kids exercise class) You see all the marks on his arms? He picks. When he started getting heavier and taller and they were calling him, big fat Santa, sweaty Santa. (P06) A 15-year-old girl noted, "I was bullied a lot and just people just saying unnecessary things. It made me even more upset with myself because I thought that I was doing something wrong." (C04)

Impact on family members. Parents described the impact of the child's obesity management on their immediate and extended family as often causing stress and conflicts between family members, particularly siblings. Dietary changes, specifically reducing sugary foods and beverages, was a theme that was prevalent. One single mom of a 12-year-old boy with 2 younger siblings shared, "It was very roller coaster in the beginning because I think the whole sugar detox. I don't even think I realized how much sugar they got in just normal foods like

yogurt, not looking at the sugar content in yogurt. We thought it was healthy, but there was a lot of sugar in it. And just kinda cutting them off cold turkey, there was a lot of attitude and crying and cranky and they seemed to fight more. (P05) Parents of children who have been coming to the clinic for some time reported feeling overwhelmed and weary from the constant need to monitor food and try and maintain the recommendations day after day. Children described how the removal of sugary foods and beverages negatively affected their siblings, (i.e., their siblings voiced dislike and even anger at these changes). A 14-year-old girl with a younger brother noted, “So, I think we both (child and brother) got cranky because we didn't get sugar. So, we both a little bit mad with our parents, but deep down inside of me, down on all that anger, I knew that it was for the best. (C14)

The theme of blaming for their child’s obesity was prevalent and had a negative impact on the parents who described these experiences. A mom (she works 7 days/week and whose husband had a serious health condition) of a 14-year-old girl stated, “They say it's my fault because I'm the one who buys the food. So, yeah, my husband told me a lot, too, "Oh, because you're the one who gets and makes the food and stuff," but also, the nutritionist also said it was my fault.” (P14) Another mom of a 15-year-old girl shared, “It's so stressful on the parents, you know? Even her growing up, people would look at me like ‘what did you do to your kid?’ I would get constant looks. Like ‘you're the mom, look at you, look at her.’ Like ‘what are you doing?’ Like I was hurting her. No. ‘What are you feeding her?’ Like I was trying to kill her or something. I was constantly getting comments and stuff as I'm like searching for help… I'm like are you kidding?” (P04)

Future expectations. Parents described the future expectations of their child’s obesity in three main themes: obesity as a lifelong condition that would need to constantly be monitored,

ambivalence about leaving the accountability of the clinic, and anticipating a time they could leave the clinic when their child reached a healthy weight. A father of a 15 year old boy noted, “This is a problem, or a situation that we have to keep in mind every day for the rest of his life, because in the point when he just put it away, he’s gonna start gaining weight, and weight and weight and obviously all the rest of the bad health you can get from overweight. So, he knows, he knows. (P03) Children described the need to maintain accountability with either the clinic or other healthcare setting and identified that staying on track with healthy habits can be difficult once your goal is reached. A 14-year-old girl stated, “Staying on track is difficult. Once you're reached your goal, it's hard to keep moving forward, eating healthy. You don't have anything to stick you to it….. I think the most difficult part would be sticking to not and keep going through it. It's easy to stick to ... I have to live with it. I'm healthy now and kinda stay healthy. (C15) Parents and children who described a time they could be discharged from the care of the clinic said it would mean they were healthy and happy.

Knowledge of the consequences of obesity. Knowledge of the consequences of obesity, an additional dimension identified, was defined as knowledge about the physical and/or psychological consequences of obesity. Parents and children were able to discuss the physiological impacts of obesity both in the short and long term. They described understanding how their metabolism affects their weight, the impact of sugar on the liver and insulin levels, how sleep affects their ability to lose weight, and why they need to take medication. A 12-year-old boy explained, “Carbs turn into sugar, turn into energy, but if you have too much sugar, it turns into fat and it's like, whoa. Ruin ... wasn't that your kidney? Liver, The liver can’t process it.” (C05) Only one parent specifically described psychological consequences as a direct result of their child’s obesity. This single mom of a 12-year-old boy shared, “We didn’t even know about

the insulin levels until we went there (the clinic), which is good. I mean there was another step of getting him to realize that what he ate really is affecting him. He has anxiety issues, so we focused on that for a couple of years. That's under control. (P05)

Discussion

This study aimed to 1) document the experiences of parents and children with severe obesity who attend a clinic-based obesity treatment program; 2) explore how parents and children manage the treatment of severe obesity on a day to day basis; 3) evaluate the applicability of the FMSF to families and children with severe obesity. This study is one of the first to describe the experiences of families and children with severe obesity who attend a clinic-based obesity treatment. In telling their stories, parents and children described their journey which led up to seeking care for their child's obesity and their challenges and successes in managing the treatment on a day to day basis. results of this study document some challenges parents and children experience in daily management, particularly challenges in consistently following dietary and exercise recommendations received. This was the first study to apply the FMSF to families whose children suffer from obesity and one of a few studies which have included children's perspectives of obesity, and their treatment. We found evidence that parents of children with obesity and children's views were a good fit into the overall FMSF components and dimensions with some additional dimensions specific to obesity.

Parents and children had largely congruent views on how they viewed their child or themselves, their journey to seeking treatment, and daily management of obesity (i.e., definition of the situation in the FMSF). These perceptions affected how families described both congruent and discrepant views in family attitudes and actions to support the child with obesity and the existence and effectiveness of their day to day routines. Prior investigators found lack of family

support, both nuclear and extended, and its impact on healthy lifestyle interventions and outcomes of obesity management is important to understand in order to improve long term outcomes for children with obesity (Katzmarzyk et al., 2014). The application of the FMSF in families of children with obesity and specifically identifying family's unique management styles could help clinicians in setting goals and tailoring interventions to individual family and child needs.

Parents and children described largely congruent experiences in the family focus dimension of the FMSF. Relationships among family members were negatively impacted primarily due to dietary changes being disliked by siblings or the other parent and the effort needed to maintain consistency in habits day to day in the midst of busy lives. Parent and child expectations for the future were uncertain and guarded in regard to the child's obesity outcome and the continued treatment and management. Parents and children overall understood the need for long term management and voiced a desire to have the continued support of someone outside of their immediate family. These findings are consistent with previous research (Campbell et al., 2011; Owen et al., 2009; Sousa, Gaspar, Fonseca, & Gaspar, 2017; Stewart, Chapple, Hughes, Poustie, & Reilly, 2008). Specialized obesity care is scarce for children and often falls on the primary care provider who may or may not have the knowledge and expertise to manage the complexities of obesity. Creative approaches to multidisciplinary care, which includes engaging nursing in care delivery and coordination is an area to address this limitation in current practice. Family systems nursing directs care at the family unit and focuses on the interaction among family members in caring for a particular family member with an illness (Wright & Leahey, 1990). Utilizing a family nursing approach in the care of families of children with obesity is an

option to increasing access to care and resources for children currently in treatment and needing access to additional support and services.

We identified three additional dimensions to the FMSF which provide important data in understanding family management of children with obesity; perceived barriers, perceived facilitators, and knowledge of the consequences of obesity. Barriers identified in this study in managing obesity included access and cost of healthy food options, lack of time and control to engage in healthy behaviors, access and lack of knowledge to meet physical activity requirements, preferred lifestyle behaviors and medications. Facilitators identified in managing obesity included sustained support from providers, family and peers and more structure and specific plans for both diet and exercise. Children also endorsed their own mindset and viewing themselves as capable of making changes as a facilitator. These findings support previous research aimed at understanding barriers and facilitators to lifestyle change in children with obesity (Alm et al., 2008; Banks, Cramer, Deborah, Shield, & Katrina, 2014; Bishop, Irby, & Skelton, 2015; Campbell, Benton, & Werk, 2011; Murtagh, Dixey, & Rudolf, 2006; Owen, Sharp, Shield, & Turner, 2009; Sallinen Gaffka, Frank, Hampl, Santos, & Rhodes, 2013; Skelton, Martin, & Irby, 2016). Better understanding of barriers and facilitators to how parents and children view and perceive their ability to manage their treatment regimen allows for providers and researchers to identify areas where interventions can be targeted. Parent and children's knowledge of the consequences of obesity provide are salient in assessing their understanding or lack thereof regarding the immediate and long-term sequelae of the child's obesity. These data are necessary and should be used by providers to better engage parents and children in their treatment, set specific goals and evaluate interventions and treatment.

Parents and children described their experiences with weight-based stigma and bias including self-stigma and internalized weight bias. Almost all children in this study described their experiences with weight-based stigma and many parents and children identified the need to have the ability to connect with other children 'like them' so they know they are not the only ones. Consequences of weight stigma affect the psychological, social and physical health of children with obesity, increasing their risk for of depression, anxiety, substance use, low self-esteem, and poor body image (Pont, Puhl, Cook, & Slusser, 2017; Puhl & Suh, 2015). Children who suffer weight related stigma have decreased levels of physical activity and avoidance of school activities including physical education class (Puhl & Luedicke, 2012). The source of weight stigma is often bullying from peers, however parents, healthcare providers, educators and the media have also been identified as perpetrators (Pont et al., 2017). Self-stigma (assigning negative weight-based stereotypes toward oneself) or internalized weight bias by children has been associated with poor psychological function, disordered and binge eating behaviors, poor body image and lower self-esteem (Puhl & Himmelstein, 2018; Puhl & Suh, 2015). The themes of weight-stigma and internalized weight bias need further attention in both practice and research as they could potentially be the most salient concepts to understand how they relate to children with severe obesity and treatment outcomes, specifically BMI and long-term health consequences.

Strengths and Limitations

The strengths of this study include obtaining both children and parents perspectives regarding management of severe obesity using the FMSF as a theoretical framework. Ethnographic data from clinic observations and interviews conducted in the family's home allowed for triangulation of data during analysis. Conducting interviews away from the clinic

and by someone not involved in the child's care potentially reduced power dynamics or negative/positive perceptions associated with healthcare providers and the clinic. The sample was diverse in gender for children and over half identified as Hispanic/Latino/a. Only two of the families were from the urban clinic as opposed to the suburban clinic so comparisons between families who attend different locations was not possible. Data from parents was largely provided by mothers and therefore paternal perspectives, which may differ from maternal perspectives, were limited in this study. The smaller sample size did not allow for identification of specific family management styles in the FMSF or comparison within and among subgroups related to age, race, socioeconomic status, or other important variables. Lastly, Spanish interviews were transcribed from the English translation and not word for word from the Spanish responses. It is possible that some content or context was lost during this process.

Implications

The FMSF provides a more complete understanding of family life in the context of children with severe obesity, and can be used to direct researchers' and clinicians' efforts to assess family response and, particularly in regard to how obesity management is incorporated into everyday life (Knafl, Deatrick, & Gallo, 2008). Providing specific meal plans that account for the family's particular tastes and substitution ideas could reduce the time and burden on busy families and increase the likelihood families will change dietary habits long term. Similarly, some families noted their children were unable to participate in sports and did not enjoy exercise or know what specifically to do for exercise. The addition of an exercise specialist who could tailor a program specific to the child after a fitness evaluation and provide more frequent monitoring and follow up may encourage the child and family to set more specific fitness goals and maintain consistent routines for exercise. This specific intervention may be particularly

significant in helping children with severe obesity reduce BMI as a recent study examining medical, demographic and behavioral factors associated with the reduction in BMI for children receiving care at a tertiary care obesity management clinic found only lack of depression and increasing physical activity as significant predictors of reduction in BMIp95 (Gorecki, Feinglass, & Binns, 2019).

Due to the relatively smaller sample size of this study the researcher did not attempt to identify the specific management styles described in the FMSF. Knafl, et al., (1996) identified five specific family management styles exhibited in families of children with a chronic condition: thriving, accommodating, enduring, struggling, and floundering. This foundational work produced a quantitative measure, the Family Management Measure (FaMM). The FaMM should be applied both clinically and in research in order to gain a more complete understanding of child adaptation and family function and more precisely understand factors that may support or impede children with obesity in reducing their BMI (Knafl et al., 2011). Based on the results of this study next steps in research would be applying the FaMM to understand the relationship between family response to obesity and the child and family outcomes, specifically reduction in BMI.

Families in this study identified the need for increased peer support that would encourage children to realize there are other kids like them, decrease isolation related to their obesity diagnosis, and provide accountability in daily management. Children and parents also identified that children struggled with meeting recommendations for physical activity, largely due to access and disliking competitive sports or exercise in general. Children described preferring to participate in group exercise. Technology interventions could be investigated in order to address this challenge. Remote exercise coaching or classes in conjunction with a peer support

component where children engaged in obesity treatment could interact with one another should be piloted to determine feasibility in terms of clinic resources and child and family engagement. Next steps in research should focus on understanding and comparing family management of obesity in children and possibly testing the extent family management may mediate the impact of a structured exercise program in the context of peer support on BMI outcomes.

Conclusion

Children with severe obesity and their families who seek treatment for their obesity have complex needs both physically and psychologically. In most cases, the families in this study have been on a long journey seeking help, support and results for several years prior to seeking clinic-based care. The complex social networks, health care systems and resources available to families and children directly impact their ability to define and manage their child's obesity and the effect obesity has on their family life presently and in the future. Though this study was small in sample, these data are salient to understand the family's day to day experiences in managing children with obesity and provide family focused interventions. Interventions should target increasing peer support, providing a tailored exercise component, and reducing the effects of weight-based stigma to improve long term outcomes.

This study adds to the current science of obesity, specifically the understanding of families of children with severe obesity in treatment. These data provided parent and children's perspectives on their obesity diagnosis, management, and understanding of physical and psychological consequences of obesity. These data can be used by providers of child obesity treatment to tailor current interventions and lays the foundation for future interventional research for these children and families.

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Table V.

Interview Guide-Sample Questions

Tell me the story about your journey up until the point that brought you/your child to the clinic.
Talk to me about what you expected and what you hoped for prior to coming to the clinic.
Can you describe for me the plan you/your child received at the first visit?
Talk about how the plan is working on a day to day basis.
How has the plan affected others living in your home?
Talk about what you think would be the most important thing you might need to help you/your child be successful
People come to this clinic and may hope for a day when they don't need to come back. Can you describe what that might look like or how you feel about that?

Table VI.

Parent Characteristics

Parent	***N* or *Mdn* (range)**
• **Mother**	15
• **Father**	2
Age in years	44 (30-54)
Number of people living in the home	
• **Four**	11
• **Five**	5
• **Six**	1
Education	
• **Less than high school**	3
• **High school/GED**	3
• **Some college/no degree**	3
• **Associate degree**	2
• **Bachelor's degree**	1
• **Graduate degree**	5
Employment	
• **10-19 hours/week**	1
• **20-39 hours/week**	4
• **40 plus hours/week**	10
• **Not employed-looking**	1
• **Not employed-not looking**	1
Home ownership	13
Household income (US dollars	
• **Less than $10,000**	1
• **$11,000-20,000**	1
• **$21,000-30,000**	3
• **More than $50,000**	11
• **Prefer not to answer**	1
Public aid	
• **SNAP**	3
• **Public aid**	3
• **None**	11
Race	
• **White**	16
• **Multiple**	1
Hispanic/Latino	
• **Not Hispanic or Latino**	5
• **Mexican**	3
• **Mexican American**	9

Table VII.

Child Characteristics

Child	***N* or *Mdn* (range)**
• **Female**	6
• **Male**	8
Age	13 (12-16)
School accommodations	6
Work hours	
• **Not employed**	10
• **1-10 hours/week**	2
• **10-19 hours/week**	1
• **20-39 hours/week**	1
Extra-curricular hours	
• **Do not participate**	2
• **1- 5 hours/week**	7
• **6-10 hours/week**	3
• **16-20 hours/week**	1
• **Greater than 20 hours/week**	1
Race	
• **White**	10
• **Multiple**	4
Hispanic/Latino	
• **Not Hispanic or Latino**	5
• **Mexican**	4
• **Mexican American**	5
Age at first visit	11.8 (8.6-14.8)
Number of clinic visits	5 (2-11)
BMIp95 baseline	138 (117-219)
BMIp95 recent	135 (119-208)
Medications	
• **Metformin**	11
• **Vitamin D**	12
• **Topiramate**	3
• **Phentermine**	1
Other health care providers	
• **Psychiatrist/counselor**	5
• **Physical therapy**	3
• **Endocrinologist**	1
Dietary habits	
• **Dairy ≥ 2/day**	11
• **Dairy < 2/day**	4
• **Fruits and vegetables > 2/day**	10
• **Fruits and vegetables ≤ 2/day**	5
• **Grains > 6/day**	6

• **Grains ≤ 6/day**	9
Activity habits-recent	
• **Physical activity 0-1 day/week**	2
• **Physical activity 2-4 days/week**	7
• **Physical activity 5 + days/week**	4
Screen time-recent	
• **≤ 2 hours/day**	3
• **> 2 hours/day**	9
Insulin resistance > 17mcIU/ml or presence of acanthosis nigricans	14
Hypertriglyceridemia ≥ 90 mg/dl	10
Obstructive sleep apnea	5
Hypovitaminosis D < 20 ng/ml	8
Elevated hemoglobin A1c > 5.7 mmol/mol	3
History of depressive symptoms	3
Anxiety	3

Table VIII.

Example of the content analysis process using the FMSF

Component	Dimensions	Quotes	
		Parent	Child
Definition of the Situation	Child Identify	Because he really does try really hard. He's a fighter. He even has a picture of what he wants to look like. You've got a long way to go, but keep going baby, it's okay. So yeah, he doesn't give up, he tries it. (P09)	Uh, sometimes I really, I don't feel, I don't really feel. I don't feel really uh, self-confident about it (his weight). I mainly just accept it and I know I have to do something about it and change it. So, yeah that's-that's what I do. (C06)
	Management Mindset	He tells me, "But it's so hard to lose weight," and I'm like, "But I can help. We've already got to the right doctor and they're telling you that you're losing weight." (P11)	I mean I've always wanted to lose weight, but it's been hard. So as soon as they were like, "Yeah, we know a person." I'm like, "Okay, I'm down with that. We can do that. That's cool." I had to like work out more. Which is boring. (C12)
	Family Mutuality	Not having anything (snacks and junk food) in the house. I mean, I get yelled at by everybody else in the house because my husband and other daughter are like, "But we're healthy. Why can't we have stuff?" I'm like, "Well, because you can't." (P08)	So, he doesn't really help honestly because he works for McDonalds right now and he brings home a lot of food. And I'm like, "Okay, can you not?" And my mom was, "Can you not?" And I'm like, "Okay, cool." Well, my mom will yell at him and then throw it away and he's just like, "Oh okay. Cool. Whatever." (C12)
	View of Condition	She had been getting a little heavy, but then over a year period she really gained a lot of weight. That's where it became a concern. She just kept gaining weight. (P15)	I think they've all been a little bit worried about my weight since I was tiny, but I don't think they questioned so much about it. Well, maybe once I got to a certain

Component	Dimensions	Quotes	
		Parent	Child
			amount, they got a lot more worried. (C14)
	Perceived Barriers	We are on a very tight budget. I'm a single mom and a full-time student. The snacks they recommend, they're like "Beef jerky" You realize a bag of beef jerky's 7 bucks? So, it's really hard for us besides certain regular vegetables, it's hard to figure out snacks that we can also afford and fit in the criteria. (P05)	Yeah, metformin, the big ones (pills are very large). Ever since I have this stomachache and I threw up a couple times, and it's mentally where my body didn't like taking it because I will remember smells from things. (C05)
	Perceived Facilitators	I hate to say it, but I want to be told "this is what you can do to help him. This is what you should do." Rather than figuring out and navigating it ourselves. (P02)	I think my parents. Even though sometimes they get on my nerves, they're still trying to help me out. They're still pushing me to do it. (C03)

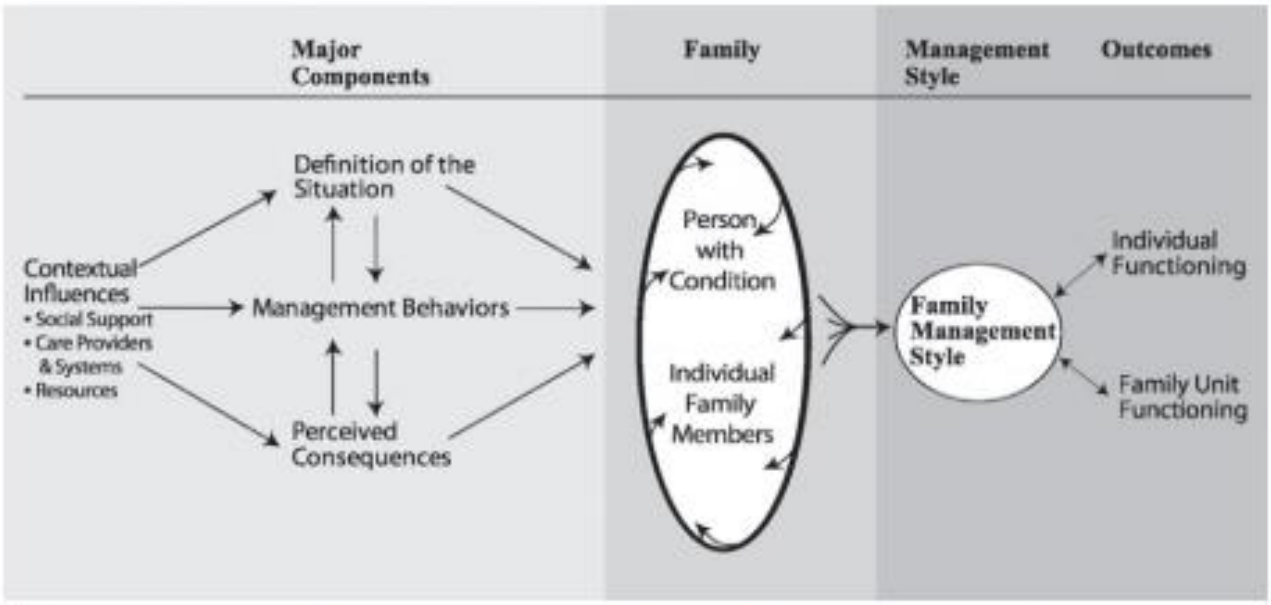

Figure 2. Current model of the family management style framework

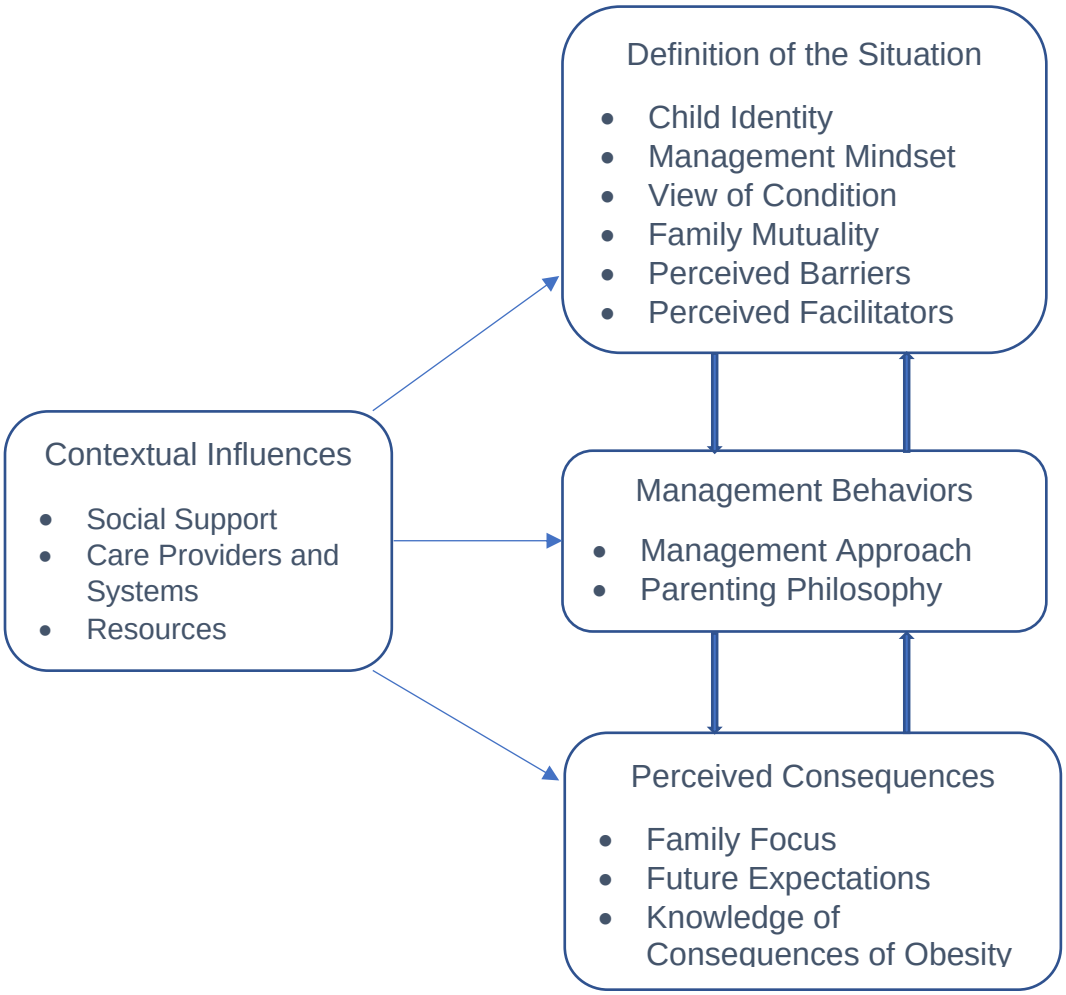

Figure 3. Adapted family management styles framework

Appendix

IRB Approval

Reply all | Delete Junk | ...

IRB 2018-2244 - Initial: Expedited Initial Approval Letter

IRB@luriechildrens.org Reply all |
Wed 11/7/2018 9:21 AM
To: AAriza@luriechildrens.org; hbinns@northwestern.edu; Roberts, Karyn J; kschaller@luriechildrens.org; lbolanos@luriechildrens.org

Inbox

Ann & Robert H. Lurie Children's Hospital of Chicago

Association for the Accreditation of Human Research Protection Programs, Inc. Full Accreditation

Expedited Initial Review Approval Letter

Karyn Roberts, MSN, RN
Department of Pediatrics

PROTOCOL TITLE: Experiences of Families with Children Attending a Clinic-Based Weight Management Program: A Qualitative Study

IRB 2018-2244

IRB APPROVAL DATE: November 7, 2018

IRB EXPIRATION DATE: October 31, 2019

This protocol was approved under the following risk/benefit determination as described in 45 CFR 46, Subpart D/21 CFR 50, Subpart D:

45 CFR 46.404/21 CFR 50.51 Research not involving greater than minimal risk

The Ann & Robert H. Lurie Children's Hospital of Chicago Institutional Review Board (Lurie Children's IRB) reviewed and approved the above-named protocol as authorized by 45 CFR 46.111/21 CFR 56.111 and via expedited review as authorized by 45 CFR 46.110/21 CFR 56.110. It is the expectation of this IRB that the rights and welfare of the individuals who are enrolled will be completely respected and that informed consent will be obtained in a manner consistent with Lurie Children's IRB policy governing the protection of human subjects.

The IRB approved and stamped consent document(s) for this submission is/are located in a comment posted in the " **Supporting Documents**" section of the Cayuse IRB application. Only the current Lurie

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Policies & Procedures Manual Section 11.1.F.

This research was reviewed and approved under expedited review **category #5**: Research involving materials (data, documents, records, or specimens) that has been collected, or will be collected solely for non-research purposes (such as medical treatment or diagnosis).

This research was reviewed and approved under expedited review **category #7**: Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Partial Waiver of HIPAA Authorization: The Lurie Children's IRB granted a partial waiver of authorization under 45 CFR 164.512(i) for the sole purpose of recruiting potential subjects. Once subjects have been recruited, they are required to sign authorization for use of their PHI.

Refer to the PDF of the Cayuse application for a full list of documents included with this submission.

Federal regulations require that an IRB conduct continuing review of research not less than once per year, regardless of whether initial approval was via full board or expedited procedures. Please note the expiration date for your current IRB approval and be aware that you must submit a progress report for IRB review prior to the expiration in order to obtain IRB approval for the next approval period. If the current approval expires and you do not obtain approval for another approval period, research on this study, including subject enrollment, must cease until you regain approval. If you have questions about your obligations as principal investigator, please contact the ORIC staff as listed on the ORIC website: https://www.luriechildrens.org/en-us/research/management/toolkit/Pages/research-directory.aspx

YOUR OBLIGATIONS AS PRINCIPAL INVESTIGATOR:
As the Principal Investigator, you are ultimately responsible for the conduct of the use, the protection of the rights and welfare of human subjects and adherence to the Lurie Children's IRB and hospital policies and procedures (Lurie Children's IRB Policy and Procedure Manual), including, but not limited to Section 5: Investigator Responsibilities and the following:

1. Ensure that all individuals who will work on the approved protocol are qualified, listed as Research Personnel in the Cayuse IRB application, and have completed the human subject protections education requirement.

2. Submit the renewal progress report for review and approval in advance of the expiration date.

3. Do not implement changes in the approved protocol or consent form(s) without prior IRB approval (except to eliminate apparent immediate hazards to safeguard the well-being of human subjects).

4. Obtain the legally effective written informed consent from human subjects or their legally authorized representatives as is applicable, using only the currently approved Lurie Children's IRB stamped consent form(s).

5. Report any unanticipated problems or noncompliance per IRB policies.

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Contact the Office of Sponsored Programs for information about the status of the clinical trial agreement or grant award.

7. Register your study: Applicable clinical trials (i.e., interventional studies of FDA-regulated drugs, biological products, or devices) must be registered on clinicaltrials.gov by the responsible party, typically the sponsor or a PI if designated by the sponsor (refer to FDAAA 801). In addition, the International Committee of Medical Journal Editors (ICMJE) recommends that all medical journal editors require registration of clinical trials in a public trials registry at, or before, the time of first patient enrollment as a condition of consideration for publication. Their definition of a clinical trial is much broader than federal requirements. Please refer to the ICMJE recommendations Section IIIK. Your study will be listed on the Clinical and Translational Research webpage for the hospital. If you do not wish your trial to be listed on this webpage, contact Marianne Reed within 10 days of this approval letter.

Sincerely,

Institutional Review Board
Ann & Robert H. Lurie Children's Hospital of Chicago

Institutional Review Board (IRB) Authorization Agreement

Name of Institution or Organization Providing IRB Review (Institution/Organization A):

Ann & Robert H. Lurie Children's Hospital of Chicago (Panel #1/Panel #2)

IRB Registration #: 00000624/00009723 Federalwide Assurance (FWA) #, if any 00001011

Name of Institution Relying on the Designated IRB (Institution B):

The University of Illinois at Chilcago

FWA #: 00000083

The Officials signing below agree that Karyn Roberts may rely on the designated IRB for review and continuing oversight of its human subjects research described below: (*check one*)

☒ This agreement is limited to the following specific protocol(s):

Name of Research Project: Experiences of Families with Children Attending a Clinic-Based Weight Management Program
Name of Principal Investigator: Karyn Roberts
Sponsor or Funding Agency: No Sponsor Award Number, if any: _____

☐ Other (*describe*): _____

The review performed by the designated IRB will meet the human subject protection requirements of Institution B's OHRP-approved FWA. The IRB at Institution/Organization A will follow written procedures for reporting its findings and actions to appropriate officials at Institution B. Relevant minutes of IRB meetings will be made available to Institution B upon request. Institution B remains responsible for ensuring compliance with the IRB's determinations and with the Terms of its OHRP-approved FWA. This document must be kept on file by both parties and provided to OHRP upon request.

Signature of Signatory Official (Institution/Organization A):

Cassandra L. Lucas Date: 10/3/2018

Printed Name: Cassandra Lucas, PhD Title/Institution: Chief Operating Officer
Stanley Manne Children's Research Institute
Ann & Robert H. Lurie Children's Hospital of Chicago

Signature of Signatory Official (Institution B):

Date: 10/1/18

Printed Name: JOANNA GRODEN Title/Institution: Vice Chancellor for Research, UIC

CURRICULM VITAE

Karyn Roberts MSN, RN, CHSE, CPEN

University of Illinois at Chicago, College of Nursing

Department of Women, Children and Family Health Sciences

845 S Damen Ave. Rm 838

Chicago, IL 60612-7350

office phone 312-355-0746/fax 312-996-8871

phone 847-393-3539

email: krober25@uic.edu

Education

University of Illinois at Chicago, Chicago, IL

2015- Current PhD Candidate-expected graduation December 2019

Dissertation Title: **Experiences of Families with Children Attending a Clinic-Based Weight Management Program: A Qualitative Study**

Research interests: pediatric obesity particularly in high risk populations; Latino, African American and low socioeconomic communities, family focused research of children with chronic illness, simulation implementation and outcomes

Grand Canyon University, College of Nursing, Phoenix, AZ

2012 MSN-Nursing Education

Madonna University, College of Nursing, Livonia, MI

1995 BSN Nursing – with High Honors

Current License and Certifications

2019-2022 Certified Healthcare Simulation Educator (CHSE)-Society Of Simulation in Healthcare

1993-2020 BLS-Healthcare Provider-American Heart Association

1995-2020 Michigan RN # 4704201513

2003-2020 Illinois RN #041338578

2019- 2020 Wisconsin RN #248941-30

Professional Experience

University of Illinois at Chicago, College of Nursing, Chicago, IL

2012-Present Teaching Associate/Course Coordinator

Northwest Community Hospital, Arlington Heights, IL

2010-2018 Pediatric Advanced Life Support (PALS) Instructor

co-coordinator from 2011-2016

Northwest Community Hospital, Arlington Heights, IL

2008-2017 Staff Nurse-Pediatric Emergency Department; Pediatric Unit, Ambulatory Infusion Clinic; Surgical Case Reviewer-Quality Improvement Resource Specialist

Kaplan INC

2011-2012 Nursing Faculty-NCLEX review courses

International Teams, Dushanbe, Tajikistan

2007 International Worker/Relief and Development

Northwest Community Hospital, Arlington Heights, IL

2005-2006 Staff Nurse- Pediatrics

Condell Medical Center, Libertyville, IL

2004-2005 Staff Nurse-Pediatrics

Midwest District Christian and Missionary Alliance, Bloomingdale, IL

2003-2007 Assistant Director of Russian Ministries

Christian and Missionary Alliance, Moscow, Russia

1999-2003 International Worker-Hospitality and Logistics

Christian and Missionary Alliance/CoMission, Astrakhan, Russia

1996-1997 International Worker-Educational Consultant

Children's Hospital of Michigan, Detroit, MI

1995-1996 Staff Nurse, Neurosurgery Unit

Grants

2019	Sigma Small Grants- Sigma Theta Tau International Nursing Honor Society
2019	Seth and Denise Rosen Memorial Research Award- UIC College of Nursing
2019	Sigma-Alpha Lambda Chapter Research Award – UIC College of Nursing

Honors and Awards

2013	Daisy Faculty Award-UIC, College of Nursing
2011	Kathy Reno Scholarship Recipient, Northwest Community Hospital, Arlington Heights, IL
2011	Giness Advance Practice Scholarship Recipient-Emergency Nurses Association
1994-Present	Sigma Theta Tau National Nursing Honor Society

Research

Ann and Robert E. Lurie's Childrens Hospital-Wellness and Weight Management Clinic, Chicago, IL & University of Illinois College of Nursing, Chicago, IL

2019-current Principal Investigator-Doctoral Dissertation "*Experiences of Families with Children Attending a Clinic-Based Weight Management Program: A Qualitative Study"*

University of Illinois College of Nursing, Chicago, IL

2018 Research Assistant/Recruitment and Enrollment for Doctoral research study "*Maternal Weight, Placental Expression of Growth Factors, and Birth Weight*."

University of Illinois College of Nursing, Chicago, IL

2017 Data Coder for doctoral research study "*Possible Selves, Psychological Well-Being, and Substance Use in Young Men Post-Incareration*

Northwest Community Hospital, Arlington Heights, IL

2009-2010 Nursing Research Fellowship Fellow, IRB study "*What are nurses' perceptions in regards to caring for the culturally diverse patient?"*

Relevant Training

2019 National Institue of Nursing Reserach Boot Camp- Precision Health: Smart Technologies, Smart Health. July 15-18, 2019. National Institutes of Health, Bethesda, Maryland.

Professional Activities

International Association for Clinical Simulation and Learning (INACSL)-member

Midwest Nursing Research Society (MNRS)- member

Sigma Theta Tau International-Kappa Iota Chapter-member

International Family Nursing Association (IFNA)- member and member of the Research Subcommittee

Conference Meetings/Presentations

Local

2014
Roberts, K.J., Duback, K., Sava, K. & Obrecht, J.(2014). Podium Presentation *"Integrating Nursing Education and Practice: Utilizing Clinical Partnerships To Provide Simulation Experiences to Nursing Students."* 2nd Annual Advocate Healthcare Nursing Research Symposium. Chicago, IL. April 9, 2014.

2011
Roberts, K.J., Reidinger, G., & Koran, Z. (2011) Poster Presentation: *Cultural Competence: Nurses' Perceptions Regarding the Culturally Diverse Patient* Exemplary Professional Practice in Action: Research and Education: Advocate Christ Medical Center, Oaklawn, IL, April 12, 2011.

Regional

2018
Johnson, A., Corte, C., **Roberts, K.J.** (2018). Poster Presentation "*Possible Selves, Psychological Well-Being, and Substance Use in Young Men Post-Incarceration*". Midwest Nursing Research Society 42nd Annual Research Conference: The Future of Nursing Research: Economic Realities and Creative Solutions. Cleveland, OH April 14, 2018.

National

2015
Kendrick, A., **Roberts, K. J**. Poster Presentation "*Utilizing Simulation to Bridge Gaps in Clinical Nursing Education*". 40th Annual March of Dimes Perinatal Conference: Improving Perinatal Outcomes: 40 Years of Success! Westin, Lombard, IL March 9 & 10, 2015.

2014
Roberts, K.J., Duback, K., Sava, K. & Obrecht, J.(2014). Poster Presentation *"Integrating Nursing Education and Practice: Utilizing Clinical Partnerships To Provide Simulation Experiences to Nursing Students."* 9th Annual NLN/Elsevier Technology Conference: What's Happening Now? Nashville, TN. October 25, 2014.

International

2019
Roberts, K. J., & Gallo, A.M. Poster Presentation "Experiences *of Families with Children Attending a Clinic-Based Weight Management Program: A Qualitative Study."* 14th International Family Nursing Conference (IFNC14). Washington DC, August 14, 2019.

2016
Roberts, K.J., O'Rourke, J. Poster Presentation *"Using Multiple Hybrid Patient Simulation to Teach Prioritization, Safety and Communication."* INACSL (International Nursing Association for Clinical Simulation & Learning) Conference 2016. Grapevine, TX June 16, 2016.

Educational Activities

2017 IPE Immersion Day April 8- faculty faciliator for this campus wide event for students in the health and social science colleges.

2017 DocuCare EMR Faciliator spring 2017, working specifically with NUPR 405, the Graduate Entry fundamentals course, to gain a greater understanding of how this tool can be utilized in clinical and classroom courses, create assignments that will help students acclimate to the EMR as well as integrate concepts they are learning across courses, and provided workshop based education for faculty in order to facilitate their implementation of DocuCare into their courses. Collaborating with a CON-IT staff to integrate DocuCare with our Pyxis system in the CRLC, as well as identify barriers to implementation.

2017 Course Development NURS 377 Integrative Practicum Experience UIC-CON 2017; worked with faculty from multiple campuses to develop content for this new course, NURS 377 Integrated practicum, which is meant to be largely simulation and lab experiences for the BSN program.

2016 Faculty Facilitator for Essentials of Clinical Practice and Professionalism 2-Patient Care Handoffs-UIC College of Medicine: Facilitated classroom activity with fourth year medical students on patient handoffs for observing and giving feedback to students on patient handoffs.

2015-2017 Simulation Curriculum Integration Leadership Team-intercampus team for designing and implementing standardized simulation into the new BSN curriculum, UIC College of Nursing, 2015-2017, part of working group to integrate 24% simulation

into clinical courses, faculty who will be specifically implementing and debriefing simulation, and help develop other facutly for competency in simulation creation, implementation and debriefing

2015 Reviewer/Consultant for Faculty Simulation Development Online modules for UIC College of Nursing

2015 (Summer) Team Lead/Facilitator for the development of a new pre-licensure clinical evaluation tool,

2014 (July) Reveiwer/Consultant for Pediatric Master's Curriculum University of Rwanda

2014 (July) Reviewer/Consultant for Undergraduate Pediatric Curriculum University of Rwanda

Volunteer and Service

2019, 2017 (August) Volunteer with Little by Little Haiti. Medical mission trip to Gramothe, Haiti for one week to work at a clinic providing medical care to patients,

2018 (Summer) Service Learning Liason/Coordinator with UIC College of Nursing through Little by Little Haiti. Coordinated 5 pre-licensure nursing students for a service learning experience in Haiti providing direct care to patients in medical clinic in Gramothe, Haiti for one week.

Teaching

University of Illiinois at Chicago-College of Nursing

Course	Level	Semester	Year
NURS 210 Health Assessment	BSN	Fall	2013, 2014, 2015
NURS 242 Concepts and Processes in Contemporary Nursing	RN-BSN	Spring	2013
NURS 212 Health Assessment and Communication	RN-BSN	Spring	2016, 2017, 2018
NURS 314 Nursing Care of Children and Families	BSN	Fall	2018
NURS 371 Acute Care Nursing Care Management	BSN	Spring	2018
NURS 377	BSN	Fall	2017

Integrative Practice Experience			
NURS 355 Clinical Concepts and Processes of Child and Family Nursing	BSN	Spring	2016
NURS 530 Introduction to the CNS Role	Graduate	Spring	2013, 2014, 2015
NUPR 415 Integrated Practicum III- Women and Children's	Graduate Entry	Fall, Spring	2012, 2013, 2014, 2015,2016, 2017, 2019
NUPR 420 Clinical Synthesis	Graduate Entry	Spring/Summer	2013, 2014, 2015, 2017, 2018,2019
NUPR 520 Clinical Synthesis Practicum	Graduate	Summer/Fall	2016, 2017, 2018.2019
NUPR 569 Pediatric/Perinatal CNS Practicum I	Graduate	Summer	2013, 2014, 2015, 2016
NUPR 570 Pediatric/Perinatal CNS Practicum II	Graduate	Fall	2013, 2014, 2015, 2016
NUPR 571 Pediatric/Perinatal CNS Practicum III	Graduate	Spring	2013, 2014, 2015, 2016, 2017

Educational Presentations

2017 "Reflective Teaching, Practice and Leadership"- Presentation for Director of Clinical Simulation and Learning- UIC College of Nursing

2014 NCLEX exam overview—Graduate entry students, University of Illinois at Chicago. Chicago IL

2012-2014 Simulation creation, implementation and integration into courses for GEP Courses, NUPR 415, 420

Mentor/Preceptor Activities

2019 Summer: Mentoring BSN student in research methods and qualtiative interviewing.

2019 Spring: Mentored new clinical faculty in their teaching role in both clinical and in simulation faciliattion and debriefing.

2018 Fall: Mentored new faculty in their role as course coordinator and several new clinical faculty their clinical teaching role and in simulation facilitation and debriefing.

2018 Fall: Precepted a graduate student from Olivet Nazarene University for her final practicum experience in MSN-Nursing education program. Supervised her in the role of clinical instructor with 8 prelicensure student at the clinical site for 14 weeks and facilitated her experiences with didactic faculty and simulation.

2017 Summer: Precepted/mentored Advanced Generalist Masters student in simulation activities of coordinating, facilitating and debriefing simulations for pre-licensure students.

2016 Spring/Summer: Helped to provide support to the new director of clinical simulation lab since departure of Director of Clinical Learning Center, worked to try and develop small team of clinical faculty and graduate assistants to implement simulation integration into new BSN curriculum beginning Fall 2016

2015 Fall: Mentored new clinical facutly (NUPR 415) in observing and debriefing of simulation based on INACSL Standards of Best Practice in Simulation

2015 Fall: Mentored CNS student in the clinical faculty role (NUPR 415) at a clinical site for the semester as well as gave direction in simulation creation and implementation

2014 (Fall)-2015 (Spring): Mentored CNS student specifically in simulation development and implementation as well as abstract writing for poster submission/ and helped with poster development