FOOD AND PHYSICAL ACTIVITY CHOICES TO PREVENT OVERWEIGHT IN CHILDREN WITH SPINA BIFIDA

by

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ABSTRACT

Purpose: To explore how parents develop and form health promotion beliefs and practices related to food and physical activity choices for children with spina bifida to prevent overweight.

Significance: Overweight rates for U.S. children exceed the rates of previous generations. For children with physical disabilities, overweight rates are 30%, as compared to 17% for their peers without disabilities. For children with physical disabilities, overweight has a greater impact on physical functioning and quality of life, acting as a secondary condition or disability.

Specific Aims: To (a) describe how parents of children with physical disabilities understand and make decisions about food and physical activities choices, (b) determine barriers and supports for parents related to food and physical activity choices for their children, and (c) describe how parents of children manage and prevent overweight in their children with spina bifida.

Methods: Descriptive, exploratory, qualitative design using semistructured interviews with parents of children with spina bifida (6 to 12 years of age) with verbatim transcription and constant-comparative analysis.

Results: Three themes related to health promotion for children with spina bifida were (a) promoting health by maintaining healthy bowel function and managing spina bifida, (b) managing food, and (c) encouraging physical activity. Health promotion for these parents was based on maintaining optimal bowel function and disease management for their children. Managing food involved teaching, monitoring, adapting, portioning, awareness of overweight risk, and restricting food. Encouraging physical activity included facilitating, hindering, and dealing with becoming sedentary and overweight as children reached puberty.

Implications: Knowledge from this study may assist parents and healthcare providers change their focus from disease-related systems and function to more holistic perspective by assessment of social interaction and participation in physical activities. Anticipatory guidance can be enhanced to include promoting the use of food substitution and minimizing food restriction practices and assessing school-age children for their current level of physical activity with encouragement for them to remain physically active.

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CHAPTER ONE

INTRODUCTION

Statement of the Problem

The Expert Committee on childhood overweight and obesity reported that 17% of U.S. children are overweight and concluded that all children are at risk for overweight (2007). Important to this study is that rates of overweight for children with physical disabilities in the US are 30 to 36% (Rimmer, Rowland, & Yamaki, 2007). Overweight for these children is due in part to decreased physical function, limited mobility, and, altered family environments created by the presence of a disability (Wallander & Varni, 1998). The risk of becoming overweight is increasing for children with physical disabilities and presents more health and functional problems as compared to nondisabled children (Rimmer et al., 2007).

For children with physical disabilities, overweight has a greater impact on physical functioning and quality of life, acting as a secondary disability that affects their compromised physical function (Liou, Pi-Sunyer, & Laferrere, 2005; Rimmer et al., 2007; U.S. Department of Health and Human Services., 2000). Family environments are challenged to maintain or improve physical function and quality of life for their children. Children with physical disabilities live in family environments affected by the presence of a physical disability and challenged to care for complex health care needs for the child that compete with parent's focus and care on overweight and obesity (Seligman & Darling, 1997). Additionally, medical care needs may be viewed as more important by parents than teaching health promotion or preventing overweight (Wallander & Varni, 1998).

Assessment of a child's overweight status is complicated by the presence of a physical disability. Overweight and obesity are most commonly assessed as body mass index percentile (BMI) measurement. BMI percentile scores are based on norm-referenced data of populations of nondisabled children, offering practitioners and parents an estimation of an individual's weight status as compared to average populations (CDC, 2005). National U.S. data was used to calculate the age- and sex-specific percentiles, providing *z*-scores for height and weight, which represent a child's BMI status relative to all U.S. children (Freedman et al., 2005). A BMI score greater than 85th percentile is at risk of overweight, greater than 99th percentile is obese, and percentiles between 5th and 85th are within normal weight (U. S. Preventive Services Task Force., 2005). However, a BMI score based on norm-referenced data does not accurately reflect the overweight or obesity status of a child with physical disabilities as BMI data is norm-referenced for a nondisabled population. Norm-referenced populations do not represent altered body morphology of height-to-weight ratios seen in conditions of populations with physical disabilities. Thus, healthcare practitioners and parents lack accurate data sources to assess overweight and obesity status for their children.

Overweight and obesity add more risk for a child with physical disabilities. In addition to the primary health risks of hyperlipidemia, high blood pressure, diabetes, cardiovascular complications, and metabolic syndrome (Baker et al., 2005; Wofford, 2008), overweight adds unique long-term consequences such as decreased physical function of compromised musculoskeletal and pulmonary systems; increased stigmatization leading to limitations in peer socialization; and decreased opportunities for recreational, social, leisure, and work activity (Odding, Roebroeck, & Stam, 2006; Rimmer et al., 2007). Overweight undermines compromised physical and psychosocial functioning and ultimately undermines self-care, self-concept and independence (Rimmer et al., 2007).

Parents provide the most significant impact on how children develop and internalize health promotion behaviors (Roden, 2004; Wallander & Varni, 1998). They form their child's health promotion skills within the family environment. Their desire to direct health promotion to prevent overweight is based on their individual risk perception of the problem developing for their child (Birch & Davidson, 2001). And for their children, parents play a central role in modeling food and physical activity patterns, such as supervising food choice, availability and quantity; as well as modeling participation in physical activity. Yet, parents' ability to teach health promotion can be negatively affected by stress, depression, overweight risk perception, availability to monitor and supervise, as well as family disorganization and ineffective parenting styles (Bond & Burns, 1998; Wallander & Varni, 1998).

Spina Bifida as a Prototype

Spina bifida was used as a prototype for physical disabilities in this study because this condition represents a complex range of physical and functional disabilities. A range of like physical abilities provided this study a group of similar parent tasks, actions, and challenges. The range of disability for these children includes limited mobility, altered feeding practices, bowel and bladder control, fragility in infancy, use of adaptive devices, stigmatization, and limited access to community (Mita et al., 1993; Simeonsson, McMillen, & Huntington, 2002). Additionally, overweight is a common occurrence in children with spina bifida (Simeonsson et al., 2002).

Conceptual Framework

Bronfenbrenner's ecology framework of human development (Bronfenbrenner, 1979) was used as a conceptual framework to describe the interactions of environmental systems affecting the development of children. Bronfenbrenner's framework was used to describe how health promotion skills are developed for children and to describe how parents create an environment for their child with physical disabilities that promotes healthy food and physical activity choices to prevent overweight and obesity. Bronfenbrenner's microsystem is the immediate setting for the child and family. The microsystem includes all social contacts such as those in the child's school and community. The mesosystem includes interactions with the social agents within the microsystem for the child, family, and immediate community. Descriptions and interactions in both the microsystem and the mesosystem have been gathered in the interviews and are reported in the Results section.

Obesiogenic Environment for Children with Physical Disabilities

The family environment may be an obesiogenic microsystem, meaning that family patterns promote the development of overweight within the immediate interactive systems surrounding the child (Ritchie, Welk, Styne, Gerstein, & Crawford, 2005). Parents and the family environment model food and physical activity patterns for all children. Parental factors that can promote an obesiogenic environment for children with physical disabilities are on-going health care and treatment burden, specific health teaching needs related to their child's physical disability, and decreased social interaction for children and parents— all of which combine to promote poor food and physical activity patterns modeled by parents (Bandini, Curtin, Hamad, Tybor, & Must, 2005; Rimmer et al., 2007). Additionally, the social environment for children with physical disabilities has altered socialization patterns, altered uses of food as comfort or entertainment, and food used to fill the social gaps left by limited peer interaction (Field, Jette, & Martin, 2006).

Thus, family and social environments for children with physical disabilities have additional risks to be obesiogenic as compared to nondisabled children because of the limitations and alterations in the microsystem environment (Latner, Stunkard, & Wilson, 2005; Rimmer et al., 2007; Simeonsson et al., 2002). Indeed, evidence supports that microsystems create more overweight and obesity for children with physical disabilities (Field et al., 2006; Rimmer et al., 2007). Current knowledge also informs nursing that the addition of overweight and obesity for these children further threatens the ability of parents to effectively care for their children as they move through physical and developmental stages to adulthood (Betz, 2008; Rimmer et al., 2007).

Antecedents and Consequences to Overweight for Children with Physical Disabilities

A concept analysis of the antecedents and consequences of overweight for children with physical disabilities was conducted (Luther, 2006).The analysis provides an extensive background analysis of current research related to overweight and obesity that creates an obesiogenic environment for children with physical disabilities and is reviewed as compared to nondisabled children in Table 1. For children with physical disabilities such as spina bifida, antecedents to overweight and obesity include decreased physical activity due to immobility or pain, decreased physical functioning due to impaired neuromuscular systems, pressured feeding activities, decreased socialization, and lack of resources to adapt the child's environment to permit activity (Rimmer et al., 2007).

Krebs et al. (2007) reviewed over 300 studies on adiposity measurement in children in current literature. Findings indicate that for all children, especially children with physical disabilities, the environment can be obesiogenic and inaccurate measurement promotes weight misclassification. Krebs et al. (2007) demonstrates measuring and treating overweight is complicated by inaccuracy of a child's overweight status as well as inaccurate prediction of the trajectory of a child's overweight status. Parent and healthcare providers' perceptions can be that a child will grow out of their overweight status with their next growth spurt versus being physically active, thus postponing treatment (Edmunds, 2005; Ritchie et al., 2005; Towns & D'Auria, 2009). Edmunds (2005) interviewed 40 parents about their interactions with healthcare providers (HCP) about their child's weight status. Edmunds (2005) reports that parents rate healthcare providers interaction outcomes from mildly helpful to dismissive about their concern for their child's overweight and the effect of their current overweight status. Ritchie et al. (2005) provide a review of current nationally recognized literature of environmental factors promoting overweight, concluding that HCPs influence the care and focus of families by providing an accurate overweight assessment and should indeed help parents modify their beliefs to accurately reflect their child's risk of overweight. Towns and D'Auria (2009) reviewed 17 studies of parental perceptions of child overweight studies (not specific to children with disabilities) and concluded that parents

Table 1 Antecedents of Overweight

	Nondisabled Child	Child with Physical Disabilities
Physical Function	No or minimal physical functioning alterations but changes in physical activity of ↓ availability and duration at home and school as well as ↑ in sedentary behaviors	↓ physical function as well as changes in physical activity availability and duration at home and school as well as ↑ sedentary behaviors
Food	Altered food quality in amount and frequency of consumption of energy dense foods	Use of food as comfort and emotional replacement for decreased social and peer interaction
Immobilization	No immobilization	Impaired mobilization
Adaptive Needs	No need for adaptive environment to promote physical activity	Lack of adaptive environment to promote physica activity
Stigmatization	No stigmatization from peers with normal wt.	↑ stigmatization from peers due to disability
Socialization	Normal socialization with peers	↓ socialization with peers

Parent Task	Nondisabled Child	Child with Physical Disabilities
Self-care and Independence	Focus on teaching self-care and independence	Focus on care and survival of the child's disabilit rather than quality of life, self-care, independence or health promotion
Caregiving Tasks	Normal family/work/community caregiving task for parents	↑ Caregiver burden due to tasks and concerns of disability
Stress and Coping	Normal stress and coping patterns	↑Stressors and ↓ coping strategies due to presence of disability
Food and Eating Patterns	Normal food and eating pattern development as per family	Altered food and eating patterns
Assessment of Overweight	Ability to accurately detect overweight with Ht/Wt (BMI) chart and/or visual assessment of child	↓ ability to detect overweight due to altered body morphology of child and inaccurate BMI charts.

inaccurately assess their child's overweight status and do not perceive the severity of health risk due to overweight for their children. While the studies reviewed were all cross-sectional designs and not all conducted in populations of children with disabilities, these studies were important to understand parent's current perceptions of overweight status and risk from overweight. Parents, and healthcare providers, need accurate assessment of overweight and an accurate perception of overweight risk as early intervention is key for the treatment of overweight (Edmunds, 2008; Krebs et al., 2007; Towns & D'Auria, 2009).

Parents of children with physical disabilities also have altered attitudes towards physical activity to prevent overweight (Rimmer et al., 2007). Rimmer et al. (2007) reviewed four environmental factors of physical activity, nutrition, knowledge, and social participation demonstrating that the micro- and mesosystems for children with disabilities have barriers and attitudes about being physically active that promote overweight. Simeonsson et al. (2002) provide a review specific to the secondary conditions present in the environment for children with spina bifida and report that parents often have lower expectations of participation for children with disabilities in their systematic review. Parents may believe their child cannot be physically active or have a belief that if their child is overweight, they will outgrow their overweight status in the future (Simeonsson et al., 2002). The presence of a physical disability affects and alters the parent's ability to form and develop health promotion practices related to physical activity to prevent overweight in children with physical disabilities.

Alterations in the use of food for children with physical disabilities can create an obesiogenic environment because food is often used as comfort or emotional support

(Baughcum, Burklow, Deeks, Powers, & Whitaker, 1998). Additionally, parents fear that limiting or controlling their child's food intake might be interpreted as lack of nurturance and parents may be afraid to address issues of overweight with their child due to possible negative emotions and the effect on their parent-child relationship (Borra, Kelly, Shirreffs, Neville, & Geiger, 2003). However, using food restriction to control weight has been known to promote the development of poor food choices and ultimately creates hidden eating patterns for children leading to overweight (Birch & Davidson, 2001; Ritchie et al., 2005).

Parent strategies directed toward monitoring food need to change as their child grows and develops to prevent the child from becoming overweight (Ritchie et al., 2005). Effective parenting to prevent obesity, as children grow and develop, requires parents to respond to stressors within their environment to continually recognize, reassess, and adjust food and physical activity patterns. However, the trajectory of parenting a child with a physical disability and how strategies of parenting are formed within the environment of a physical disability helps examine the antecedents and consequences of overweight within the family microsystem.

Consequences and Trajectory of Overweight

After becoming medically and nutritionally stable in infancy, children with physical disabilities can move from being nutritionally at-risk and underweight to becoming overweight .Specific events that can promote the development of overweight for children with physical disabilities during the school-age developmental period (6 to 11 years) include the following: (a) if a child is identified as being overweight, their parents may not be able to adjust feeding patterns and practices currently in place in the family environment; (b) due to the maturational changes and physical limitations, as well as limited resources and time, parents may not be able to increase their child's physical activity; and (c) parents and healthcare providers do not have a clear indication of the severity of a child's overweight status due to inaccurate growth grids and body mass index (BMI) because of altered body morphology for children with physical disabilities. The combination of these factors may contribute to parents being less likely to assess their child as overweight; thus, parents are less likely to alter the child's environment to prevent or treat overweight. Parents may not identify changes of decreased physical abilities and increased overweight as their child's body develops during childhood and adolescence. Although spina bifida is not a progressive disorder, it can appear progressive in that children with physical disabilities often lose functional ability as their body nears maturation. At an adult body size, the school-age child with physical disabilities often does not possess the strength to move in their environment as compared to the mobility they once had as a younger child. Table 2 outlines the consequences of overweight as well as consequences of overweight as compared to nondisabled children.

Feeding Practices with Children with Physical Disabilities

Children with physical disabilities, such as spina bifida, often have unstable weight as infants, requiring parents to learn practices that persuade a child to eat. Parents' previous food and feeding strategies when their infant was struggling to survive were most often formulated to help their child gain weight. However, as the child enters middle childhood, the overweight child no longer needs to gain weight. A consequence of

Table 2 Consequences of Overweight to Children

	Overweight Child	Overweight Child with Physical Disabilities
Physical Function	Risks of overweight such as: hyperlipidemia, diabetes, heart disease, ↓ pulmonary and musculoskeletal functioning, ↓cardiovascular function	Same cardiovascular and hepatic risks as for Overweight Child as well as change in already compromised systems of: ↓cardiovascular function, ↓ physical function and mobilization ↑ risk for secondary disabilities of: skin breakdown, pain, fatigue, depression
Immobilization	Impaired mobilization	Impaired mobilization
Adaptive Needs	Minimal threat to self-care and independence	↑ threat to self-care and independence
Stigmatization	↑ stigmatization from peers due to presence of overweight	↑ stigmatization from peers due to presence of overweight and disability
Socialization	Unknown socialization changes with peers due to presence of overweight	↓ socialization with peers due to presence of disability and possibly due to overweight
Parent Task	Overweight Child	Overweight Child with Physical Disabilities
Self-care and Independence	↑ need to focus on quality of life but minimal threat to independence or child's physical activity opportunities	↑ need to focus on quality of life and self-care/independence skill development
Caregiving Tasks	Additional tasks related to care of overweight	Additional tasks of care of physical disability as well as care of overweight. Inability to ↑ physical activity due to presence of disability and sedentary
Stress and Coping	↑Stressors and ↓ coping strategies due to presence of overweight	↑Stressors and ↓ Coping Strategies due to presence of overweight and the presence of the child's disability
Food and Eating Patterns	Changes to ↓ child's consumption of energy dense foods	Greater difficulty of changing food choices as food is also comfort and/or emotional replacement for socialization
Assessment of Overweight	Ability to accurately detect overweight with Ht/wt (BMI) chart and/or visual assessment of child	↓ ability to detect overweight due to altered body morphology of child and inaccurate BMI charts.

persuasion or coaching feeding practices is that as a child gains independence, and are expected to make their own food choices, they have tendencies to choose forbidden or off-limits food and avoid healthy foods (Birch & Davidson, 2001). Parents state that food is used to comfort their children with physical disabilities in an environment of restricted activities (Field et al., 2006); however, these feeding practices used to satisfy children's emotional needs also promote overweight (Birch & Davidson, 2001).

Physical Activity, Social Isolation, and Physical Disabilities

Many children with physical disabilities experience more barriers to physical activity, are more likely to be sedentary, and need their environment to be adapted to their disability in order to be active (Rimmer et al., 2007). They need assistance from parents and others to be able to safely navigate curbs, sidewalks, and playgrounds. At the same time, children with physical disabilities experience decreased peer interaction as compared to their nondisabled peers due to the presence of their disability (Blum, Resnick, Nelson, & St Germaine, 1991; Field et al., 2006). Isolation from peers and lack of an accessible environment for children with physical disabilities promotes being sedentary at home rather than being physically active in the community (Ritchie et al., 2005).

Stress and Coping

Families with children who have physical disabilities are affected by the unique stressors and need for implementation of specialized coping strategies brought on by the presence of a physical disability in the child and family's environment (Seligman & Darling, 1997). Stress and coping is a developmental and transactional framework representing positive and negative influences/stressors on individuals within the family (La Greca, Siegel, Wallander, & Walker, 1992). Adaptation to stress and the use of available coping strategies affect a family's ability to attend to food and physical activity needs of their child with physical disabilities (Ayyangar, 2002). The additional care concerns related to raising a child with a physical disability create unique stressors for parents that overshadow health promotion concerns about food and physical activity.

Specific Aims

This studies specific aims were to (a) describe how parents of children with physical disabilities understand and make decisions about food and physical activities choices, (b) determine barriers and supports for parents related to food and physical activity choices for their children, and (c) describe how parents of children manage and prevent overweight in their children with spina bifida.

Purpose

Current research purports that children with physical disabilities are at an increased risk of overweight and that the presence of overweight threatens their ability to effectively care for themselves as they move through physical and developmental stages to adulthood (Rimmer et al., 2007). Additionally, parents are challenged to detect overweight or obesity in their children with physical disabilities. And finally, parents of children with disabilities may have more pressing concerns about their child's overall health than concerns directed to decreasing their child's risk for overweight and obesity. Discovery of family mechanisms that detect or promote overweight in children with physical disabilities will enhance nursing knowledge, as well as enhance development of nursing interventions needed to overcome barriers to preventing overweight and obesity in children with physical disabilities. Thus, the purpose of this study was to explore how parents develop and form health promotion beliefs and practices related to food and physical activity choices for children with spina bifida to prevent overweight.

Summary

At present, investigators demonstrate the occurrence of overweight in children with physical disabilities (Bandini et al., 2005) and show alterations in a child's microsystem that can promote overweight (Rhee, Lumeng, Apugliese, Kciroti, & Bradley, 2006; Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004). The environment for children with physical disabilities is at greater risk to become obesiogenic due to the presence of a physical disability (Blum et al., 1991; Rimmer et al., 2007). Gaps in current knowledge include accurate descriptions of parents' understanding and ability to detect or prevent overweight as well as a description of parental beliefs, attitudes, barriers, and supports related to promoting healthy food and physical activity to prevent overweight. Findings from this study will describe the microsystem parents' form for children with physical disabilities related to food and physical activity in the prevention or treatment of overweight. Findings will also guide the development of nursing interventions to prevent overweight and obesity in children with physical disabilities.

CHAPTER TWO

REVIEW OF LITERATURE

This review of literature explores the constructs of obesiogenic environments, including parenting style, effective parenting, family environment, and health promotion. Antecedents to overweight such as poor feeding practices, decreased physical activity, poor development of self-regulation, and social isolation as related to overweight are presented as well. Bronfenbrenner's (1979) ecology framework of human development is presented as a conceptual framework for the variables in family environments for children with physical disabilities. Spina bifida was used as a prototype for children with physical disabilities. Stress and coping research is reviewed in relationship to how parents react to stimuli in their environment as they care for their child with physical disabilities. A concept analysis of the antecedents (Table 1) and consequences (Table 2) of the obesiogenic environment for children with physical disabilities (Luther, 2006) are also reviewed as background to this study.

Bronfenbrenner's Ecological Framework of Human Development

Bronfenbrenner's (1979) ecological framework of human development is a socio-cultural framework and explains the interrelatedness between the child and family. Interaction in the environment is how children learn health promotion, specifically food and physical activity choice development. Bronfenbrenner outlines five systems of interaction that affect children as they develop and incorporate health promotion messages from their environment (Figure 1). Using a framework in overweight and obesity studies, as in other studies, increases the power of explanation of results and decreases the complexity of the phenomena (Clark, 2008). Two of those five systems in Bronfenbrenner's framework, the microsystem and mesosystem, are a focus for this study because they represent the most interactive and immediate systems for the child and family. Microsystem is the setting in which the child is positioned as well as the child's family, school, and neighborhood. The mesosystem is the relationship between all the experiences and persons in the microsystem.

In Bronfenbrenner's (1979) framework, the microsystem represents the center of the framework and includes the child and immediate family (Figure 1). The microsystem contains direct interactions between children, parents, siblings, family, peers, schools, and neighborhoods that construct self beliefs for children. The microsystem has the most interaction with social agents and helps individuals construct their setting. The mesosystem represents all the relationships between the microsystem present in the child and family's environment. The exosystem encompasses the experiences in which an individual does not have an active role but that influence them in an immediate context such as community policies related to disability access. A macrosystem represents the consistent patterns and attitudes in society surrounding the child and family that hold the blueprint for the immediate environment. The chronosystem in Bronfenbrenner's theory are the patterns of environmental events over long periods of time or at critically intense periods in time that pervasively affect the permanent images of a culture or society.

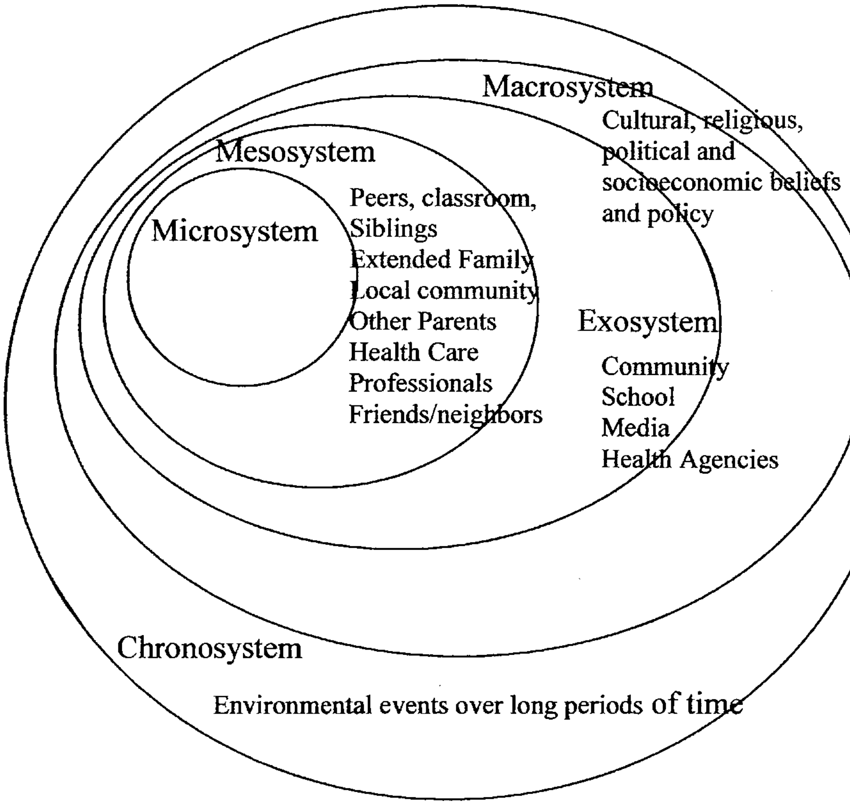

Figure 1. Bronfenbrenner's Ecology Framework of Human Development (Bronfenbrenner, 1979)

Application of Bronfenbrenner for Children with Physical Disabilities

A child with spina bifida has a microsystem that includes family, siblings, peers at school, and neighborhood. The child with physical disabilities has interactions with peers during school hours and limited interaction with peers in the neighborhood (Blum et al., 1991). Thus, the main social agents for a child with spina bifida are their family and those within their home environment, school, and neighborhood. This child's microsystem is impaired by availability to fewer social agents to facilitate interaction, limited mobility in their home, school, and community, and decreased socialization with peers as compared to an nondisabled child (Blum et al., 1991).

The mesosystem, interaction within the microsystem agents, is affected by the presence of the child's disability. The time for valuable mesosystem interactions compete with medical care needs and are additionally affected by the presence of social isolation for the child and the family. The mesosystem for a child with spina bifida can be impaired due to the limited number and interactions with social agents and social situations and thus affect how children incorporate concepts of self and self-care into their personal self-concepts. An example of the mesosystem for a child with spina bifida includes more interactions that are focused on providing care for the child's disability than interactions that support them as a developing child. A system for children with physical disabilities has different interactions than systems that surround nondisabled children, such as teachers adapting the environment for access at school, parents working on teaching physical self-care skills, and social interactions with peers requiring support and assistance to be physically activity. Environments for nondisabled children typically have less need for constant adaptation to accommodate for special needs such as multiple caregivers, adaptive equipment, or accommodation for medical needs. Additionally, children with physical disabilities have fewer social agents in their environment who bring valuable interaction that support their human development.

The exosystem for children with physical disabilities is the organization of forces surrounding the child and family over which the child or family may have limited control but by which they are affected on a daily basis. An example of this for children with spina bifida is how funding or policy of parks, community recreation, or access to physical activity is generally oriented to people without disabilities. The child with spina bifida may not be able to fully access or participate in some physical activities due to the influence of the exosystem framework.

A child with spina bifida and their families have a macrosystem that contains beliefs that these children have decreased ability to participate in physical activity, have decreased ability to interact with peers and society, and have complex care needs. As a result, children with spina bifida are more difficult to integrate into society than their nondisabled peers. An example of the macrosystem (attitudes and cultural beliefs) for children with spina bifida is illustrated by the beliefs within societies and cultures that children with physical disabilities do not have the ability to fully participate in work, recreation and relationships. This macrosystem also demonstrates pervasive patterns of decreased social support and formal networks of care that positively affect caregiver burden for these parents, social isolation from peers and community groups outside of the family, and overriding societal beliefs that the value of a child with a physical disability is less than that of their nondisabled peers (Seligman & Darling, 1997).

Obesiogenic Environment for Children with Physical Disabilities

Bronfenbrenner indicates interaction between the microsystem and mesosystem represents the most immediate environment for children and families. Specific for this study is the description of pervasive patterns in families of children with physical disabilities as they detect, prevent, or treat overweight and obesity. Family environments model food and activity patterns for all children; this environment may be obesiogenic in that it promotes the development of overweight (Barlow & The Expert Committee, 2007; Kools, Kennedy, Engler, & Engler, 2008; Ritchie et al., 2005). The environment for children with physical disabilities has more risk to become obesiogenic because these children experience limitations secondary to their physical condition, lack of physical activity, barriers to physical activity, social isolation, and lack of interaction with peers (Rimmer et al., 2007). The family environment is also at-risk to be obesiogenic as parenting skills are focused on medical healthcare needs and care of their child with physical disabilities rather than preventing overweight (Rimmer et al., 2007; Simeonsson et al., 2002). Parenting skills and abilities are influenced by caregiver burden as well as stress and coping processes related to parenting a child with a physical disability.

Parents supervise food choice (availability and quantity) as well as participation in physical activity. However, parenting skills to enact these health promotion activities can be negatively affected by parental stress, depression, availability to monitor and supervise food and physical activity, as well as family disorganization and noneffective parenting styles (Bond & Burns, 1998; Wallander & Varni, 1998). Parents of children with physical disabilities have the increased burden of complex and specialty concerns at the same time as teaching health promotion self-care skills to their children (Seligman & Darling, 1997; Wallander & Varni, 1998).

The environmental factors related to caring for a child with a physical disability such as decreased social participation, on-going health care and treatment needs, and specific teaching needs related to their physical disability combine to create an obesiogenic environment for children with physical disabilities (Bandini et al., 2005; Rimmer et al., 2007). Indeed, there is evidence that children with physical disabilities have a greater incidence of overweight and obesity than their peers without disabilities and have potential to be more at risk to exist within an obesiogenic environment due to the presence of their disability (Rimmer et al., 2007). Joint and muscle pain related to the presence of a disability adversely impacts a child's ability to participate in activity (Rimmer et al., 2007). Lack of available recreation programs, environment inaccessibility, and competing health care needs contribute to decreased interaction in a physically active environment. Thus, the presence of a physical disability in a child's environment impairs participation in physically challenging activities, makes expenditures of energy more difficult, and ultimately participates in creating an obesogenic environment (Bandini et al., 2005; Rimmer et al., 2007).

Parenting Style

Parenting style is a known part of an obesiogenic environment for all children (Rhee et al., 2006). While parenting styles have been associated with overweight, understanding about how different parenting styles promote overweight in children is still unknown (Lederman et al., 2004). Parenting styles represent the manner and extent to which parents employ behavior modification and anticipatory guidance for their children

(Baumrind, 2005). Baumrind (1971) identifies four parenting typologies: (a) authoritative– having respect for the child's opinion, value of self-will and self-discipline, high expectation of behaviors and, yet, sensitivity to the child's ability to respond to their expectations; (b) authoritarian– being a strict disciplinarian, values obedience, favors punitive actions with low sensitivity to a child's opinion, yet high expectation of a child's behavior; (c) permissive– having low expectations of the child, but high sensitivity to their child's opinions; and (d) neglectful– having low expectations of the child's behavior and low sensitivity to their opinions with no rule setting. Parenting style is a combination of demandingness (or how parents place controls on children) and sensitivity (allowing children to make their own choices with varying degrees of interaction from parents) regarding choice and development of personal patterns (Damon, 1983).

Neglectful, permissive, and authoritarian parenting styles all employ less effective interaction with their children, and thus, less opportunity for self-selection and integration of choices into the child's concept of health (Birch & Davidson, 2001). Rhee et al. (2006) found authoritarian parenting associated with greater overweight in children. An explanation of this may be explained as parents demanding obedience without providing the child verbal give-and-take negotiations. Lissau and Sorenson (1994) also found associations between neglectful parenting styles and greater overweight in children. Authoritarian (Rhee et al., 2006) and neglectful (Lissau & Sorensen, 1994) parenting styles have been associated with overweight, but how different parenting styles promote overweight in children is still unknown (Lederman et al., 2004). Understanding how parenting style affects children with physical disabilities and the development of overweight is an important part in developing and promoting interventions directed to improving effective parenting (Rimmer et al., 2007).

Effective Parenting for a Child with a Physical Disability in the Prevention of Overweight

Recommendations from The Expert Committee on overweight and obesity for children encourage effective parenting by engaging families, encouraging authoritative parenting within highly responsive and demanding family environments, while discouraging restrictive eating practices and promoting physical activity within the family and community environments (Davis et al., 2007). Examining how effective parenting skills for health promotion work for parents raising children with physical disabilities can be a key to overweight prevention and treatment.

Effective parenting to prevent overweight in all children involves supervising a child's environment related to food and physical activity. Parents supervise most food choices, availability, and quantity, as well as physical activity choices (Rimmer et al., 2007). Learning how to facilitate food and physical activity choices are part of the family's health promotion beliefs and values that are formed in and passed on to their children (Roden, 2004). For families of children with physical disabilities, effective parenting is influenced negatively by caregiver burden, social isolation, and financial hardships (Blomquist, 2006; Rimmer et al., 2007; Seligman & Darling, 1997). Effective parenting forms enduring health promotion beliefs and values that last into adulthood and affect a child's lifestyle, thereby promoting health and quality of life, while minimizing the effects of overweight.

Parents of children with physical disabilities begin parenting by creating a protective environment consisting of vigilance, uncertainty, and sometimes, grief (Allen & Vessey, 2004). From birth to school-age, parents focus on their child being able to survive their disability (Luther, 2001). Parents hone skills of protection, sometimes moving to over-protection (Allen & Vessey, 2004). Parents often experience interactions with others (family members, respite support staff, spouses) who are not able to provide specialized care for their child (Pelchat, Lefebvre, & Perreault, 2003) creating a sense of hypervigilant responsibility for the primary caregiver as they often become the "only expert" in their child's care.

Trajectory of Parenting a Child with a Physical Disability

Parents of children with nonprogressive physical disabilities may experience a feeling of latency, or breathing room, from the beginning of school (5 to 6 years) to prepubescence (11 to 13 years), as their child successfully passes the critical time-period of infancy (Luther, 2001). Their vigilance has supported their child through infancy and they have experienced one of the first of many transitions—the transition from home to school. Their child may have become successful in ambulating independently with adaptive support devices and they may have succeeded at continence management. As their child grows and develops, the flurry of the care needs during infancy has diminished and parents are able to move from the previously dependent parenting model to focus on developing their child's independence in self-care. However, parents struggle to let go of protective behaviors that were in place to maintain health for their child.

Ideally, parents enter a proactive period of preparation for independence as their child moves through puberty (11 to 14 years) to aid in the development of the skills and interactions that will provide their child with experiences of independence. For typical teens, this period is characterized by the ability to independently perform self-care skills, the ability to socialize and join peer groups, and the ability to envision the future. For children with physical disabilities, many barriers are present that limit interactions and independent skill development. Parents focus on decreasing isolation and increasing their child's independence. While parents are seeking to provide necessary interactions and attainment of self-care skills, they are also experiencing new problems that they did not anticipate, such as struggles with encouraging independence and dealing with their child's grief and stigma about their disability (Blomquist, Brown, Peersen, & Presler, 1998; Luther, 2001). Parents experience the push/pull of protecting their children as they are not able to be present or prevent all hurt or demands in the child's new expanded environments (Luther, 2001). Parents model, teach, and promote self-care skills necessary for successful transition to adolescence and adulthood while also being watchful to not overwhelm their teen with too much learning; this developmental time demonstrates how goals of independence and self-care compete with health promotion goals (Blomquist, 2006).

Family Environment Related to Health Promotion

Health promotion skills for children with physical disabilities are formed in a family environment and parents provide the most significant impact on how children develop and internalize health promotion behaviors (Roden, 2004; Snethen et al., 2008). Family environment and function affect how children develop and internalize health promotion behaviors (Wallander & Varni, 1998). Parents are the most significant influence of the development of health promotion behaviors and habits (Bond & Burns, 1998). However, parents' perception of their child's risk of overweight, as well as available stress and coping strategies, affect a family's ability to attend to the health promotion needs of their child (Birch & Davidson, 2001). Important to note is that stress and coping is a developmental and transactional framework that represents negative and positive stimuli on individuals and families. As parents care for their child with a disability, they are acting upon and reacting to the special care needs of their children, as well as their own development as a parent of a child with a disability. Parents are also acting upon and reacting to stress stimuli from the immediate community surrounding the microsystem of the family and child (Bronfenbrenner, 1979).

Parents of children with physical disabilities often have different priorities, as well as increased burden in teaching health promotion skills and self-care skills as compared to parents of nondisabled children (Seligman & Darling, 1997; Wallander & Varni, 1998). Parents form and direct the development of self-care skills related to the child's disability, in addition to providing care to their child to prevent overweight and obesity (Seligman & Darling, 1997; Stein, Epstein, Raynor, Kilanowski, & Paluch, 2005). Thus, parents of children with physical disabilities should have specific knowledge of health promotion in the prevention of overweight for their children.

A pilot study was conducted previously with 4 mothers of children without disabilities to explore the family environment related to the development of food and activity choices (Luther, 2006). Constant comparative methods were used to analyze the interviews and test effectiveness and feasibility of a structured interview guide. Food themes emerged from the data analysis of the following: quality and availability of food is a constant activity for mothers; nutrition, availability, habits and use of food are based on family of origin patterns; and fear of their child being overweight is a constant in the background of mothers' thoughts and actions. Physical activity themes included the following: physical activity is part of a family's social and personal environment; and access (gyms, equipment, teams) and availability (time, conflicting schedules) affects quantity and quality of physical activity. Further refinement and revision of the interview questions was done for children with physical disabilities and used as foundation for the development of this study.

Antecedents to Overweight

For children with physical disabilities, such as spina bifida, environmental antecedents (see Table 1) may include decreased physical activity due to immobility or pain, decreased physical functioning, and lack of resources to adapt the child's environment to permit activity (Rimmer et al., 2004). Parents may also promote antecedents by their lack of understanding that their child with a disability can be physically active (Rimmer et al., 2004). Food may be used for emotional comfort more so than its nutritive value (Birch & Davidson, 2001). Parents may experience feelings that limiting or controlling their child's food intake might be interpreted as lack of nurturance (Seligman & Darling, 1997). Parents may have decreased ability to direct health promotion activities to improve physical functioning of their child (Simeonsson et al., 2002). Parents may fear addressing issues of overweight and obesity with their child due to possible negative emotions and the effect on their relationship (Edmunds, 2005). Additionally, parents may believe that children will grow out of their overweight status with their next growth spurt, thus postponing treatment (Borra et al., 2003; Ritchie et al., 2005). Environmental and parental conditions and practices for children with physical disabilities can exist in the environment and act to promote overweight or deter treatment of overweight.

Feeding Practices

Feeding practices for children with physical disabilities may be altered, focusing on providing consistent calories to promote physical development due to the child's history of unstable weight as an infant. Persuasion, or pressure to eat, may be interpreted by a child as coaching to eat, without the presence of hunger and leads to poor self-regulation abilities of children to make their own food choices (Birch & Davidson, 2001). Birch and Davidson (2001) point out that coaching and pressuring food choices decreases a child's ability to form their own self-regulatory skills.

In contradiction to being pressured to eat, food restriction to control weight also promotes overweight by way of developing poor food choices and creating hidden eating patterns (Birch & Davidson, 2001; Ritchie et al., 2005). Teaching positive food choices, rather than restricting, promotes a child's self control and self selection of food. Restriction without sensitive teaching (authoritative parenting style) increases a child's desire for the forbidden food and ultimately decreases their ability to regulate food intake based on their physiologic needs as they transition to independent food choices (Birch & Davidson, 2001; Ritchie et al., 2005). Thus, a consequence of coaching, pressuring, or restricting food choices for children impairs a child's expected and necessary ability to make their own positive and healthy food choices. Children with an impaired ability to make healthy food choices show a tendency to choose food that is forbidden or off-limits and they lose their natural ability to respond to the physiologic cues that tell them they are satisfied; thus, they learn to overeat and avoid healthy foods (Birch & Davidson, 2001).

Borra et al. (2003) report food for children also plays an emotional role by replacing the activities and interactions with peers and play, leaving food and overeating to fill the gaps left by limited social interaction. Borra and colleagues (2003) reported that parents more often use food as comfort for their nondisabled children if they had restricted activities for a variety of reasons. Birch and Davidson (2001) report feeding practices used to satisfy children's emotional needs promotes overweight. Further, parents' previous feeding strategies, when their medically-fragile infant was struggling to survive, were formulated to help the child gain weight. Many children with physical disabilities enter middle childhood and become medically stable – no longer need to gain weight. Thus, as the child grows, parental feeding strategies must be changed to prevent their child from becoming overweight.

Physical Activity and Physical Disabilities

Children with physical disabilities experience more barriers to physical activity, are more likely to be sedentary, and typically need their environment to be adapted to their disability in order to be active (Rimmer et al., 2007). Negotiating physical barriers in the environment require adults who are trained in assisting a child in a wheelchair or using adaptive devices; thus, these children need assistance from parents and others to be able to safely move about home, school, and community. In addition to the physical barriers of accessibility, these children may experience stigmatization and social isolation due to the presence of their disability, leading to decreased peer interaction as compared to their nondisabled peers, which promotes an isolated and sedentary lifestyle for children with physical disabilities – all of which contributes to overweight (Rimmer et al., 2007).

Development of Self-Regulation

Children form self-regulatory skills as they experience situations that allow them to make their own choices outside the control and regulation of their parents (Seligman & Darling, 1997). The environment for children with physical disabilities is at-risk to promote fewer opportunities for self-regulation experiences because these children are more likely to live in protected environments isolated from peers, offering them less opportunity to experience self-directed choices (Blum et al., 1991; Simeonsson et al., 2002). Consequently, children with physical disabilities have less experience with making their own choices and developing their own self-direction due to their protected environment. A protected environment threatens a child's development of self-regulation and places them more at-risk of selecting sedentary activities (Ritchie et al., 2005).

Social Isolation and Stigmatization

Blum et al. (1991) report children with physical disabilities often experience stigmatization and social isolation as compared to their nondisabled peers. Rimmer et al. (2007) add that stigmatization due to a physical disability places children more at-risk to be sedentary at home than physically active in the community with peers. For all children, Pearce, Boergers and Prinstein (2002) find overweight is associated with negative psychosocial effects and stigmatization in peer relationships. Thus, when children with physical disabilities are overweight, they have additional risk for stigmatization by their peers (Latner et al., 2005; Rimmer et al., 2007; Sjoberg, Nilsson, & Leppert, 2005). When children are isolated from isolation or stigmatization, they miss opportunities to make connections to their peers and community that are often linked with physical activity and opportunities for activities outside of their home. Lack of socialization and stigmatization promotes barriers to the development of self-choice and self-regulatory skills necessary for independent participation in community and school activities.

Stress and Coping for Parents of Children with Physical Disabilities

Stress and coping is a developmental and transactional framework for individuals representing positive and negative influences and stressors. Within the family, parents and children both react to stress stimuli from their microsystem environment (La Greca et al., 1992). Parents and children experience stressors and implement coping strategies, sometimes as a unit or a dyad or an individual (Seligman & Darling, 1997). Adaptation to stress and use of available coping strategies affect a family's ability and capacity to attend to the health promotion needs of their child (Ayyangar, 2002). Child and parent interact in a dynamic manner as the family experiences stress; they implement coping strategies and they transform their environment as a unit. Thus, stress and coping is transactional and developmental in that parent and child affect and are affected by the other, growth and change in one affects growth and change in the other (La Greca et al., 1992). For parents dealing with children who have physical disabilities, this process is also affected by the unique stressors of caregiving and condition acceptance. Children and parents dealing with disabilities implement specialized coping strategies brought on by the presence of a physical disability.

Stress and coping is viewed as a study of the relationships between the developing child and the people and settings in which they are involved (La Greca et al., 1992). Stressors in the family environment brought on by the presence of a physical disability stimulate developing coping strategies in response to the child's diagnoses, as well as the setting in which these parents live as individual and family members. Using stress and coping theory and terms as a method to examine the obesiogenic environment is valuable to understanding a parent's responses to stressors as they form and direct health promotion activities for their child.

Review of stress and coping literature contributes the discovery of the protective factors in the family environment (Lazarus, 2000). Protective factors moderate stress created in the family environment by the presence of a disability. Research in stress and coping related to the parent's experiences of raising a child with a physical disability describes the ability and capacity parents have to develop or focus on health promotion messages for their children (La Greca et al., 1992). Stress and coping research has practical application for healthcare professionals and is used to assist pediatric healthcare providers to develop and evaluate anticipatory guidance and teaching.

Stress for Parents Raising a Child with a Disability

Pelchat, Ricard, Bouchard, Perreault, and Saucier (1999) studied stress of mothers and fathers of children with three disabilities (Down's Syndrome, Congenital Heart Disease, Cleft Lip and Palate) and a control group of parents of children born without disabilities. They found that mothers had more stress, more role restriction, and more psychological distress than fathers. Overall, all parents reported more stress related to a child with a disability than parents of children without disabilities. Further, early years of parenting a child with a disability had stress due to the uncertainty about future health and abilities of their child. Pelchat and colleagues (1999) reported that parents' appraisal of stress is constantly changing during infancy with each new symptom as their child develops. Thus, unknown to parents is their child's full potential for cognitive or physical growth.

Mothers' reported more stress than fathers' related to role restrictions brought on by the new cares and needs of their child, greater sense of threat of their child's condition, and overall higher psychological distress (Pelchat et al., 1999). Pelchat et al. (1999) described the trajectory of emotions, roles, and gender differences for the early years of parenting a child with a disability. Stress and distress, uncertainty of survival and function, and differences in how mothers and fathers perceived and experienced stress was part of the parenting experience for parents of children with physical disabilities. Previous research on transition to adulthood (Blomquist et al., 1998) and the stress and coping patterns started in early years of parenting (Luther, 2001) mirrored the trajectory experience of these parents reported by Pelchat et al. (1999).

Stress Differences for Mothers and Fathers

Pelchat et al. (2003) described differences between mothers' and fathers' role experiences when parenting a child with Down's syndrome. Two main themes were identified: (a) actual versus expected parenting roles for each gender and (b) normalization versus stigmatization of the child. Pelchat et al. (2003) reported mothers' in this group were concerned with marital and parenting issues, mother role expectations focused on their abilities, and mothers expected that they were to provide their child. Pelchat et al. (2003) reported that fathers focused on the world outside of their families, with less direct care of their children or concerns about coordinating the care of their child. Mothers had high performance standards for their child's care and assessed themselves as more qualified than fathers to provide care to their children. However, mothers expressed dissatisfaction with the division of labor roles within the household. Mothers had labor role concepts that were in conflict; they believed they could perform caregiver roles better than others, including their spouse, and yet they were not satisfied with the inequitable division of labor. Mothers recognized that they may be a cause of their spouses' decreased participation in the complex and specialized care for their children. Two factors may explain why fathers were less participatory than mothers: (a) mothers did not focus on teaching fathers how to competently care for their child, and (b) at times, mothers did not allow fathers to help if they were not competent in performing skills.

Stress and Well-Being for Parents of Children with Disabilities

Dellve, Samuelsson, Tallborn, Fasth, and Hallberg (2006) examined stress and well-being for parents of children with rare diseases, including physical conditions such as hearing impairment and heart transplant as well as physical and behavioral conditions such as Fragile X syndrome, Cornelia de Lange syndrome, and Prader-Willi syndrome. Dellve and colleagues (2006) found that mothers, especially single mothers or mothers of more than one child, showed more stress than fathers. They suggested that the presence of a disability contributed to mothers returning to more traditional male/female family roles and relationships because mothers more often take on the additional parenting tasks of healthcare management, behavior-modification, and education for their child with disabilities. Fathers' related high stress about their perceived incompetence to care for their child and thus reported negative effects on their overall life satisfaction (Dellve, Samuelsson, Tallborn, Fasth, & Hallberg, 2006). Increased caregiver burden, additional caregiving tasks, and reallocation of attention and time by mothers may have had a negative effect upon fathers in this study. A noncaregiving spouse can still experience the effects of caregiver burden in that they could receive less support from their spouse. Families are systems that affect one another. When one member in a system becomes overburdened, or their routine family care tasks reorganized, the system is unable (at times) to meet the individual needs of other family members in the system. Dellve and colleagues (2006) found that mothers reported more care burden, which affected their spouses' health and feelings of support over time.

Stress and Adaptation for Mothers of Children with Cerebral Palsy

Manuel, Naughton, Balkrishnan, Smith, and Koman (2003) described results that are often counterintuitive to beliefs of pediatric healthcare providers- disabilities that are less severe created more stress for mothers. Manuel and colleagues (2003) studied the moderating factors of stress and adaptation based on functional status, disease severity, and maternal appraisal of the support and protective factors within the environment and found that social support moderated the relationship between child functioning and maternal depression. They conducted a descriptive study with 270 mothers of children with cerebral palsy from ages 1 to 18 years old. Social support moderated the relationship between maternal depression and child functional status by increasing protective factors present in the family environment, which in turn affected maternal adaptation to the child's function. When people in the environment perceived the child as having fewer demands on their mother, mothers experienced less support from the social environment, and fewer protective factors were available to moderate the effects of stress. One-third of the mothers expressed significant depressive symptoms, yet disability severity did not predict maternal depression. Mothers of highly functioning children experienced more distress when they perceived their levels of social support to be low. Higher function in a child with a disability can create more stress for mothers in that the social support network is not fully activated and fails to provide protective actions that may decrease maternal stress.

The effects of social support and its relationship to maternal adaptation reported by Manuel et al. (2003) is of interest, as well as the presence of depression and its effect on parenting capacity and adaptation to disability. The counterintuitive findings of higher functioning children being related to more depression in mothers is an important area for future research into the psychological burden and less social support mothers' experience for their children with mild disability conditions. Common belief is that severity of a child's disability is associated with the severity of family stressors. This study demonstrated that disability level affects maternal depression negatively. Mild and moderate disabilities do not trigger social support, which in turn affects the parenting capacity of mothers.

Marital Adaptation to Childhood Disability

Greenly, Holmbeck, and Rose (2006) presented a study of two groups of 68 families of children with spina bifida compared to healthy children. Higher marital adjustment was associated with increased reports of positive maternal behavioral control versus psychological control. Behavior control is directing a child to change their behavior with specific behavior guidance or cues. Psychological control uses a threat of punishment to influence children to change their behavior. Behavior control was associated with more frequent levels of conflict between parent and child as parents and children are engaged with each other to resolve their conflict. Short-term conflict has a positive outcome in that parents had experienced conflict and were adjusting parenting strategies over time, and thus, increased their acceptance of their child and reduced their use of psychological control over their child. Short-term conflict during the middle childhood years acted as a signal to parents of impending conflict in later adolescent times and encouraged them to change or adjust their parenting practices to allow for more autonomy in their child.

Fathers who had high levels of acceptance, behavioral control, and psychological control of their children reported higher stress in their marriage. Greenly and colleagues (2006) reported that incorporating behavior control and acceptance caused increased stress for parents. Higher levels of behavior control caused parents higher levels of stress; behavior control required engagement with a child that, in itself, produced stress. Parental demands produced conflict, yet ultimately, help children learn to adapt their behavior to their parent's expectations (Baumrind, 1991). Parenting demands positively affect child development as they promote the development of children's abilities, self-competence, and autonomy (Barber & Harmon, 2002). Children with spina bifida traditionally experience family relationships that display overprotectiveness and less conflict, thus threatening a child's ability to exert control of their own environment or behavior (Allen & Vessey, 2004).

Parenting Stress and Coping

Lazarus (2000) built on the work of Selye's general adaptation and stress theory and developed a framework of stress and coping that is an appraisal (relational meaning) by the individual of the stimuli in their environment. Parenting stress and coping research represents how stressors and coping strategies affect parents as they construct their meaning of parenting a child with a disability or chronic illness. Personal goals, belief, and social and physical environments are factors in how parents construct their appraisal of stress and employ coping mechanisms in their environment. Stress appraisal is personal and contextual for each parent and for children with physical disabilities. Parents are influenced by the severity of the child's condition, their immediate supportive environment, and their past and present biography.

Stress and coping research suggests that the environment surrounding parents influences their ability to react to stress and form coping patterns. Parents create their environment, as well as react to their environment. Parents do not perform their vital tasks within a vacuum that is immune to the presence or absence of supports in their environment. Single parent families, working parents, and parents without support report higher levels of stress in caring for their children with disabilities (Dellve et al., 2006).

Gender plays a role in a parent's appraisal of stress as well. Mothers report more stress, and different stress appraisal, than fathers (Pelchat et al., 1999). Traditional male/female roles lead to stressors for mothers accommodating to new tasks, cares, and worries (Pelchat et al., 2003). Parents of children with disabilities face more stress and engage in more coping strategies necessary to promote autonomy and independent child functioning than parents of children without disabilities (Greenley et al., 2006).

Caregiver burden, uncertainty, and grief are stressors reported and measured in stress and coping. Adaptation, accommodation, appraisal, and reappraisal are coping patterns reported and measured in literature. Nurses provide an integral part of the parent's external environment as parents are learning the complex process of parenting a child with a disability. Understanding how parents commonly appraise stressors in their environment and assisting them to employ coping strategies to those stressors stimulate nurses to prepare, assess, and intervene when common environmental conditions, such as single-parents, working-parents, male/female beliefs, and patterns of parenting exist. Parents of a child with a disability should be considered a vulnerable population because they are more at-risk to experience stressors related to caregiving.

The environment of parents of children with physical disabilities is influenced by how stress and coping affects the formation of health promotion beliefs for their children related to food and activity choices. Whether parents appraise overweight in their child with physical disabilities and whether or not they can intervene and act positively upon these threats with effective coping strategies is concerning. Whether parents have the ability to teach health promotion practices that may affect overweight in their child's life is unknown in current literature (Ayyangar, 2002).

Gaps in Current Research

Gaps present in current research exist related to how a parent of a child with a physical disability, specifically spina bifida, is prepared to prevent or treat overweight and obesity. Families of children with physical disabilities are challenged with competing healthcare needs in their child's environment related to the presence of their disability that may be perceived as more important than caring for healthy food and physical activity needs. Parents of children with physical disabilities are challenged to accurately assess their child's overweight and obesity status. Children are at-risk to have a history of altered feeding patterns and inability to overcome barriers in the community for physical activity that may affect their parent's ability to teach their child positive health beliefs related to food and physical activity. Families are also affected by additional stress and caregiver burden in their environment that compete with their ability to form positive health promotion concepts related to food and physical activity for their child.

Recommendations for Future Research

Future research should examine how parents perceive their ability or capacity to prevent or influence the overweight status of their child with a physical disability. Future research should investigate whether parents of children with physical disabilities can detect overweight, prevent overweight, and provide treatment for overweight. Future research should investigate whether or not parents of children with a physical disability accurately appraise the threat of overweight and whether their beliefs and patterns are conducive to developing positive coping strategies related to preventing or treating overweight and obesity for their children.

Summary

The family environment for children with physical disabilities is challenged with competing health promotion needs and beliefs, increased presence of stress, and altered coping strategies, as well as complex care needs, resulting in these children with physical disabilities being at-risk for overweight and obesity. Thus, the environment for children with physical disabilities is at-risk to become obesiogenic for many reasons. Moreover, overweight is increasing for children with physical disabilities and threatens the quality of their lives (Betz, 2008).

CHAPTER THREE

METHODS

Design

A descriptive, exploratory, qualitative design was used to explore parental practices, beliefs, and values to describe how parents form and direct food and physical activity choices for their children with physical disabilities in the prevention of overweight and obesity (Denzin & Lincoln, 2005; Polit & Beck, 2008).

Setting

The settings for this study were Salt Lake Shriners Hospital for Children and Primary Children's Medical Center, both located in Salt Lake City, Utah. Primary Children's Medical Center provides tertiary services for five intermountain states of Utah, Wyoming, Idaho, eastern Nevada, and western Colorado, with approximately 300 children being served in a multidisciplinary Spina Bifida clinic. Salt Lake Shriners Hospital for Children provides service to 4,000 children with physical disabilities in seven intermountain states of Utah, Wyoming, Idaho, Montana, Nevada, Arizona, and Colorado with approximately 160 children diagnosed with spina bifida and their families who are all referred to Primary Children's Medical Center for coordinated care. These two clinics are the only specialty clinics providing multidisciplinary care in the intermountain west region. All children with spina bifida within this catchment area are referred for care to these facilities. The PI has established relationships with staff of both Primary Children's Medical Center and Shriners Hospital for Children with 20 years of clinical experience working with children with Spina Bifida and their families. The PI was Director of Care Coordination Services at Shriners Hospital and has access to this setting and has conducted focus groups with parents in this setting. The PI has also worked as a university-affiliated clinical instructor at Primary Children's Medical Center.

Sample

A purposive sample was recruited from these two regional specialty clinics. The sample was comprised of 12 parents who are primary caregivers of their children (children between 6 and 12 years of age) diagnosed with spina bifida, and who are wheelchair ambulators. The sample was limited to two types of spina bifida (meningocele and myelomeningocele) because these conditions impact self-care, functional capacity, and mobility of the child. Single-parent and two-parent primary caregivers participated in this study.

Limiting the age groups to children from 6 to 12 years of age created a focus on a specific school-age developmental period marked by a child's readiness to learn and accept guidance and direction from adults (Erikson, 1980; Sroufe, Cooper, & DeHart, 1992). Willingness to learn self-care and health promotion skills is optimal at this developmental period and influences the child's concept of self. In addition, limiting the children to the school-age period of 6 to 12 years of age included only children who are prepubescent.

Inclusion Criteria

1. Parents of children ages 6 to 12 with spina bifida at all levels of meningocele and myelomeningocele and who were wheelchair ambulators.
2. Parents over 18 years of age who were primary caregivers.
3. Parents were able to read and speak English.
4. Special efforts were made when reviewing clinic records to recruit a balance between ethnically diverse participants based on ethnic backgrounds and SES.

Exclusion Criteria

1. Children diagnosed with spina bifida occulta were not included because this condition does not affect a child's physical functional ability and mobility.
2. Parents of children with shunt malfunction, systemic infection, or any other condition rendering them medically fragile were excluded because their parents would be more concerned with their child's life-threatening condition rather than the concepts of health promotion as related to food and physical activity.
3. Parents under 18 were excluded from this study as they are below the age of informed consent.

Recruitment

Upon IRB approval (Appendix A), the PI conducted organizational meetings with staff of Primary Children's Medical Center Spina Bifida Clinic and Shriners Hospital Care Coordination Department to communicate participant inclusion criteria for the study. Parents meeting the inclusion criteria were called by staff of the participating institutions as part of the two-step HIPAA process. Staff at each institution asked if parents would agree to participate in the study. The staff at each participating institution filled out the recruitment flyer with contact information and contacted the PI. Seventeen parents meet the inclusion criteria and agreed to be contacted by the principal investigator. Two parents refused (one due to the arrival of a new baby and one due to illnesses in their family) and three parents did not return phone calls. Thus, 12 parents participated in the study. All parents chose to be interviewed at their homes.

All participants had the first step of HIPAA consent process documented on the recruitment flyer by the institution staff (Appendix B). Those agreeing to participate had their recruitment flyer faxed to the PI at a secure fax machine. The PI contacted parents agreeing to participate and interviewed them in the location of their choice. All parents chose to be interviewed in their homes. Participants signed informed consent before their interviews.

Human Subjects and Ethical Considerations

Informed consent via the HIPAA two-step process for consent to participate was obtained. The study represented minimal risks to participants, including sharing information and emotional stress/strain by revealing beliefs and values the participants may have been unaware of prior to the interview. No parents reported to the PI or the

University of Utah IRB offices that they experienced any emotional stress or strain or reported any other complications related to this research.

Confidentiality and anonymity of participants was maintained by data storage in a password-protected computer and storage of printed materials of participant responses in locked and protected file cabinet at the investigator's office. None of the transcribed interview data identified participants' names. A master list linking participants to their data was kept in a secured and locked cabinet in the PI's office.

Instruments

Parents completed demographic data (i.e., age, gender, race and ethnicity, income, and education, self-report height and weight) after informed consent (Appendix C). Parents were asked to report their child's height, weight, age, grade, race, and ethnicity. A chart review tool, IRB approved, was developed to collect any information from the children's medical records if parents were unable to provide height, weight, or diagnosis (Appendix D). All parents were able to provide all information on their children, thus this tool was not used.

Semistructured interviews with open-ended questions (Appendix E) were used to (a) explore the parents' understanding about specific food choices and physical activities for their children with physical disabilities to prevent overweight, (b) identify barriers and supports related to food and activity choices, and (c) describe how parents manage and prevent obesity and overweight in their child with physical disabilities.

Data Collection Procedures

Institutional Review Board approval was attained through the collaborative University of Utah Health Sciences Center IRB board for both Primary Children's Medical Center and Shriners Hospital for Children (Appendix A). After IRB approval, the PI conducted organizational meetings with the staff of both institutions. After review of clinic patient lists by staff at the institutions, parents who met the inclusion criteria were contacted by the staff of the two clinics. As part of the two-step HIPAA process, initial parent participation was sought by the staff of the institution. The institutional staff completed the intent to enroll recruitment flyer available at the clinic and also collected telephone contact information for the PI (See Appendix B). The PI followed the institution's verbal consent from parents to participate in the study and provided a detailed explanation of the study in verbal and written form to parent participants. The PI obtained verbal and written informed consent.

Parent interviews were scheduled by the PI at a convenient time as selected by each parent. Interviews were conducted between 1 day and 36 days subsequent to recruitment. All parents were interviewed in their homes. After explanation of the study procedures, risks, and benefits, parents were asked to complete the informed consent, demographic form (Appendix C), and the chart review form (Appendix D). Interviews were conducted using the semistructured interview guide (Appendix E). Interviews were approximately 45 minutes to 2 hours in duration. Interviews occurred at a pacing of 1 to 2 per week over 3 months. Participants received a $25 gift card upon completion of the interview. Field notes described overall impressions of the interview, conditions during the interview, and awareness of emotions, reactions, or biases of the PI. Field notes were recorded immediately after each interview. Interviews and field notes were digitally recorded and transcribed verbatim by a professional transcriptionist. Transcribed interviews were digitally uploaded to a web-based, password protected transcription service and returned to the same password protected webpage. All transcriptions were completed within 24 to 72 hours and downloaded to the PI's password protected computer.

Data Analysis Methods

Recruitment and data collection continued until information saturation was achieved. The tenets of qualitative methodology prescribe that a target sample be large enough to access variability in the phenomena for unstructured interview techniques, yet small enough to allow in-depth interviewing and data collection necessary to meet the study aims (Morse, 1994). Use of semistructured interview questions allowed this researcher to use a smaller sample to reach saturation of data (Morse, 1995). Sampling sufficient and specific events of the phenomena studied to reach saturation and redundancies of the phenomena is critical to the qualitative process (Sandelowski, 1995). Final sample size was determined when saturation of the categories during data analysis was achieved by repetition in the responses of the category dimensions and properties. Recruitment and data collection was stopped when there were no new concepts being generated. Saturation and redundancy were confirmed by one expert pediatric nurse from the researcher's dissertation committee.

Qualitative interview data and field notes were analyzed by the PI starting with the first transcribed interview, and accompanying field notes of the PI, using an open coding technique. In this fluid and dynamic process, the data were broken down into discrete concepts. Concepts are the incidents, thoughts, beliefs, or events identified from the transcribed interviews, the data, of the study (Strauss & Corbin, 1994). Concepts were labeled and became codes representing phenomena. Coding was a process of describing the phenomena by identifying and conceptualizing what was represented. The PI subsumed many codes to discreet categories. The PI elaborated on the dimensions of the categories and individual codes with memoing to ground the conceptualizations within the data. Memoing occurred when a code developed from the data to describe the initial analysis of each code's conceptualization. Memoing described the PI's concepts of the range of the code (properties and dimensions), how the code fit within the category, and examination of the code for what it represented as well as what it did not represent; in this way, memos were analytical tools. Interview questions were enriched (added to) based on the emerging data to prompt defining or redefining categories of the data. In this way, data analysis is comparative within the data and with each new interview.

Coding

Constant-comparative analysis, open, axial, and selective coding and categorization of properties and dimensions of concepts occur iteratively during data collection (Glaser & Strauss, 1999). Constant-comparative analysis is aimed at generating theory grounded in the data by way of comparing incidents of each category developed, integrating categories, delimiting theory, and writing theory (Glaser & Strauss, 1999). Open coding was the initial stage of describing overall features of the phenomenon under study by selecting and naming categories (Strauss & Corbin, 1994). Variables were identified, labeled, categorized, and related together. Properties of a category were described and placed along a continuum within a range of possible values (Strauss & Corbin, 1994). Axial coding followed open coding as the researcher identified relationships between categories (Strauss & Corbin, 1994). The aim of axial coding was to make connections between categories and subcategories.

Individual interviews were analyzed by coding, categorizing, and linking categories using the systematic method outlined by Glaser and Strauss (1999). Initial coding of data was accomplished by reviewing each transcript several times to identify and label data with substantive codes that described the parents' perceptions and experiences. Codes were compared with conceptually related codes and grouped into categories. Throughout analysis, the properties, or characteristics, and dimensions of categories were developed. Some categories were regrouped together and subsumed as one category after examination of similar properties. Written memos documented the PI's ideas about the emerging categories and the properties and dimensions of the categories.

ATLAS/ti$^{©}$ software was also used for data analysis of the qualitative interviews and field note data (Scientific Software Development, 2009). ATLAS/ti$^{©}$ is especially suited to linking documents (multiple individual interviews, memos, and field notes) and developing concepts from constant comparative analysis with open, axial, and selective coding, as developed by Anslem Strauss (Glaser & Strauss, 1999).

Open Coding

Open coding is an analytic process of identifying concepts and their properties and dimensions discovered within the data (Strauss & Corbin, 1994). The transcribed interviews and field notes of the researcher in this study were closely examined during the open coding stages of data analysis. Systematic examination of all the transcripts occurred at a paragraph and question level as answers to each semi-structured interview question was examined. Preliminary categories were identified. Categories and their subcategories were identified and gathered from the data. Properties and dimensions of the categories were explored and recorded via memos. The data were then analyzed at a sentence and a phrase level as codes were linked to the data. ATLAS/ti® software was employed to describe the web of interaction and connection between developed categories (Scientific Software Development, 2009). During open coding, broad concepts emerged from the data by identifying, naming, categorizing, and describing phenomena found in the transcripts. Memos describing the code dimensions and properties were collected to provide directions for the researcher and situate the code within defined contexts and situations.

Axial Coding

Axial coding is relating categories and properties of codes developed during open coding (Strauss & Corbin, 1994). Axial coding defines what is missing in the data sets as well as what is revealed as the researcher seeks to understand the logic within the data. An example of axial coding within this data set is the relationships of (a) recognizing overweight status and (b) accuracy of parent assessment. Memoing was used during axial coding as well to record the product of analysis for future reference and direction to the researcher.

Selective Coding

Selective coding techniques are a process of integrating major categories (Strauss & Corbin, 1994). Selective coding was conducted with the assistance of the PI's chair as a methodology expert. In this study, selective coding was used to answer the broader research questions presented by the researcher prior to data analysis that drove the questions and methodology of this study. The findings of the study were then presented as a set of interrelated concepts about how parents develop and promote the health of their child with spina bifida as related to preventing or treating overweight.

Demographic data were analyzed with descriptive statistics including frequencies, means, and standard deviations. BMI calculations were based on parent participant self-reported height and weight for the parents and children (Centers for Disease Control and Prevention, 2009).

Reaching Saturation

Saturation of a category was determined when no new information emerged during coding; no new conditions, examples, dimensions or consequences of the category appeared from the data (Strauss & Corbin, 1994). Between each interview, this researcher examined the written interviews, field notes, and memos. Interview questions were added as new concepts emerged. The researcher noted content for further description and exploration via additional probe questions after each interview to be used in subsequent interviews: for example, comments made about physical activity as a preventative task for overweight were questioned with subsequent interviews to determine patterns of the use of physical activity for prevention or intervention as compared to food. After the eighth interview, the main descriptions from the semistructured interview questions were reaching saturation as evidenced by redundancy in responses to each question, to probes, and to confirmation of emerging categories during constant comparative analysis between interviews. Subcategories were beginning to be repeated, allowing for rich description related to the research questions and aims of the study. Repetition of the themes became apparent during the eighth interview. The researcher continued to interview 4 more participants for further definition of the properties and dimensions of the categories developed as well as to confirm the categories and subcategories developed.

Trustworthiness and Credibility of Data

Confirmation of categories and their properties and dimensions was obtained by an ongoing iterative process with forthcoming interviews, as well as confirmation with an expert panel (Denzin & Lincoln, 2005; Sandelowski, 2007). Trustworthiness and credibility of data in this study was assured at several levels. A member check of emerging categories was performed with parent participants during each subsequent interview and continued until saturation of categories, as well as properties and dimensions of the categories, developed (Creswell, 1997). Coding and category development were developed in collaboration with the PI's Dissertation Chair. Open, axial, and selective coding processes were discussed and confirmed during two in-depth, face-to-face meetings with the PI's dissertation chair. The PI's dissertation chair (Dr. B. J. Christian) served as a methodology and content expert by way of process review for the development of codes and categories.

CHAPTER FOUR

RESULTS

In this chapter, characteristics of the sample of parents and their children with spina bifida are summarized and thematic analyses of qualitative results are described. Parent demographics characteristics are presented in Table 4, and child demographics characteristics are presented in Table 5. Qualitative data analysis was conducted according to the methods of Strauss and Corbin (1994), with three stages of data analysis: (a) open coding, (b) axial coding, and (c) selective coding. Themes with subthemes were developed using qualitative methodology and techniques, including memos, diagrams, and development of probe questions until saturation of the themes and subthemes was attained. Three key themes were identified that described parents' perceptions of promoting health in children with spina bifida: (a) promoting health by maintaining healthy bowel function and managing spina bifida care, (b) managing food for children with spina bifida, and (c) encouraging physical activity for children with spina bifida.

Description of the Sample

Parent Characteristics

Twelve parents (9 mothers and 3 fathers) represented 12 different children (6 girls and 6 boys) between the ages of 6 years and 12 years. Parent characteristics are presented

Table 4. Parent Characteristics (*n*=12)

Mothers ($n = 9$)		
Age (mean)	37 years	(Range 31 to 49 years)
Height (mean)	66 in.	(Range 61 to 69 in.)
Weight (mean)	149 lbs	(Range 120 to 220 lb)
BMI (mean)	24.8 *	(Healthy BMI = 18 to 24.9 *)
BMI (range)	19.4 to 36.6	
BMI (SD)	6.32	
Fathers ($n = 3$)		
Age (mean)	41 years	(Range 30 to 48 years)
Height (mean)	72 in.	(Range 71 to 72 in.)
Weight (mean)	192 lbs.	(Range 165 to 210 lbs)
BMI (mean)	26 *	(Healthy BMI = 18 to 24.9 *)
BMI (range)	23.6 to 28.7	
BMI (SD)	2.74	

		Frequencies
Race/Ethnicity	Caucasian	11
	Asian	1
	Hispanic	0
Marital Status	Married	11
	Separated	1
Education	High School:	6
	College Graduate:	6
Employment	Full-Time	5
	Part-Time	5
	Does Not Work Outside the Home	2
Income (mean)	$49,833	
(ranges)	< $29,000	1
	$30 to 59,000	3
	> $60,000	8

Note: Height and weight data were reported by parents.

* Centers for Disease Control and Prevention, BMI Adult Calculator

Table 5. Child Characteristics ($n = 12$)

	Numbers
All Children ($n = 12$)	
Age (mean)	10-years, 1-months
Range	7-years, 6-months to 11-years, 11-months
Child Race/Ethnicity	Caucasian: 11; Hispanic: 1
Height (mean)	52 in.
Range	48 to 60 inches
Weight (mean)	86 lbs
Range	49 to 185
BMI (mean)	20.2
Range	14.9 to 27.8
SD	7.69
BMI Percentile	71st * (Healthy BMI = 5th to 85th Percentile)
Range	26th to 100th Percentile
Female ($n = 6$)	
Age (mean)	11-years, 7-months
Range	10-years, 3-months to 11-years, 11-months
Height (mean)	54 in.
Range	48 to 60 inches
Weight (mean)	97 lbs
Range	53 to 125 lbs
BMI (mean)	23.3
Range	14.9 to 27.8
SD	4.80
BMI Percentile	84th* (Healthy BMI = 5th to 85th Percentile)
Range	28th to 98th Percentile
Male ($n = 6$)	
Age (mean)	8-years, 6-months
Range	7-years, 8-months to 10-years, 11-months
Height (mean)	51 in.
Range	48 to 56 in.
Weight (mean)	80 lbs
Range	49 to 185 lbs
BMI (mean)	28.9
Range	14.9 to 41
SD	10.15
BMI Percentile	60th* (Healthy BMI = 5th to 85th Percentile)
Range	26th to 100th Percentile

Note: Parents reported all data.

*Center for Disease Control and Prevention, BMI Calculator in Table 4. Parent mean age was 38 years old with mean gross family income of $49,833 (mode= $60,000, *n*=8). Eleven parents were married and 1 parent reported being separated. Parents lived in a suburban metropolitan area within 50 miles of a specialty spina bifida clinic. The parents were primarily Caucasian (*n*=11), with one parent reporting race to be Asian. Parent education levels were reported as half (*n*=6) being high school graduates, with half (*n*=6) having some college or being college graduates. An equal number of parents worked full-time (*n*=5) and part-time (*n*=5). Two parents did not work outside of their home. Mothers' mean BMI was in the uppermost range of healthy at 24.8 (18 to 24.9), and fathers' mean BMI was in the lower range of overweight at 26 (25 to 29.9). BMI calculation and categories from Centers for Disease Control and Prevention were used (Centers for Disease Control and Prevention, 2009).

Child Characteristics

Children with spina bifida were an average age of 10 years, 2 months with a range of 7 years and 6 months to 11 years and 11 months of age at time of enrollment in the study (Table 5). Eleven children were reported to be Caucasian and 1 girl was reported to be Hispanic. Even though one parent self-identified as Asian, she characterized her child as Caucasian. BMIs for children were calculated for all children, by gender and in two age groups: younger children (6 to 10 years and 6 months of age) and older children (10 years and 6 months to 12 years of age). BMI-for-age percentile classifications for children are underweight as < 5th percentile, healthy weight as > 5th percentile to the 85th percentile, overweight as 85th percentile to < 95th percentile, and obese as $\geq$ 95th percentile (Centers for Disease Control and Prevention, 2009).

All younger children (1 girl, 5 boys) were calculated to be at healthy weight BMI-for-age, with the only younger girl BMI-for-age at 14.9 (28th percentile) and the younger boys' mean BMI-for-age at 18.4 (82nd percentile). The 5 older girls (≥10 years and 6 months) were calculated as either overweight (*n*=3) in the 85th to ≤ 95th percentile or obese (*n*=2) ≥ 95th percentile. The only older boy (10 years and 11 months) was calculated as obese with a BMI-for-age of 41 (> 99th percentile). Younger children (<10 years and 6 months) were all healthy weight for age, while older children (≥10 years and 6 months) were all overweight or obese for their age (Figure 2). For this reason, the age of 10 years and 6 months was used as a dividing point for comparisons of two groups: healthy weight (*n*=6) and overweight (*n*=5) or obese (*n*=1). The two groups of younger and older children were equally divided, with 6 children being under 10 years and 6 months and 6 children at equal to and older than 10 years and 6 months (Table 6). With data analysis, children naturally divided into younger and older age groups based on their level of physical activity and BMI status. Parents of younger children reported different physical activity and desires to be active than older children. Older children (≥ 10 years and 6 months) were nearing puberty, attaining adult body size, and described changing to more sedentary behaviors. In this way, describing the physical characteristics of the two groups of younger and older children provided more information that facilitated interpretation of the findings. Although characteristics of puberty were not measured in this study, parents described their child's pubertal status and how puberty related to their child's body size, overweight development, ambulation, and physical activity.

All children were diagnosed with spina bifida (*n*=12). Parents reported the levels of spinal cord defect to be lumbar lesions between L3 to L5. All parents reported that their children had bowel and bladder incontinence problems requiring ongoing

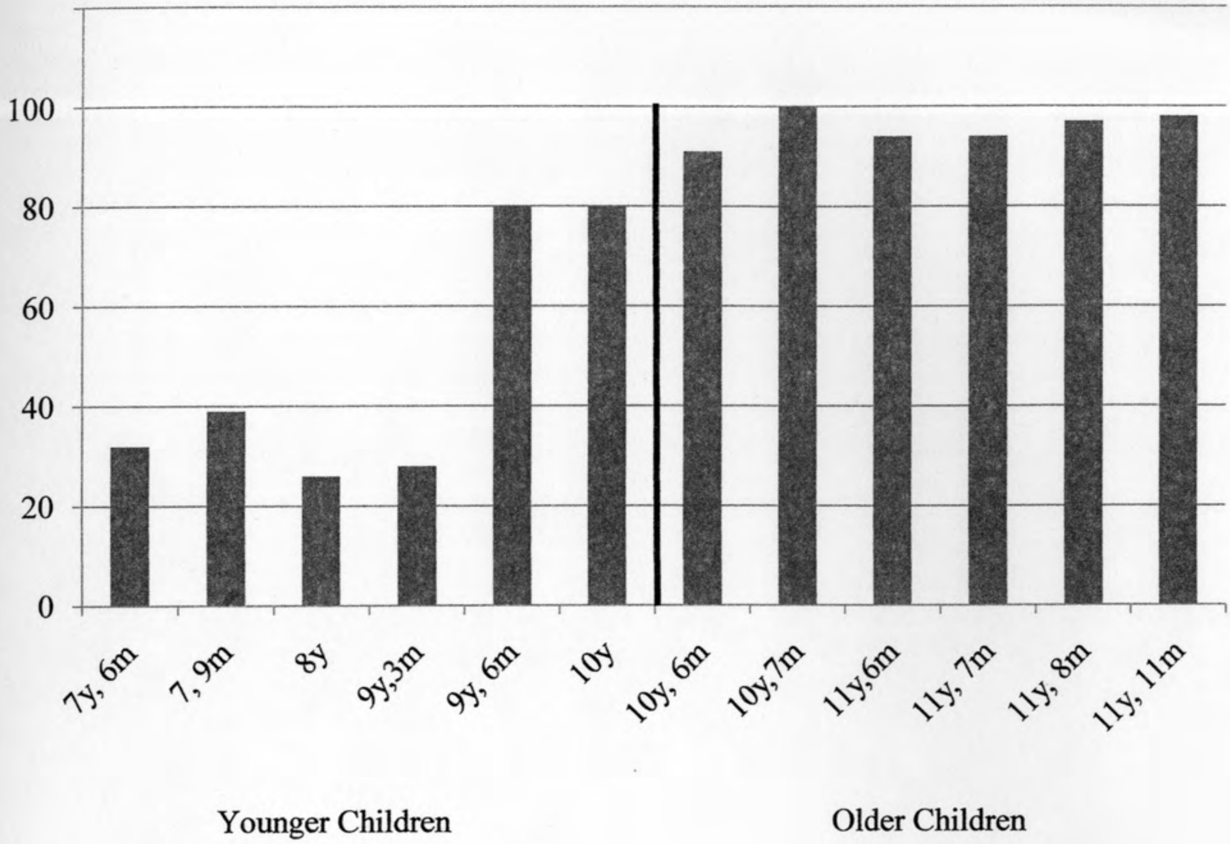

Figure 2. BMI Percentiles by Age Group

Table 6. Younger (*n*=6) and Older Child (*n*=6) Characteristics

	Numbers
Younger Children	(*n* = 6, representing 5 boys and 1 girl)
Age (mean)	8-years, 9-months
(range)	7-years, 6-months to 10-years
Height (mean)	52 in.
Range	48 to 52 inches
Weight (mean)	58 lbs
Range	49 to 72 lbs
BMI (mean)	16.3
Range	14.9 to 18.7
SD	25.55
BMI Percentile	47.5th * (Healthy BMI = 5th to 85th Percentile)
Range	26th to 80th Percentile
Older Children	(*n* = 6, representing 5 girls and 1 boy)
Age (mean)	11-years, 3-months
Range	10-years to 12-years
Height (mean)	55 in.
Range	48 to 60 inches
Weight (mean)	119 lbs
Range	80 to 185 lbs
BMI (mean)	27.6
Range	21 to 41
SD	3
BMI Percentile	96th * (Healthy BMI = 5th to 85th Percentile)
Range	91st to 100th Percentile

Note: Height and weight data were self-reported by parents. * Centers for Disease Control and Prevention, BMI Calculator intermittent catheterizations and daily bowel regimes. Younger children (*n*=6), (<10 years and 6 months) used combinations of crutches, walkers, and wheelchairs for ambulation, and additionally were reported by parents to scoot or crawl on the floor in their homes. Older children (*n*=6), (≥10 years and 6 months), were wheelchair ambulators only. Older children were reported by parents as still being able to scoot or crawl on the floor, but were reported to do so less frequently than younger children. Four of the older children continued to use assistive devices (braces and crutches) for ambulation of very short distances within their home or school and always required transfer assistance out of their wheelchairs. Two of the older children only used wheelchairs for ambulation, did not use any assistive devices of crutches or walkers, and were only able to perform assisted standing pivot transfers with minimal weight-bearing on their lower extremities.

Major Themes-Health Promotion Practices for Children with Spina Bifida

Parents described health promotion practices for their children with spina bifida to prevent overweight and obesity with three primary themes: (a) promoting health by maintaining bowel function and managing spina bifida care, (b) managing food, and (c) encouraging physical activity (Table 7). Managing care for children with spina bifida is a complex process that parents engaged in on a daily basis. Preventing overweight and obesity for parents existed within an environment that was focused on the medical and health needs of their child related to the presence of spina bifida. Parents described constant attention to their child's physiologic systems and specifically as monitoring bowel function. The research questions of this study targeted key behaviors and patterns related to food and physical activity that parents direct and control to promote the health

Table 7. Promoting Health for Children with Spina Bifida

Major Themes
Promoting Health by Maintaining Bowel Function and Managing Spina Bifida Care
Managing Food for Children with Spina Bifida
Encouraging Physical Activity for Children with Spina Bifida

of their children with spina bifida in an environment affected by the presence of a physical disability.

Promoting Health by Maintaining Bowel Function and Managing Spina Bifida Care

Maintaining bowel function and managing spina bifida care were considered to be the key health promotion activities for these parents (Table 8). When parents were asked about health promotion activities that they did for their child with spina bifida, the question routinely required clarification. The term "health promotion" did not bring immediate responses of plans, concerns, or goals for their children with spina bifida. Instead, parents defined health promotion for their children as maintaining healthy bowel function and managing spina bifida care needs. Getting adequate health care directed to maintaining function of physiologic systems affected by spina bifida was important for promoting the health of their child. All parents reported monitoring their child's bowel

Table 8. Promoting Health for Children with Spina Bifida by Maintaining Bowel Function and Managing Spina Bifida Care

Sub-Themes	Components
Maintaining Bowel Function	• Monitoring bowel function • Structure and substance of food, fiber, and hydration • Avoiding constipation and diarrhea • Making time for bowel care • Teaching children routine and schedule
Managing Spina Bifida Care	• Attention to specialized medical care needs • Constant monitoring of child's condition • Early and ongoing health messages of overweight risk

routines on a daily basis as their most important health promotion activity. Thus, health promotion was defined by these parents as spina bifida care management activities.

Maintaining Bowel Function

All parents reported that maintaining healthy bowel function was *the most important* daily activity for promoting good health for their children with spina bifida. Although bowel function was the key activity for promoting health for these parents, it was considered to be separate from managing their child's overall spina bifida care because the level of daily attention for bowel care and how bowel function affected the way their children felt physically. Parents explained that keeping a routine of adequate bowel function meant that they were keeping their child with spina bifida healthy. A mother *(parent #2)* of an 11-year, 6-month-old girl described how her initial concerns for her daughter's health were related to bowel function and her child feeling well:

> Well, there's things we have to worry about. You know? She has, as far as like going to the bathroom, I have to make sure she's on a really regular schedule and that she takes her medicines and things like that. That's our biggest concern. If that's healthy (*bowels*) and she's doing well at that (*bowel function*), then usually she's doing really well.

Bowel routine management was described as a health promotion activity because without adequate bowel function, children with spina bifida experienced pain, incontinence, and constipation, influencing how children felt on a daily basis. A mother *(parent #5)* of a 8-year-old boy described the bowel care plan for promoting her son's health:

> He has bowel and bladder issues. So the first thing when you say that (*what I do to promote the health of my child*), my first thought is that I need to keep him going to the bathroom and keep him regular, so that his body will do something, so he won't be constipated or have diarrhea.

Establishing and maintaining bowel routines and functioning was defined as health by these parents because with adequate bowel function, their child with spina bifida would not only be comfortable and free of pain, but also be able to participate in activities within their environment. Being free of constipation or diarrhea allowed their child to do activities of daily living, have a good appetite, and achieve bowel continence throughout the day. Neurologic impairment with spina bifida causes low bowel motility in children with spina bifida and results in less than optimal bowel function. Managing bowel routines focused on avoiding constipation, managing incontinence, and promoting self-care. Promoting bowel motility required that parents managed medications, monitored food and water intake, and added fiber through diet and medications as needed, as well as managing pain and discomfort when their children were constipated. Parents reported seeking healthcare providers' assistance to learn how to promote bowel motility to achieve healthy bowel function for their child with spina bifida. Without proper routine bowel management and adequate bowel function, their child's appetite and their levels of physical activity were negatively affected, and this influenced their overall health.

Parents reported that the structure and substance of food included fiber and hydration to promote soft, formed stools. Fiber and hydration were important to promote adequate bowel function for their children with spina bifida. Parents focused on teaching their children about how their bowels work, and how fiber and food influenced the way their child felt physically. For example, one mother *(parent #1)* of an 11-year, 7-month-old girl described teaching her daughter about fiber in food and how constipation related to how she feels:

> So it (*constipation*) just has a lot to do with how she's feeling physically, and then she'll eat in accordance with that. That's just one example I try to teach. For her, a lot of what we do to promote her health would be to keep her on that kind of routine, help her see how food makes her feel. All for bowel management. I see food as structure that makes her bowels work. I know food is nutrition, but I don't worry about her getting enough nutrition, I worry about her getting enough structure and her feeling good.

Children were reported by parents as not eating well when they were constipated; thus, they were unable to attend school or be physically active. Parents were focused on teaching their child what foods have fiber and structure to promote formed stools and avoid constipation. Parents reported that they were assured their children were getting adequate nutrition. However, parents were worried about their child getting adequate fiber and water on a routine basis to avoid constipation and promote good bowel function. For these parents, bowel management made the structure of food as important as their child receiving adequate nutrition from food.

Maintaining a bowel care routine for their children involved parents having adequate time to promote bowel evacuation and to teach about medication, hydration, and fiber. Parents reported their children did not want to focus their time and effort on bowel care. For example, a mother *(parent #2)* of an 11-year, 6-month-old girl reported how her daughter resisted taking the time for bowel care and the negative relationship effects on mother and daughter:

> She still makes it hard for me. She still is resistant to doing it (*bowel care*). She does not enjoy the process. She pushes to do it, every day or every other day. We find she'd like to push it to every three days, or pushing the envelope a little further than it should be. I think it's just going to take a while still before I don't have to worry about it.

Thus, bowel care and managing food to promote bowel function was a parental activity, whereby they monitored and managed their child's bowel routine. Parents reported difficulty in helping their child learn skills of bowel routines, such as maintaining a regular schedule and taking enough time for their bowel routine. In contrast, most of these children had already learned the skills of bladder self-catheterizations. In the same manner, parents tried to help their child learn bowel management skills to ultimately achieve bowel continence. However, the majority of parents reported less success in their child's ability to manage bowel routines during school-age years, as compared to learning bladder management for their children.

For these parents, promoting healthy bowel function involved teaching their children about how low bowel motility works, how fiber and medications interact with food to improve bowel motility, and how an established bowel routine trains their gastrointestinal system. Parents reported that most of the difficulties they experienced in promoting healthy bowels for their children were associated with their children not recognizing the effect of food on their bowels. Additionally, parents explained that their child did not want to establish a routine time and schedule to evacuate their bowels. These children with spina bifida did not like to take medications and fiber to encourage bowel evacuation. Some parents reported small gains in their child's ability to make positive choices about food and fiber for bowel routines. For example, a mother *(parent #1)* of an 11-year, 7-month-old girl reported:

> I suppose that's something we've seen progress in, as far as making food choices towards fiber to help her bowels. She will offset the bad with the good.
> For example, she packs her own lunch. She knows if she packs a bag of Cheetos, she better stick some carrots in there. She better put an apple or a cheese stick or something. When we first started doing that, a couple of years ago, it was hard for her to understand that that balance needs to happen, that junk food has no fiber. But she's gotten really good at it now.

This mother also related how her daughter had achieved a mostly successful bowel routine and how bowel control positively affected how her daughter felt and functioned. It is important to note that this girl had a cecostomy procedure with a Chait door to assist with bowel evacuation on a routine basis, rather than rely solely upon food, hydration, and medications to achieve adequate bowel function. Two of the older children in this study had cecostomy procedures that parents' reported had improved their child's bowel management routines. The cecostomy with a Chait door allowed antegrade instillation of fluid into the cecum by way of a permanently placed percutaneous catheter through the abdominal wall which aids in flushing bowel contents through the large bowel (Chait, Shandling, Richards, & Connolly, 1997). Parents or their child delivered fluid into the bowel on a routine basis to empty bowels, which significantly decreased constipation, diarrhea, and incontinence. This 11-year, 7-month-old girl had learned her own bowel routine of instilling fluid into her bowel and waiting for bowel evacuation. While her mother *(parent #1)* reported less concern, she still provided on-going monitoring of her daughter's bowel care even though her daughter was performing her own bowel management:

> Things changed when she had the Cecostomy procedure done. She'll evacuate her bowels with about 500 cc's of water. ...it has been working wonderfully for her. That has really alleviated some of our biggest problems with her feeling good and being healthy. Because she now can pretty much eat whatever she wants and still gets the balance moved because it's filtrated with the water. It (*bowel routine*) used to be a huge deal.

Another parent reported how his younger son (7 years, 9 months) had bowel problems from infancy and was now achieving a bowel routine through adequate management of food, additional fiber supplements, adequate hydration, and making time for bowel evacuation. This father (*parent* #4) reported improvements in his son's bowel routine as he got older:

> Throughout his life, yes (*we have always had to manage his bowels*). When he was born till probably a year old, a lot of constipation problems, to the point of we would have to remove it ourselves. Pretty much have always had to take Miralax and sometimes other things. He still will complain about how he's having a hard time using the bathroom... Miralax, watching his food, water, to the bathroom at night until he goes unless we are too busy. Now, as far as bladder, you know, we've been really lucky. He's been ok with his routine. He did (*have trouble*), just before his surgery (*tethered cord release*), which is what prompted the last surgery. He was getting to where he would have to use a bathroom and he couldn't go. It would be like an hour later before he would finally actually use the bathroom.

Managing Spina Bifida Care

The complex care management for children with spina bifida involves daily attention to multiple systems: neurologic, musculoskeletal, gastrointestinal, urinary, and integumentary (Lazzaretti & Pearson, 2004). Daily care needs for a child's neurologic system involve assessing for shunt malfunctions and infections. Headaches, fevers, lethargy, and pain must first be assessed for their relationship to a possible neurologic problem. Musculoskeletal system needs involve assessing for the presence of new contractures, and/or progressive weaknesses, and attending ongoing physical therapy to maintain adequate strength and range of motion. Daily care needs for a child's musculoskeletal system involve assessing whether or not adaptive equipment (e.g., braces, crutches, and wheelchairs) fit properly, need adjustment, or will be needed for that day's activity. Daily care needs for a child's gastrointestinal system involve assessing that bowels are adequately evacuated for children to be comfortable, assessing for constipation, and establishing a bowel routine. Food and water intake are assessed daily to ensure children are getting enough fiber and hydration to maintain adequate bowel motility; if they have taken in enough fiber in medication or food form to maintain soft, formed stools; or if parents anticipated accidents and would want their child to wear an incontinence pad that day. Gastrointestinal care includes managing constipation to diarrhea on a daily basis for these children (Sawin & Thompson, 2009). Parents were aware of their child's bowel function and adapted their care (food, hydration, fiber, and bowel evacuation) to promote bowel motility. Daily care needs for a child's urinary system involves managing bladder continence by teaching and monitoring their child's performance of intermittent bladder catheterizations every 2 to 4 hours at home, school, and in the community, as well as assessing for the presence of urinary tract infections. School-age children with spina bifida often can perform their own bladder catherizations. However, these children still need prompting to assure that they catheterize routinely to prevent infections and bladder distension that can cause permanent kidney and bladder damage. Some children are unable to learn to perform self-catheterization and need a trained adult available to catheterize them frequently throughout the day. Daily skin care for children with spina bifida involves assessing for skin breakdown or damage and avoiding pressure areas that children may be unaware of due to insensate skin. Parents perform skin care needs ranging from skin observation to dressing changes to support optimal healing of skin breakdown from braces or wheelchairs or pressure. Daily care needs for children with spina bifida additionally involve teaching and providing support to other caregivers, teachers, and family members about how to care for all systems and manage any problems that may arise for their children with spina bifida.

Parents in this study reported that they focused on managing their child's spina bifida care and any problems associated with spina bifida as promoting health for their child. Parents noted that they were attending to all the health needs of their child with spina bifida by (a) following healthcare providers' recommendations, (b) attending spina bifida specialty clinics, and (c) maintaining ongoing contact with all healthcare providers. A mother *(parent #12)* of a 10-year, 6-month-old girl explained how she monitored her daughter's health and how this provided her an assessment of overall health for her daughter:

> In general, I try to follow her with the clinic closely, do the things they tell me to do, watch her bowels, watch her skin, make sure her wheelchair is working, get her to therapy. She had a lot of surgery last year so we were at the clinic and the hospital for visits and surgeries. I have to watch her for any signs of trouble to keep her healthy and avoid problems.

The function of physiologic systems affected by spina bifida were the focus of many parent's health management concerns for their children with spina bifida. These parents described that health management of spina bifida included monitoring systems, such as neurological, orthopedic, and urinary systems. The majority of parents replied that they focused on attending specialized health care clinic visits related to spina bifida, and following the prescribed health regimens of therapy or surgery for their children. Additionally, all parents reported that they monitored their child's bowel and bladder function. Parents described attending to ongoing spina bifida care regimes of their child's disability-related needs, as well as meeting functional needs through physical therapy, braces, and wheelchairs, as important aspects of healthy living for their children. These parents believed monitoring their child's body systems affected by spina bifida were the best way to promote health for their children. For example, one mother *(parent #3)* of a

9-year, 6-month-old girl described health promotion beliefs that defined her vigilance about monitoring her child's physiologic systems:

> The first thing that comes to mind is making sure she gets to all of her doctors' appointments. Getting her to the doctor and following all the doctors' orders is a big part of insuring that she's healthy. Insuring that she's actually getting everything that she needs and that she's going to be healthy, to able to go on and do… Making sure that she's eating healthy and doing the activities that she needs to do and everything is there too. But I have to watch her condition so she can do all these things. Because, I mean, if we don't take care of her spine and legs, she's going to get to the point where she can't move around and where she can't do the activities that she'd like to be able to do. So, definitely, the first thing that I have to do is make sure that she's getting the health care that she needs.

For these parents, managing spina bifida equated to managing the health and bodily functions of their children. Managing spina bifida was part of promoting their child's health through diligent monitoring, assessment, and care management of body systems affected by spina bifida.

Summary

Promoting health was defined by these parents as focused on maintaining bowel function and managing their child's spina bifida care. Parents of children with spina bifida described their daily concerns about healthy bowels and preventing important system-related threats to their child's health. All parents reported that following the care regimens prescribed for their child with spina bifida guided their health promotion routines. Parents identified the importance of managing the care related to their child's diagnosis of spina bifida as promoting their child's health. Parents focused on physiologic system care, functional assessments of physical ability, and responding to ongoing care needs related to their child's spina bifida, most specifically to their child's bowel care needs and function.

Adequate bowel function was the most important daily health care regime for these parents. Parents reported that if their child's bowels were functional, they considered their child with spina bifida to be healthy. Achieving bowel function and control involved monitoring medications, food, hydration, and scheduling time to establish regular routines. In addition, parents identified that health promotion involved teaching their child to understand the importance of food, medications, and hydration to maintain adequate bowel function. Parents focused on teaching their children with spina bifida that good bowel function affects how they feel physically and how they function in their environment. Thus, bowel function was a measure of health and interpreted by parents as a health promotion practice for their children with spina bifida.

Managing Food for Children with Spina Bifida

The second theme described by parents involved managing food for their children with spina bifida. Managing food to prevent overweight in children with spina bifida involved (a) teaching about food, (b) monitoring food intake, (c) adapting food patterns, (d) portioning food, (e) awareness of overweight risk, and (f) restricting food to prevent overweight (Table 9). Managing food included the role of food, how children reacted to the way their parents controlled and restricted food, and how food was used to prevent overweight and provide adequate nutrition. Parents reported they believed that their children were receiving adequate nutrition. Parents described food intake, food patterns, and food control to prevent and treat overweight for their children with spina bifida.

Table 9. Managing Food for Children with Spina Bifida

Sub-Themes
Teaching About Food
Monitoring Food Intake
Adapting Food Patterns
Portioning Food
Awareness of Overweight Risk
Restricting Food

Teaching About Food

Parents described teaching their children with spina bifida about food choices, praising their child for healthy or good food choices, and reinforcing healthy food choices in all parts of their child's environment. Parents focused frequently on using 'only good food options' when offering food choices to teach their children with spina bifida how to select healthy food. Parents focused on promoting self-regulation over food for their children with spina bifida by offering good food choices and praising their child's choices. Parents modeled food choices and preparation as well as in their own behavior to help teach their child healthy food choices. By continually teaching the child with spina bifida about healthy food choices, these parents described their goals for developing their child's ability to achieve self-regulation over food, rather than parents relying solely on using food restriction to teach healthy eating. For these parents, teaching was focused on developing healthy self-regulation skills through offering healthy food choices. For example, a mother *(parent #6)* of a 7-year, 6-month-old boy reported:

> We have always praised him for good choices. He loves pretty much all fruit, especially when we lived in Idaho. He would like to go pick the berries in grandpa's backyard. He loved doing that. He eats a lot like his dad. He takes after his dad, eating such a variety. He'll try anything and I think this is because of the reward he got from his grandfather and his father. He controls his snacks based on what he knows we want him to pick.

Less frequently, parents (*n*=4) reported teaching their child with spina bifida that they needed food to maintain energy to function during the day, especially during school. All parents recognized that food intake provides energy and was essential for their child with spina bifida to function throughout the day at school and most parents reported minimal concern about that their child having enough energy throughout the day. However, one mother *(parent #9)* reported the difficulty in teaching her 11-year, 8-month-old daughter with spina bifida that food is energy and affects her ability to function. Describing the complex relationship, this mother explained:

> She's not really hungry at lunch, she doesn't eat breakfast. Her teacher mentioned to me, "I think she is tired because she's not eating lunch." She said, "She gets really lethargic for the afternoon classes." So I sent some foods and some juices and stuff and I said, "This is for you, if you feel like you didn't eat lunch. You're lethargic. You feel like you can't focus." She (*her teacher*) said, "Her eyes won't even focus." And with that, she still will not eat it. I sent all this stuff to the school and it's in the fridge and she won't eat it. So I don't understand. This is hard to teach her right now. Yet she is hungry when she gets home.

Another mother *(parent #6)* of a 7-year, 6-month-old boy related that her son frequently asked her about healthy food practices, but noted he is still learning how food can make him feel. She described the difficulties with teaching about poor food choices related to her son's bowel function:

> I think he kind of associates it (*poor bowel function*) with the food that he's been eating because, after a bout with some constipation, that's when

> he's a little more conscious of what he's eating. This (*effect of food*) is about the hardest thing for us right now to teach and regulate.

Parents described that their children with spina bifida learned that 'bad' or 'unhealthy food' was a trigger food that would make them feel physically ill. Besides the nutritive value of food, children with spina bifida learned about the physical effects of food on their bowel function. Parents noted that children would occasionally make poor food choices despite the fact that they knew the food was a 'bad' food or a 'trigger' food (i.e., pizza) that would cause diarrhea and stomach aches. It is important to note that 'bad' or 'trigger' foods for children with spina bifida were described as such by parents because of the negative effects on their child's bowel function, rather than poor nutritional quality, high caloric content, or food that promotes binge eating. For example, a mother *(parent #12)* of a 10-year, 6-month-old girl described her daughter's awareness of 'trigger' food:

> Pizza can be really hard on her system, and I don't know if it's like a combination of-- You know, it's a lot of carbohydrates and cheese and so she's very wary of it sometimes. I think it's because she's had upset stomachs from it. So I think that kind of stuff, she'll know, "Oh, I don't want to eat it. Even though it tastes so good, I don't want to eat it because it makes so my stomach hurts in the morning." So she does know that, but she will still eat it with her friends at times. I feel I still have to remind her not to eat food that makes her stomach upset. Maybe it is good that bad food upsets her, maybe she will eat it less.

Although parents stated their children were making good food choices when they were present, they still had concerns about their child being able to avoid and restrict trigger foods when they were not present. Parents had difficulty teaching their children that they needed food to be able to function at school throughout the day. Thus, teaching children about good food choices for these parents was focused on multiple issues:

selecting healthy food for nutrition, maintaining adequate bowel function by avoiding trigger foods, maintaining energy for physical function, and preventing overweight.

Monitoring Food Intake

Parents were confident that they could recall most of what their child with spina bifida ate throughout the day and what their child would choose or select for upcoming meals and snacks. Parents were aware of their child's food intake, choices, patterns, and preferences within their home and in the child's immediate environment. Parents described monitoring the amount, quality, quantity, and availability of food for their children with spina bifida. Parents recalled the type of food currently in their home and what food was available at any time. For all parents, monitoring food intake was a constant task, as evidenced by the multiple examples of how parents recalled what food was available for meals and snacks and what food their child would like. This constant nature of the task of monitoring food intake for parents of children with spina bifida was described by one mother *(parent #1)* of an 11-year, 7-month-old girl:

> I pretty much know what she eats on a daily basis-- at school, our house, her friends. It is something on my mind for her. Not much of the day goes by without me aware of what they are getting in terms of nutrition and calories.

Monitoring also involved anticipating what might be expected to occur during their child's day. Events that moved their children with spina bifida out of their controlled home environment, such as going to a movie with siblings or visiting a friend at their house, involved monitoring quality and quantity of food. Most of the parents reported that environments out of their control would be similar and support their food beliefs and practices for their child with spina bifida. They were assured that their child would be given food similar to what their own family would provide. For example, a mother *(parent #11)* of a 10-year, 7-month-old boy described how she would monitor different environments her son was exposed to outside of her home. While at a friend's home, her son with spina bifida would be provided quality food choices that she would not be concerned about. However, when he was with older siblings away from supervision by their mother, these siblings did not provide adequate food controls to prevent their brother with spina bifida from overeating. This mother reported anxiety about her child with spina bifida overeating with his older siblings when she did not monitor food and food activities:

> He (*older sibling*) knows that (*child's name*) can pack it away. He knows. He's the one that gets the Big Mac meal. He'd say, "I know (*child's name*) can eat it." I know he can eat it too, but that's the problem. We don't want him to eat it. You know? I can't trust him (*older sibling*).

Monitoring food also involved knowing school lunch routines so their child with spina bifida had enough time to eat lunch, as well as to perform their bladder self-catheterizations. Parents were not as concerned about monitoring the quantity or quality of food at lunch, but were more concerned about the amount of time available to eat and engage with peers during school lunch periods. Children with spina bifida ambulated with wheelchairs to the school cafeteria and negotiated lines of children, tables, and chairs to eat their lunch, while also making time to perform intermittent bladder self-catherizations during the limited school lunch period. A mother *(parent #2)* of an 11-year, 6-month-old girl described her daughter's lunch time and monitoring of her child's ability to have adequate time for eating lunch, socializing with peers, and performing bladder self-catheterizations:

> Just getting in and out of the bathroom and finishing, she's probably in there about 5-6 minutes at least, the whole time in there. Sometimes it's harder. Her clothes aren't as easy. As far as lunchtime, by the time she gets down the cafeteria and back, it's a good 10 minutes. She only has a 25-minute lunch. That's not much time to eat. I have to make sure she has good quality food during that short time. That has also affected her food choices a little, I think. I'd rather she take something conveniently packaged and easy. So she gets in trouble at lunch at school because that's also a cathing time. So she really doesn't have much time to eat. She always comes home with food from lunch that she hasn't eaten.

Parents also described monitoring school lunch time for their children with spina bifida was focused on helping them find time to socialize with their peers. Opportunity for socialization with peers was decreased for these children because their wheelchair required them to sit at special tables that accommodated wheelchairs. Children with spina bifida also commonly had adults checking on them for assistance with bladder self-catheterization, which interfered with peer interactions and socialization. The mother *(parent #9)* of an 11-year, 8-month-old girl explained the problems her daughter encountered with lunch at school:

> There's nothing social about lunch for her. She's moved around so much during the day. She doesn't have a chance to be social in school. She's only in one room for 40 minutes at a time and it's intensive. Then she is in the cafeteria at lunch, being checked on by the school secretary for cathing and trying to sit at tables with people she wants to be with. She gives up and just goes to the office to eat with the secretary. We keep working with the school on ways that she can be at lunch with others and talk with friends.

Parents described children as not having enough time and attention to select good food choices during school lunch time. Parents reported that their children with spina bifida had to coordinate bladder routines with lunchtime needs and how these two events decreased the available time to select food and eat as compared with their peers. Lunch time for these children at school served to highlight their differences from their peers.

Children with spina bifida had bladder routines, as well as wheelchair ambulation, that interfered with time to eat lunch and promote peer socialization. Parents monitored and intervened with school administration to try to make lunch more nutritious, as well as a more socially engaging experience for their children with spina bifida.

Adapting Food Practices

Adapting food practices was characterized by parents when they described the use and role of food, not using food as a reward, and the social function of food. Parents frequently adapted food practices to manage spina bifida to prevent overweight for their child with spina bifida to normalize food activities with their family, siblings and peers. Parents identified their child's special food needs and adapted those needs within the social and family environment to minimize their child's differences due to their physical disability. Further, parents adapted food practices to decrease caloric intake for their child with spina bifida, as well as for their family, so their child with spina bifida would not be singled out as different due to being overweight. For example, one mother *(parent #2)* of an 11-year, 6-month-old daughter stated:

> My biggest concern or fear or thing that I want to completely steer away from is her seeing herself overweight because of the food I give her or don't give her. So I changed how we all eat. You know, (*child's name*) needs to lose weight, you know, it's not going to kill any of us to lose 10 pounds either. We can all decrease the soda and food we eat too so she can lose weight.

Parents adapted food practices and used food to accommodate special bowel function needs for their child with spina bifida. Parents reported their child's morning appetite was altered as compared to their other children. Medications and fiber administered in the morning decreased their child's appetite for breakfast before leaving for school. Parent's reported that if their children were constipated and felt bloated, they would have a decreased appetite. Thus, their child would frequently eat less food in the morning. For example, a mother *(parent #9)* of an 11-year, 8-month-old girl described how she adapted food and food intake, as well as fiber medication timing, to improve her child's appetite:

> She really loves food. But her favorite time to eat is dinner. Breakfast is out of necessity, she doesn't like it, but she will eat if we make her, she takes all of her medications and they kind of suppress her appetite. And then the cafeteria at school is too noisy, and she likes a quiet environment. That's why dinner is her favorite time. The TV is off most of the time. It's off. We might have music playing, but it is a quiet environment and she thrives on that.

Another mother (*parent #1*) of an 11-year, 7-month-old girl reported that fiber medications interfere with her daughter's appetite in the morning; thus, she had adjusted the timing of her fiber supplements to help her daughter have an appetite for breakfast and lunch during the day:

> I give her more food for school and give her fiber in the afternoon. Because there are times (*morning*) when she does not have an appetite, and I think it's directly related to how her bowel movements are forming and it's (*bowel function*) going. Constipation has a lot to do with how she's feeling physically, and then she'll eat in accordance with that. Then if she is taking her fiber medication, she doesn't like the feeling and doesn't want to eat in the morning.

All parents recognized that their child's bowel function and bowel routines affected their appetite. Parents independently adapted their child's medications and fiber intake to avoid decreasing their child's appetite. Low appetite in the morning because of poor bowel function or fiber medications caused parents to worry about their child with spina bifida eating enough food to provide them adequate energy during the day.

Portioning Food

Portioning was a method that the majority of parents (*n*=9) described as a way of controlling the amount of food their child with spina bifida took in during the day and at each meal. Some parents described 'plating' food or measuring portions in the kitchen prior to bringing food to their child. A father *(parent #10)* of an 11-year, 11-month-old girl described how he and his wife used portion-control for his daughter's food during meals:

> When we put it (*food*) on her plate, my wife portions a specific amount for our children. A specific amount that they can eat. Then when she asks for more, we, on a case-by-case, decide, "Yes, you can have a little more of this or that." That's kind of how we've always done it really at mealtime. We have snacks that she knows she can have after school and we can add to those if she is more hungry or didn't eat breakfast.

Portioning represented the parent's daily control of the food intake for their child with spina bifida. An awareness of the number of snacks throughout the day helped their child become aware that they could have a specific, limited amount of treats after school or dinner. Portioning also involved parents teaching their child with spina bifida to help them see what was an appropriate portion size to eat for a meal or a snack.

Parents stated that they met little resistance from their children about the amount of the portion of food offered. Parents noted that the portions they offered their child with spina bifida were the same as for other family members. For example, one mother *(parent #9)* of a 12-year-old girl described that she portioned food for all of her children's meals. The family ate meals together, and it was important to this mother to teach her children about appropriate portions of food and how meals were social and learning events for her family:

> We try and keep the routine the same. They will help set the table and bring their drinks over to the table. They have to wash their hands. Then they come and they wait for me to bring the plated food over. Everybody eats together. They don't want to eat by themselves. If they want more, they ask. They know this. Eating our meals is a social thing and a learning thing.

When asked about whether portions of food based on type of food, such as more fruit and vegetables or low-fat foods, differed for their child with spina bifida, parents related that they had already focused on the quality of food and the amount of fruits and vegetables. These parents did not see that their children with spina bifida would benefit from any further change in food quality. The mother *(parent #5)* of an 8-year-old boy described how good food was available in their home:

> I just try to give him good choices. He doesn't like anything that's green. He needs to not eat as much carbohydrate and fat. So that was our big struggle. Cereal is an example where we don't do those colored, sugar cereal(*s*). I buy healthy food; changing what is offered for him wouldn't help now, I already do that. My biggest work is to actually get him to eat the good food we have. Like, we have wheat bread and little junk food.

Thus, parents used portioning to control and limit food offered to their child with spina bifida. Parents explained that they were already providing good food for their children and were additionally trying to use portion control to prevent or decrease their child's overweight status. Parents related that they used meal time and snack portions to teach their child with spina bifida about eating healthy and reasonable food portions.

Awareness of Risk of Overweight and the Development of Food Restriction

All parents recalled early and ongoing conversations with healthcare providers at their specialty spina bifida clinic about the risk for a child with spina bifida becoming overweight. For example, a mother *(parent #6)* of a 7-year, 6-month-old boy recalled early messages from her spina bifida clinic with healthcare providers when her son was young that remained an integral strategy in preventing overweight:

> I know that we need to be conscious about him gaining too much weight. They have a hard time walking if they gain too much weight. I've known that since he was a baby from the clinic.

Awareness of overweight risk for their children with spina bifida was the parents' primary focus and the major reason they used their current food practices to prevent overweight. Parents reported they were taught by their healthcare providers that preventing overweight would keep their child with spina bifida healthy and promote optimal physical functioning. All other parents recalled the same early warnings from their healthcare providers to avoid too much weight gain for their children with spina bifida. Parents were aware that being overweight would hinder their child's ability to move about in their environment and exacerbate their child's functional impairments associated with spina bifida. Parents reported an awareness of the overweight risk for their children with spina bifida from early clinic visits and during ongoing healthcare provider encounters. Further, at every spina bifida clinic visit with their child's healthcare providers, parents were counseled that their child with spina bifida had a substantial risk of being overweight.

When asked what their healthcare providers told them to do to prevent overweight, parents responded that healthcare providers guided them to manage their child's food intake by avoiding and restricting fatty and energy-dense foods. For example, a mother *(parent #11)* of a 10-year, 7-month-old boy remembered being told to control her son's food intake. She recounted being provided information from healthcare providers over time, as well as learning about spina bifida from books that she sought out at the library when she learned of her son's diagnosis. This mother stated:

> When I found out I was pregnant, I was in a really small town. I went to the library and remember reading about them being overweight. Since he was born I learned from the clinic to watch fatty food and when I go to clinic they are always talking about his weight and watching bad food.

Parents understood that spina bifida impaired their child's musculoskeletal and neurologic function and decreased their mobility. Additionally, parents understood that overweight placed their children at-risk for further impaired functional ability. Avoiding overweight was a consistent message parents received from their healthcare providers to promote physical functioning for their children with spina bifida. Parents reported being instructed on food quality and quantity at the same time that they were warned about the risk of their child with spina bifida being overweight. The importance of restricting or avoiding unhealthy food to prevent overweight was highlighted in all conversations with their healthcare providers. The consistent health message parents of children with spina bifida heard from their child's healthcare providers was to avoid unhealthy, fatty, energy-dense foods in their child's diet to prevent overweight. A father (*parent #10*) of an 11-year, 11-month-old girl reported his memory of early conversations with healthcare providers as:

> When she was a baby, they said, "You're going to have to watch her weight and her food." We knew, the whole time. The clinic is so good. All their resources, they-- Everything they've said, since she was born, that they predicted would come true, has come true. So they kept saying-- They have that Nutritionist that comes by and says, "Okay. This is where her height and weight is and we need to cut back on calories" and "We need to avoid fatty food." But we didn't think she would become overweight, and here she is. They were right again.

Parents were asked how they prepared for the possibility that their child with spina bifida might become overweight. These parents' responses varied by the child's age and how parents of younger children with spina bifida believed that their children would not become overweight even with repeated and consistent warnings from healthcare providers. Parents of children under 10 years, 6 months old did not believe that their children with spina bifida were at-risk for overweight, as suggested by their healthcare providers. Contrary to warnings by the healthcare providers, these parents believed they were managing food well enough, with adequate nutrition and control; thus, their younger children with spina bifida were not at-risk of becoming overweight. They based this belief on the visible evidence that their younger children with spina bifida were not currently overweight. Indeed, parent-reported weights for their younger children (*n*=6) confirmed that their children were at healthy weight and BMI for-age. When specifically asked if they thought their child could become overweight in the future, they responded, 'No, not my child.' Parents of younger children with spina bifida did not anticipate that their child would become overweight or that their functional ability would decrease over time. For example, a father *(parent #8)* of a 9-year, 3-month-old boy did not believe that his young son was at risk of being overweight. Further, he felt he could treat overweight in the future should it occur for his son:

> I don't think my child will be overweight. And if he were to become overweight, I could treat it. So it (*obesity*) is a concern for me, but I don't have that concern with him. I just don't see it happening. He has other things besides food that are more important to him, and I just don't see it.

This father related an accurate functional assessment for his 9-year, 3-month-old son with spina bifida. His son was at a healthy BMI-for-age, but did not participate independently in most physical activities because he did not have adequate energy and stamina to use his adapted bike to ride a block requiring his parents to assist him. Further, this father had an adolescent with a physical disability secondary to a brain tumor acquired in adolescence who became overweight after a craniotomy resulting in hemiparesis. Even though this father had observed his adolescent daughter with an acquired physical disability becoming overweight and had an accurate assessment of his son's impaired mobility status, he did not believe that his son with spina bifida had the same risk for overweight as his older daughter. Rather, this father believed that he would be able to maintain his son's healthy-for-age BMI status. Additionally, this family had a health history for being at-risk for obesity; the father *(parent #8)* related that there were several other family members who were morbidly obese, weighing over 500 pounds:

> My daughter had a really cute figure before her surgeries (*and brain tumor*). And you know, obesity runs in my family. I have a huge family and we're talking-- I think, my mom's topped 500 pounds, and I have an aunt that I believe is heavier than her.

Even with risk factors evident in his son's environment, this father did not believe that his child with spina bifida was at-risk for becoming overweight despite having the knowledge that children with spina bifida are at-risk for overweight, another adolescent in their family with a physical disability had become overweight, and they had a family history of obesity. This father believed his younger child with spina bifida would be able to continue to be active enough to prevent overweight. Further, this father felt confident he could treat overweight for his son should it occur in his future.

Another father *(parent #4)* of a 7-year, 9-month-old boy provided his interpretation of his younger son's current risk of overweight:

> It's kind of weird because typically with spina bifida are problems with overweight. He's actually been very active, which is probably the big

> thing that sets him apart from the rest. We got really lucky with him I don't think he will be overweight like other kids I see.

Younger children with spina bifida (*n*=6) in this study were all prepubescent (7 years, 6 month old to 10 years old) and had not attained adult body size. These younger children were more active and mobile by using crutches and walkers for ambulation, able to transfer themselves in and out of their wheelchairs, and willing and able to scoot across the floor in their homes, at school, or at friends' homes for their mobility. Younger children were more willing to be active and were less aware of how their method of mobility and being physically active were different than their nondisabled peers and siblings. Due to their child's current mobility and healthy BMI status, parents reported they did not believe their younger children would become overweight in the future. Indeed, their children's current BMI levels were at healthy ranges for their age. For example, one mother *(parent #6)* of a 7-year, 6-month-old boy described her belief about her son's overweight risk in the future:

> He was a chubby little baby. He grows fast. He's grown faster than his brother. Like clothes-wise, he's bigger than his brother was. But with the food choices he does make and his body size (*healthy-for-age*), I don't think he'll have to worry about being overweight.

All parents of younger children (<10 years, 6 months) with spina bifida (*n*=6) believed that their children with spina bifida's BMI status or functional ability would not change over time. A father *(parent #4)* of a 7-year, 9-month-old boy described current changes in his son's physical ability and his focus on his son's care needs, yet he still believed his son was not at-risk for being overweight:

> We just had a surgery last year and we are still doing his therapy and visits. It is a lot for us. In the past, before, he was actually-- able to do more, he had his braces and crutches before his chair. We are working to

> get him back to his original strength. But no, now, I am not worried about him being overweight.

In contrast, parents of older children (≥10 years, 6 months) were asked if they thought, prior to puberty, that their child would become overweight. All but 1 parent reported that they *did not believe* that their child with spina bifida would become overweight *before* the child actually developed overweight in early adolescence. Despite the early and ongoing conversations with healthcare providers about the risk of being overweight, most parents did *not* believe being overweight was an accurate prediction of risk for their child with spina bifida until their child's weight status actually changed. Parents of younger children with spina bifida reported '*not my child,*' when asked if they anticipated their younger child would be overweight. All parents of children with spina bifida, regardless of age, reported that they knew about the potential overweight risk for their child, but only one parent anticipated this risk to *be true* for her son.

All parents of older children (≥10 years, 6 months) with spina bifida (*n*=6) noted that their children had started puberty, growing into an adult body size, and were either overweight (*n*=5) or obese (*n*=1). One father *(parent #10)* described the experience of his 11-year, 11-month-old daughter who unexpectedly became overweight:

> It (*overweight*) didn't happen until just last year. She did really well before that, just kind of going along until the last year and a half to 2 years. She's overweight now. We couldn't seem to stop it once puberty started, we didn't think it (*overweight*) would be a problem. And now she spends more time in her chair. Before, she didn't spend as much time in her chair; she would scoot around the house more. We have always watched all our food. We eat healthy in our house already, we are trying to figure out what do to now.

Only one mother *(parent #11)* of a 10-year, 7-month-old boy stated that she knew from age 5 that her child would be overweight and this had always been a concern for her:

> You know, it used to just be we wanted him to walk. Now, it's just we want him to lose weight. We've been wanting him to lose weight since he was 5. Yeah. It's been a struggle, uphill on the weight. No matter what you do. They (*healthcare providers*) have always told me to keep the fat away, degrease everything, stay away from fat for him- he'll gain weight. I have always worried and knew he would be fat.

Restricting Food to Prevent Overweight

All parents related using restriction of energy-dense, fatty food to prevent overweight for their children with spina bifida. Parents explained that restricting amounts and types of food was a practice they had used to prevent overweight since their child with spina bifida was young. Parents reported they had learned to restrict food during their healthcare visits at specialty spina bifida clinics. These parents described that restricting food included monitoring and controlling food choices offered to their children with spina bifida. Restricting food involved controlling the quality of food by avoiding energy-dense foods in their home, avoiding fast food for children, and avoiding 'bad' foods for their children with spina bifida, as well as for their whole family. Maintaining food quality was described consistently by parents as restricting 'bad' food options, rather than increasing 'good' food options. Parents reported that they already had good food available for everyone in their family, including their child with spina bifida. A mother *(parent #2)* of an 11-year, 6-month-old girl described how she restricted poor quality food in her home and had only good food choices available to her child with spina bifida:

> I try to only give her good (*food*) or good food choices. There is not a lot of junk food in our house. We can all lose somewhat. I restrict sodas, if someone wants a drink, I offer water. She knows what she can have as a snack and it is yogurt after school or an 'Otter Pop' sometimes.

A mother *(parent #5)* of an 8-year-old boy with spina bifida described how she restricted food in her home believing that food restriction would prevent overweight, and was not worried about her son becoming overweight. This mother provided insight into how her child with spina bifida responded to food control and restriction:

> (*I have*) no concerns whatsoever. Because he moderates his food. He's learned that early. He doesn't give you a lot of behaviors when you try to give him the food. He doesn't have free run either. We restrict the choices. He can't just go open the fridge and have whatever he wants at any time.

Teaching children to make healthy food choices was described by parents as a key strategy for food restriction. Parents wanted their child to feel in control of their food choices, but limited the selection available and restricted food before the child was offered choices by their parent. Most parents explained that they offered only 'good' food choices to their child. Parents described that food restriction helped their children make good food choices because their children only had good food options from which to choose. Parents reported that they preferred not to have junk food or 'bad' food choices available for their child. For example, a mother *(parent #9)* of an 11-year, 8-month-old daughter explained how she has good food choices available more often than bad choices:

> We have some snack food and I try to only make treats occasionally. Mostly she has access to sandwiches, milk, fruit snacks in addition to what we have for meals as a family. I want her to learn to pick healthy food first and see snacks as a treat to have occasionally.

Parents reported minimal resistance from their children with spina bifida when they offered good food choices. Children would try new food and generally make good food choices throughout the day when parents were home with them or when they were at school. The mother *(parent #6)* of a 7-year, 6-month-old related how her son learned about healthy food choices and how she assessed his willingness to learn about healthy food:

> He asks me, "Is this healthy?" You know, he eats some junk food, too. He loves junk food. But he does consciously make a choice (*for healthy food*). He knows that his body is different and he needs to eat certain things. He doesn't do it (*ask if food is healthy*) as much anymore. There was a little period of time where he was always asking me, "Is this healthy?" Or "I shouldn't eat this." Now he seems to know and makes choices without so many questions.

Parents noted that food was part of their child's social activities. Parents described their children with spina bifida preparing food for friends and family. These parents did not have to actively restrict food when their child was socializing with their peers. For example, the mother *(parent #12)* of a 10-year, 6-month-old girl described how her daughter enjoyed food preparation for friends, but did not always choose to eat all the choices. This mother noted that her daughter was more focused on the social aspects of food and serving food to her friends:

> Well, I think like if we make cookies or something like that, when a friend is over. We save special treats for social occasions and friends. And now that is her favorite thing to do. Like she went to a friend's last week and they made cupcakes and decorated them. It wasn't even to eat the cupcake. It was that they were decorating them. You know? So she loves to cook and kind of bake, but it's not always to pig out on. She makes it for other people to eat.

This parent did not believe that food intake in the social part of her older child's environment contributed to her child with spina bifida becoming overweight. Parents denied that their children overate at social or family events; instead, they reported that their child with spina bifida enjoyed being with the people more than eating the food at social activities. Parents viewed social events as demonstrations of healthy food activities and choices for their child with spina bifida because their children did not overindulge with food and they enjoyed preparing and sharing food with friends and family. Two parents noted that their children expressed interest in being a chef as a vocation by watching food channels on television, and preparing food. As one mother *(parent #9)* of an 11-year, 8-month-old girl stated:

> She wants to be a chef when she grows up. She'll watch a (*food show on television*). She'll get a piece of paper and she'll write down the recipe, and then we'll go to the store and get all the stuff. And then we'll come home and we'll make it. She likes doing that for us.

Summary

Parents of younger children with spina bifida felt they had placed adequate control over food intake in their child's environment and did not perceive that their children would become overweight, regardless of repeated warnings of impending overweight by healthcare providers at specialty spina bifida clinics. Parents used food restriction as their first line of defense in preventing overweight for their child with spina bifida. Most parents stated that without food restriction, their child with spina bifida would be at-risk for making 'bad' food choices. With adequate restriction in place in their child's environment, parents were able to control the type and quality of food offered to their children. Food restriction was complemented by adaptation and sensitivity to their child's skills and preferences with the goal of promoting self-regulation. Parents related that their younger children with spina bifida were not resistant to learning about healthy food choices, and were less resistant than they expected when they limited unhealthy food choices. Additionally, parents reported that food associated with social events with peers and family was a positive experience.

Parents managed food to promote health and avoid overweight for their children with spina bifida. Their patterns reflected the busy lives of parents with school-age children. These parents of children with spina bifida related key properties of managing food, including teaching about food, monitoring food intake, adapting food patterns, portioning food, awareness of overweight risk, and restricting food. As their children grew older, their focus was on helping them learn about choosing healthy food portions. Thus, the major goal for parents was to prevent overweight by adapting their child's food environment to their special needs related to spina bifida early in their child's life.

Encouraging Physical Activity for Children with Spina Bifida

The third theme described by parents involved how their children with spina bifida participated in physical activity, how physical activity changed over time, and what specific practices they employed to maintain adequate levels of physical activity for their children with spina bifida. All parents described how they encouraged physical activity, what hindered physical activity, and how physical activity choices changed when their children became older and more sedentary (Table 10). Physical activity was described by parents as a developmental trajectory with younger children with spina bifida being active for their age and ability. But parents reported that as their children with spina bifida grew older, they became less physically active, more sedentary, and ultimately overweight. Parents focused on adapting physical activity to their child's functional ability, such as transfers to and from their wheelchairs and moving about their home,

Table 10. Encouraging Physical Activity for Children with Spina Bifida

Sub-Themes
Facilitating Physical Activity
Hindering Physical Activity
Becoming Sedentary and Overweight

school, and neighborhood, as well as promoting interaction with peers and others. All parents provided examples of physical activity for recreation and were able to describe how they engaged their younger and older children with spina bifida in family, community, and disability-adapted recreation to promote their levels of physical activity, as well as their child's engagement with others during physical activity. Assessment of their child's functional ability then matching appropriate physical activities that their child with spina bifida were able to do safely was the priority for parents of *younger* children (< 10 years, 6 months old) with spina bifida (n=6). In contrast, parents of *older* children (≥10 years, 6 month old) with spina bifida (n=6) described developmental and physical changes in their child that greatly decreased their child's desire and ability to be physically active. As previously described, all older children with spina bifida ($n = 6$) were overweight or obese. Parents of overweight older children with spina bifida described how they tried to encourage their child with spina bifida to increase their levels of physical activity, decrease their time being sedentary, and, ultimately, change their current overweight status. They described how their child's activity preferences for sedentary activity changed with their growing resistance to being physically active as their children with spina bifida grew older. Parents described how their conversations with healthcare providers did not prepare them for these changes in their child's physical activity level as their children with spina bifida grew older.

Facilitating Physical Activity

Facilitating physical activity involved finding appropriate physical activities, adapting physical activity for their children with spina bifida, having skilled helpers available, having time for parent involvement, and encouraging peer engagement.

Finding physical activities for children with spina bifida focused on locating and adapting appropriate activities that helped their child with spina bifida feel as safe and comfortable as possible. Parents reported that an appropriate group activity was the most important facilitator for their child with spina bifida being more physically active. Parents reported cost, time, travel, and child's interest as all affecting their ability to engage their children in physical activity. For example, a mother *(parent #1)* of 11-year, 7-month-old girl described how many activities were available in her community and the amount of work that was involved for her to facilitate her daughter's participation in physical activity:

> We know about the things (*community activities*) that are there. We have not taken advantage of many them. I really do think it's a matter of taking the next step and signing up for something, getting her involved. There is some things too that she has tried but... it would not be possible or advantageous. Such as wheelchair sports. She would like to be involved in that. It requires a lot of travel, time, and consistency, which I don't know that we could do right now. Finding an activity is as hard as getting to them.

All parents related seeking available community programs for all children, as well as disability-adapted programs specifically developed for children with physical disabilities. Parents reported that both types of programs (community or disability-adapted) required skilled helpers, trained by parents or the program, to safely assist their children with spina bifida during activities. Skilled helpers needed to be able to perform safe transfers in and out of wheelchairs and tailor activities to meet the child's specific physical abilities, which may have been different from other children with spina bifida.

Parents also reported adapting activities at school and church. Parents were concerned about protecting their child's physical, as well as psychosocial well-being, when participating in activities in their communities. For example, the mother (*parent* #1) of an 11-year, 7-month-old girl explained problems related to a church activity not being adapted for her child and the resulting discouragement she and her child experienced. This mother's daughter was participating in a community church event with games such as Frisbee, volleyball, and water balloon toss. Her daughter experienced barriers to participating because the activity was not adequately adapted for her physical abilities. The organizers of the event had reported to the mother that they were adapting the activities for her child; however, bus transportation had not been adapted, and someone had to lift her out of her wheelchair and carry her to the seat on the bus. Further, the child could not negotiate all of the activities independently without someone helping her to maneuver curbs and grass, as this mother *(parent #1)* explained:

> I knew differently and should have spent more time teaching and training the staff so she could participate. She ended up having anxiety over the lack of preparation (*of others*) and not really being able to get around without me.

In addition to the physical activity being adapted appropriately, this mother reported that for her children to participate in physical activity, she needed to have the church activity adapted and skilled helpers available that knew how to safely move her child with spina bifida. Parents explained that their children were used to having them nearby and relied on their parent's skills of assessing and accommodation to quickly negotiate and minimize barriers, as well as physical differences. Most parents sought community activities, such as soccer, baseball, dance, or basketball, that could be adapted to their child's physical abilities. Then, parents sought teachers and coaches willing to understand and accommodate to their child's specific physical needs. Parents reported engaging people as skilled helpers to take their place and help their child to be physically active. For example, the mother *(parent #2)* of an 11-year, 6-month-old girl described how she engaged her daughter's physical education teacher to help her daughter become more active at school:

> She can do some things. She can't do some things. I think that is a mixed blessing. It's really great for her when she can participate. For example, in school, sometimes the expectation is, "Well, she can do it." And sometimes she can't, and she's not real good at verbalizing when she needs to sit out. PE is a really good example. She has communication with the teacher that is open. He likes to push her, which I appreciate. He will push her to participate because he knows her, but she may or may not say, "That's enough. I'm done. That's too hard. I'm scared I'm going to fall," etc., etc. So he and I talk a lot. I probably rely on her too much to tell us when 'enough is enough.'

While parents were typically able to have their younger children (< 10 years, 6 months old) with spina bifida involved in community group physical activities, their children's ability to participate changed as they grew older. A mother *(parent #9)* of an 11-year, 8-month-old girl described how her daughter started to reject nonadapted community programs as an outlet for physical activities and shifted to a preference for disability-adapted programs:

> She knows they (*community activities*) will have trouble with her chair or need to move her, she doesn't want to participate unless no one will focus on her. They have to be able to care for her like I do. She goes to basketball (*disability-adapted*) because they are all in wheelchairs; she really doesn't have to interact with anyone because we are there. She will do activities if she can go and do, like horseback riding at (*name of disability-adapted facility*), and then she wants to go home. I don't have to worry at (*name of disability-adapted facility*) they know how to help her without making a fuss. But without them knowing like at church events or something in the community, she doesn't want to go, it is a mess.

Another mother *(parent #11)* reported that her son (10 years, 7 months old) engaged and taught his own skilled helpers in their neighborhood, adapting his own environment and equipment so he could participate in physical activities with peers. Playing basketball with a low, free-standing hoop required the help of his younger brother and their friends in the neighborhood. This 10-year, 6-month-old boy was able to play basketball by teaching others to help him. Interestingly, his mother reported basketball in his neighborhood and at a local disability-sports program was the only physical activity he participated in. To play basketball in his neighborhood, he directed friends to lower the basketball hoop, position his wheelchair, and retrieve the ball if needed. His mother *(parent #11)* reported:

> Oh, yeah. If they're in the driveway, down at the end (*of the street*), because their rocks are a little bit thicker than ours. They'll bring him backwards. "Help me backwards. Now we've got to turn this way, so that I can get in here." So they can play basketball with him. Then they all play, his brother retrieves the ball if he needs him to. He has his qualms. He's got to be able to know somebody before he's going to ask for help. But he will do it.

Another father *(parent #4)* of a 7-year, 9-month-old boy described his concerns about his son wanting to participate in the community activities that were not specifically adapted to his son's physical ability and how this accentuated his son's physical differences from his peers:

> Mostly more (*concerned*) around protection. Honestly, physical protection, but also kind of emotional protection. You know, (*son's name*) is not nearly as good as the other kids. Because we don't want him to be the worse (*sic*) kid on the team. So we try to have him do, recently anyway, we've tried to have him do more stuff that is not team oriented. More like the swimming, where he's making more personal accomplishments. You know, at the end of swimming lessons, if he can swim, he's accomplished his goal.

For older children ($\geq$ 10 years, 6 months old) with spina bifida to be involved in any physical activity, parents reported that their children preferred doing physical activity *with their parent,* rather than skilled helpers in the community. If older children displayed interest in physical activity, their preferred physical activities were adapted sports programs rather than community programs. Parents reported older children were less likely to participate in any physical activities when their parent did not participate with them as a part of the activity. For example, an 11-year, 6-month-old girl (*parent #2*) was found to have a foot fracture and was told by her healthcare providers that she was 15 pounds overweight. After the clinic visit, she and her mother explored the community for programs in which her daughter had previously participated, many of which had included friends or siblings. Instead, this girl asked her mother to do activities with her— to take her swimming and to ride bikes with her on her adapted bike. As her mother *(parent #2)* explained:

> At one time, she would go swimming across the street at our condo with her friends or her sister. Now she wants me there with her. She wants me to exercise with her or she will not do it. She doesn't want to be there without me. She has to move out of her wheelchair or be sure her diaper is OK.

This mother realized that her daughter worried about transferring in and out of the wheelchair, bicycle, or swimming pool with anyone else except for her parents. This mother recognized that she had to participate in the physical activity with her daughter if she wanted her daughter to be physically active. Additionally, this mother noted that the lack of available time in her schedule contributed to her daughter being less physically active.

Parents were engaged in physical activities with their children with spina bifida for their child's comfort and desire not to have others know they needed help with transfers, clothing, or that they wore continence pads. Parents reported they minimized their child's differences by helping them to transfer out of their wheelchairs, negotiate barriers, and hide continence devices from others. For example, a mother *(parent #9)* of an 11-year, 8-month-old girl reported her daughter worried about transfers, displaying anxiety about participating in physical activities:

> It's the fear of going from her wheelchair, low to the ground, like the bicycle or into the sledge (*hockey*). She worries about that. Once she's in, then she'll go. She'll go hang out with the kids. She has anxiety. It's just she doesn't like to be out of control or feel like, "You're going to drop me." It's that type of fear of, "I'm going to fall and I'm going to get hurt." that keeps me having to be there.

Peer socialization facilitated participation in physical activity for children with spina bifida. If physical activities were appropriately adapted and skilled helpers were available, children with spina bifida wanted to be active in a social setting with their peers that allowed them adequate time for engaging in play. Adapted physical activity helped children with spina bifida minimize their physical differences from others, helped them be engaged with others, and ultimately increased their physical activity levels. Parents reported that if their child participated in a social activity they could do with their peers, they spent more time doing the activity and being physically active. For example, a mother *(parent #1)* of an 11-year, 7-month-old girl discovered that her daughter was able to independently transfer herself onto their neighbor's trampoline:

> The trampoline is one thing that she taught her friends to help her with. We don't have one, but she'd just love to have one. The neighbors have one. It is even with the ground. She loves to go up there to play. She will do it all day long even if nobody else wants to. If somebody else is on, you know, she becomes really unstable, that it's scary. She's not very controlled. They're all kind of athletic unfortunately. But she has taught them what they can do. She will bounce all day.

Thus, this child was more physically active when the activity was connected with peer socialization. Her daughter would stay physically active on the trampoline for long periods of time while socially engaging with her friends. This child engaged her friends to help her get onto the ground-level trampoline, while her friends to adapted their play to sitting, bouncing, and rolling together as a group. The social aspect of the physical activity was important for this child with spina bifida, as well as doing an activity that she could accomplish with little evidence of differences from her peers.

Participating in physical activity for children with spina bifida required the child to be able to independently negotiate barriers in the community, ask for help from others, or have parents present. Parents explained that their children with spina bifida had varied skills of engaging other adults and friends to help them negotiate their physical environment so they could participated in the physical activities that they wanted to do.

Hindering Physical Activity

Parents reported concerns for their child's safety, preferences, and awareness of their differences from peers as factors that hindered their child's participation in physical activity. Each of these hindrances made participation in physical activity difficult, unsafe, or undesirable for children with spina bifida.

Parents reported that they felt they were constantly required to be present to monitor their child's safety. As a mother *(parent #11)* of a 10-year, 7-month-old boy described an incident when her son was injured while playing in his wheelchair with a friend in their neighborhood:

> I try not to worry about an injury, but I feel I can't leave him. He was with (*friend's name*) and he fell in his wheelchair and his chair landed on top of him and we had to go get brain scans done and all kinds of stuff. His front tire hit a hole and so he fell forward and boom, right into the cement in the sidewalk. When he's out here and somebody else is trying to watch him, I have-- You know, I get my panic attacks.

This mother knew that protecting her son from injury hindered his level of physical activity and she struggled with letting him play, rather than being worried about his being hurt if she let him play outside unsupervised without her.

Another mother *(parent #1)* of an 11-year, 7-month-old girl reported how difficult it was to ensure her daughter's safety during physical activity, adding that lack of safety also affected her daughter's desire to participate. If staff or volunteers could safely care for her daughter, then her daughter would participate in the physical activity. However, if staff could not provide safe care, her mother had to stay and assist her daughter. Her daughter did not want her mother to be present at activities if other parents were not present. Her daughter wanted to be independent when participating in the physical activities that she chose. This mother knew that her presence, while required to assist her daughter or monitor safety, was also a hindrance to her daughter's desire to participate and her daughter's ability to engage with others. For her daughter to be able to participate in physical activities with her mother was not present, skilled helpers were required to safely adapt the environment and the activity. Thus, both mother and daughter needed assurance that physical activities were safe for her; otherwise, neither mother nor daughter were comfortable with her participation. This mother *(parent #1)* explained:

> Well, safety, number one. I do have concerns that I can't really give everybody the heads up. A lot of activities, they're already planned before I know about them. So going in after the fact and saying, "Think about the wheelchair." It's too late. You know? Yeah. I definitely have concerns. They don't have the ability to accommodate her wheelchair, they don't know how to move her, they don't know how to take care of her. I have to go with her to do all of that. She doesn't want me there, she wants to be like everyone else. She doesn't want to do an activity that I have to intervene with. And she doesn't want to do an activity that isn't going to feel safe to her.

As children with spina bifida grew older (≥ 10 years, 6 months), parents reported that their children became less active and rejected being involved in either disability-adapted or nondisabled programs within their community. Parents described that their children with spina bifida were afraid to participate in physical activity as they became older. One mother *(parent #9)* explained her 11-year, 8-month-old daughter's fear of falling and being out of control:

> Now she will worry before the activity, not want to go to the activity unless I am there. She has anxiety. It's just she doesn't like to be out of control or feel like *(she)* is going to fall and going to get hurt.

Further, this mother felt that her daughter used fear as an excuse not to participate. This mother felt that her daughter did not want strangers or peers to see the physical differences in her body, that she used incontinence pads, and that she was afraid that she might have a bowel or bladder incontinence. When her daughter was younger, her child's desire to be active outweighed any fear or embarrassment of her physical differences. But as she reached puberty, her daughter understood her physical differences related to spina bifida, the consequences of transferring in and out of her wheelchair and scooting on the floor; thus, she choose not to be physically active. This mother *(parent #9)* felt that her daughter used the excuse of safety during transfers rather than acknowledging her feelings about her differences with peers:

> I think she says 'I am afraid you will drop me' rather than saying: 'I know I am different,' 'I don't want to see how different I am,' 'I'd rather not do this,' 'I'd rather sit in my wheelchair,' 'I am embarrassed.'

This mother felt her daughter knew that by saying that she was worried about safety, her mother would not require her to participate in physical activity; rather, the mother believed that her daughter did not want to highlight her differences with her peers. As a result, her daughter became less physically active as she got older.

Parents reported that for their children with spina bifida to move around physical environmental obstructions, such as curbs, doorways, stairs, and clutter, they also had to learn how to ask for help from others. If parents were not present, their children needed the help of others to negotiate these barriers. Thus, their children frequently had to learn how to ask for help from others in their environment. Some parents (*n*=3) reported their older children with spina bifida resisted asking others for help even though these environmental barriers prevented them from participating with others in activities that they once enjoyed. For example, a mother *(parent #1)* of an 11-year, 7-month-old girl reported how her daughter would rather not do a physical activity than learn how to ask for help or allow her mother to help her if other parents were not helping their children:

> I don't think she would (*allow others to help*). They have this Field Day at the school, that they have every year. I used to go to Field Day and be with her to help her figure out ways she can participate. But now, she would rather sideline it than go. She used to want to do what she could at Field Day when she was young. Now she wants to avoid it... she won't ask for help.

Participating in physical activity without parents required that these children with spina bifida either had a companion with enough knowledge and skills to anticipate all environmental physical barriers, or that the child had the ability to ask for help. Yet, for the other older children, asking for help was a skill that parents reported that some (*n*=3) of their children with spina bifida had learned. Parents shared stories about how, with teaching and guidance, their child's skills in reaching out to others increased, embarrassment decreased, and their engagement with their environment increased. For example, a mother *(parent #12)* of a 10-year, 6-month-old described how her daughter's friends helped to prevent her being embarrassed if an activity was something her daughter could not do. Her daughter had learned to ask her friends for help:

> She has several friends that know all these things. They help her because she can ask them. I think some of them may forget that she can't do certain things. Like, "We're all riding bikes." But if she negotiates, they will find other things to do together and she will be out with them all day. I talked to one of the moms and she said, "I forget that she can't do everything that they can do. They work it out together." I can see her confidence when she plays with her friends that know her and help her.

Other parents (*n*=3) reported to have younger children who would not ask for help to be physically active. One mother *(parent #5)* reported her son (8 years old) would rather try to participate by himself, rather than have his sibling help or ask others for help:

> I am hoping he will find a way to learn this on his own.... he prefers me to anticipate his needs. It is my job as his mother to help him avoid embarrassing situations (*when being active*).

Conserving energy and endurance were dimensions of participating in physical activity that parents reported for their younger children with spina bifida. All parents of younger children with spina bifida (*n*=6) reported that their children were moving between their wheelchairs and scooting on the floor, using walkers more frequently than older children who were reported by parents to be more often confined to their wheelchairs. Younger children were more mobile in their home and at friend's homes.

Some parents (*n*=3) reported that their younger children used large amounts of energy if they walked or scooted for long periods. Parents reported their children would become tired and had to be monitored and encouraged to conserve their energy for periods when they wanted to be physically active. For example, a mother *(parent #1)* of an 11-year, 7-month-old girl described how her daughter pushed herself beyond her capacity frequently:

> She will push it until she can't move, she just flops. I don't know if it's not admitting or she doesn't want to bother anybody. You know? For her to verbalize and say, "I'm tired" doesn't happen. She wants to be independent. She wants to not always be as needy but she forgets that she will get tired.

This mother *(parent #1)* reported that her child could use her upper body strength to ambulate in the house with a walker at times, but if she wanted to move between two levels of the house or go to her friend's house, then her daughter was faced with using her wheelchair or scooting. If she choose to stay in her walker or scoot, then she would be tired by the time she arrived at her friend's house, and this would hinder her ability to participate in the physical activity. As a result, her family bought a small motorized scooter for outside that was used for going to friend's houses or playing in the neighborhood. Her mother *(parent #1)* reported how her scooter increased her ability to be physically active when she wanted to be active:

> Right now, at this time (*winter*), that's kind of when I have concerns like, "Oh, we've got to get you going." And she will do walks around, but they're short, which is understandable. One thing that's helped her physical activity is we bought her a (*brand name*) mobility scooter.

> What's good about that is it will get her to the playground area, so she doesn't have to use her crutches all the way there. She'll get there and she'll play there and then she'll come back. So that has been really positive.

This 11-year, 7-month-old girl would drive through the neighborhood on her motorized scooter, with the walker attached to the back, transfer off her scooter to her walker, and then ambulate inside her friend's house or play in the neighborhood. In this way, this child with spina bifida could be physically active and independently play outside of the house in her neighborhood. Prior to having her motorized scooter, this girl would expend all her energy trying to leave her house and negotiating the neighborhood.

> I think that overall, it (*the scooter*) doesn't keep her from activity. I think it enhances and enables her to do more (*physical activity*) because she isn't tired when she gets to what she wants to do.

Prior to having the scooter, this child would have to sit down on the sidewalk between houses to wait for her parents to bring her wheelchair. Her parents were required to be available to rescue her when she could go no further. Thus, she was not able to be independently active for long periods of time. Using a motorized scooter allowed this child to conserve energy, yet stay independent in her neighborhood with friends, and thus be more physically active. Conserving energy for this child increased her endurance to participate in physical activities that she independently selected and preferred.

Parents recognized that their children had less endurance and required monitoring to help them conserve their energy to participate in physical activities that were valuable to them. These children did not think about conserving energy naturally; rather, they would remain engaged in that activity until they did not have any energy, whether or not they were finished. Parents also reported that their children did not anticipate what adaptive equipment could do to help them play with friends or be out of their house.

Parents had to anticipate what adaptive equipment would best suit what they were currently doing. For example, a mother *(parent #5)* of an 8-year- old boy described how her son thought he could participate in school field trips without his wheelchair:

> There are activities at school that would be easier for him in his wheelchair but he thinks he can do them with his walker. I know better but I can't convince him, so he heads to school without his wheelchair those days and I worry because I know he will not have the energy to make it off the bus and through the field trip.

When asked if healthcare providers suggested strategies for adapting and creating a physically active environment for their child with spina bifida, parents reported that healthcare providers were more focused on wheelchair fittings or checking on other adaptive devices. As the mother *(parent #1)* of the girl with the motorized scooter explained, she and her husband adapted their environment for their daughter to promote their daughter being physically active:

> No, our (*healthcare*) visits are more concerned with her using her wheelchair and learning to transfer herself. We figured out the mobility scooter on our own. Our insurance covered this; when we asked her doctor for an order, he didn't offer it, we asked.

Healthcare providers and therapists were concerned with assessing their child's current functional status and improving their functional ability, rather than assessing the child's ability to engage in physical activity or to socialize with friends.

Choosing to be physically active differed for younger children (< 10 years, 6 months) and older children ($\geq$ 10 years, 6 months) with spina bifida. Parents reported that younger children with spina bifida were willing to try any activity, unconcerned that they may perform physical activities differently than their peers. For example, a mother *(parent #6)* of a 7-year, 6-month-old boy described his enthusiasm and the interest displayed by her son in choosing any physical activity that he noticed his peers or his sibling doing. She reported he would ask to participate in activities despite his physical disability and differences from his peers:

> Even today, he brought home, from school, a Boys and Girls Club thing for soccer. He's like, "Oh, can I sign up for that?" He wants to get out and do those things. I try to let him do what he can and what he wants to do. So we will look into that for him.

Another mother (*parent #9*) of an 11-year, 8-month-old reported that when her daughter was younger, she would try any activity seemingly unaware of her physical differences with her peers:

> It's just-- seriously, (*at age 11*) and just this last year, that she's really started to wake up from, "I'm different. I can't do that." Before, I think she just-- Like my mom said. She was blessed with this ability-- this not really knowing. This disability that she doesn't know. She didn't care, or seem to know. She wanted to do anything.

Despite their physical differences, these mothers reported their younger children with spina bifida chose to participate in typical physical activities that other school-age children were selecting, such as basketball, baseball, soccer, or swimming.

Another mother *(parent #3)* of a 9-year, 6-month-old girl reported her daughter enjoyed activities with her father and with friends, but still needed encouragement to switch from sedentary activities to more physical activities:

> She loves to go rock-climbing. My husband takes her, just indoor bouldering, which she loves. She's got her own little harness and her own little shoes that are so cute. She can do this with him. And she loves to ride her bike with her friends... There are times that she's, "I just want to sit and play on my computer." I'm like, "No, you've had enough computer time today... Go do something else." Most of the time she'll get out and do something.

In contrast, parents of older children ($\geq$10 years, 6 months old) had to choose what physical activity their child would do and their participation in the activity with them. For example, a mother *(parent #2)* of an 11-year, 6-month-old girl reported that she had to choose activities for her daughter to participate in and provide direction, otherwise her daughter would not leave her wheelchair or go outside to be physically active:

> I have to pick her activities or she will just stay at home, she is more comfortable to stay in her chair. I have to force her to do something she doesn't want to do it. She does like it once she goes, but she won't choose to do it. Like swimming, I have to say 'you are going' or she will pick staying at home.

Parents of older children (>10 years, 6 months old) with spina bifida did not view their older child as making any independent choices to be physically active. Rather, parents made the choice of what physical activity they were going to require their older children to participate in, and parents enrolled them in the adapted community activities, such as sledge hockey or wheelchair basketball. Parents described their older children as preferring to stay in their wheelchairs even if adapted sports that were previously enjoyed by the child were offered. For example, a mother *(parent #9)* of an 11-year, 8-month-old daughter reported her concern about her child's lack of motivation to be physically active. This parent reported that when her daughter was younger, she had previously been motivated to participate in all physical activities, but now, as she neared adolescence, her motivation had changed:

> (*I worry*) that she's not going to care. She isn't going to choose to be active. She's going to just eat whatever she wants. Sit in her wheelchair and sit her life away. Because she isn't motivated. And she doesn't care.

Parents stated that their responsibility was to offer multiple physical activity choices to their children, as well as to make choices for their child, hoping that their child would find some physical activity they could accomplish and enjoy. A mother *(parent #12)* of a 10-year, 6-month-old girl even used 'nonactive' activities, such as music and sewing classes, to get her daughter used to going out of the house to do something, hoping this would translate to her making more physically active choices:

> She has piano and other little things that she does with friends, a sewing class. You know, I try to have her in classes that are fun, that she won't be limited by her ability to get around. Something for her to do outside of our house and get her used to going to a class. In the summer, she'll be in like cooking classes and stuff like that. And it's fun because then she can go with her friends. She doesn't feel different because they're able to do something that she can't do. So I just kind of look for those kinds of things to help her be comfortable in a class, without me. She loves to do craft classes and stuff.

Becoming Sedentary and Overweight

As children with spina bifida grew older, parents stated that their children preferred more sedentary behaviors. Physical activities for older children ($\geq$ 10 years, 6 months old) were different than for younger children. Children who once transferred in and out of their wheelchairs, scooted, or walked with a walker in the house or classroom, chose to use their wheelchairs as they grew older and their bodies became larger and heavier. Parents described their children as spending more time in their wheelchair and rejected physical activity in or out of their wheelchair. For example, a mother *(parent #9)* of an 11-year, 8-month-old girl described how her daughter did not want to be active and the parental effort that was required to encourage her to become more active:

> If we don't tell her to go ride her bike, she will not... She will do nothing. She's not going to do it. She would sit do nothing for 2 hours and not move. If we didn't motivate her. We have to motivate her on an hourly basis to do anything. Anything. It's a lot easier if she decides, and it's very nice when she decides that she wants to do something. And that is only 10% of the time. ... It's control. You know, she wants to have some control over her life. We try very hard to give her control. If she would just be motivated enough to take it.

Increased sedentary behaviors of watching TV, playing video games, or just being in their wheelchair, was noted by all the parents of older children ($\geq$ 10 years, 6 months old) with spina bifida. Parents reported that at the same time that their older child was developing more sedentary behaviors and facing environmental and social barriers to being physically active, parents were also trying to increase their child's physical activity to treat overweight. None of the parents of older children with spina bifida (*n*=6) reported that they anticipated their child becoming more sedentary with age. For example, the mother *(parent #2)* of an 11-year, 6-month-old girl described how her daughter's activity level changed over time:

> It (*decreased physical activity*) didn't happen until just last year. She really did really well, but she's overweight now. Before, she didn't spend as much time in her chair. She's in school all day. She's less active now than she was when she was 5, 6, 7 years. We put her in a chair when she was 4 but she still crawled. She wouldn't be in her chair. She crawled down the hall. Now, she's not as active. No. And I didn't think it would change that much. She just doesn't crawl, move, do anything like before. She is gaining weight now and she isn't active at all.

Parents of younger children ($\geq$10 years, 6 months old) with spina bifida (*n*=6) reported that they knew their child's *functional ability could change* over time, but they did not anticipate that their child's choices about being physically active would change. For example, the father *(parent #4)* of a 7-year, 9-month-old boy described his belief that his son would always be active, despite the change in functional ability as the child grew older:

> He has had surgery in the past and before he was able to do more. I am not worried he will be active again or when he is older. He wants to play basketball, we work on kicking because his brothers are in soccer. He can't kick unless he is sitting, but he works on it since surgery.

Parents expected their younger children to continue to be as active as they were currently, and did not expect their child's activities and level of physical activity to change as they reached adolescence. Additionally, parents of younger children with spina bifida believed they would continue to be able to find activities that were interesting to their child as they became older. Parents did not report discussions with healthcare providers about possible changes in their child's physical activity preferences due to age, physical ability, physical activity level, or their child's increased desire to be more sedentary. As the mother *(parent #12)* of a 10-year, 6-month-old daughter explained:

> Well, I ask what she can do and he (*healthcare provider*) says let her do anything she wants, we talk about her contractures or her wheelchair, we don't talk about her like she is going to do less than right now.

Summary

Physical activity focused on how parents of children with spina bifida encouraged their child to be physically active in an environment affected by the presence of their child's physical disability. Three subthemes described encouraging physical activity for children with spina bifida: (a) facilitating physical activity, (b) hindering physical activity, and (c) becoming sedentary and overweight. Encouraging physical activity was the parents' key role in creating an environment for their child with spina bifida to be able to safely participate in physical activity. Parents directed their child's environment to promote and maintain physical activity for their children with differences noted between younger and older children with spina bifida. Younger children with spina bifida were willing to participate in any physical activity seemingly unaware of their physical skills or differences with peers. The majority were able to independently participate on their own in community activities, as well as disability-adapted physical activities. Older children with spina bifida demonstrated changes in their desire to be physically active, becoming more sedentary as they reached puberty. These behavioral changes were largely *unanticipated events* for these parents that contributed to their child becoming overweight.

Summary - Promoting Health for Children with Spina Bifida

Parents defined health for their child with spina bifida as maintaining healthy bowel function and managing spina bifida care. Adequate bowel function meant that their child with spina bifida was healthy, that their child felt good, and was able to participate and interact within their environment. Early healthcare provider messages were to avoid bad foods and to control and restrict food intake to manage their child's overweight risk. Parents managed food for their children with spina bifida to prevent overweight by restricting and monitoring food intake. Parents reported that their younger children with spina bifida were physically active. But their older children had less desire to be physically active, becoming sedentary and overweight.

CHAPTER FIVE

DISCUSSION

Promoting Health for Children with Spina Bifida

Three themes were developed that described parents' perceptions of health promotion practices they employed for their school-age children with spina bifida to prevent overweight: (a) promoting health by maintaining bowel function and managing spina bifida, (b) managing food for children with spina bifida, and (c) encouraging physical activity for children with spina bifida. All parents (*n*=12) were aware of the risk of impending overweight for their children with spina bifida from an early time in their child's life. Despite this awareness of overweight risk, parents of older children with spina bifida (*n*=6) were unable to change the trajectory of their child becoming overweight. All older children in this study were either overweight (*n*=5) or obese (*n*=1).

Major findings focused on discoveries of parents' perceptions and practices used to promote health for their child with spina bifida through the lens of managing their child's disability-related needs, as well as the importance of the child's daily bowel function. Parents focused on managing their children's food to promote healthy bowel function and prevent overweight. Parents of younger children with spina bifida (< 10 years, 6 months old) reported adequate physical activity for their child's age and function. They reported that their environment supported their children being physically active and that their younger children were at a healthy weight-for-age. In contrast, all older children with spina bifida (≥10 years, 6 months old) were overweight or obese. Physical activity for older children with spina bifida changed as they reached puberty with their physical activity preferences and patterns becoming more sedentary.

Managing Spina Bifida Care

Parents' health promotion practices for their children with spina bifida centered on their child's disability-related needs, specifically the daily management of their bowel function and the medical management of spina bifida. If their children with spina bifida had adequate bowel function, parents believed that they were in good health and that they were performing appropriate health promotion practices within their environment. The complex daily management of spina bifida, as demonstrated by parents in this study, was supported by the findings of Wallander and Varni (1998), who reported that parents of children with spina bifida demonstrate heavy caregiver burden, overriding medical concerns for their child's health, and difficulties to teach health promotion skills and self-care management to their children. Rimmer, Roland, and Yamaki (2007) noted that attention to the necessary physical disability-related health needs may be more powerfully imparted to parents and imprinted on the family environment by healthcare providers, as compared to a focus on general health promotion practices. Similarly, Sawin, Brei, Buran, and Fastenau (2002) reported that adolescents with spina bifida, and their parents, wanted a broader view of the whole-person with healthcare encounters to be directed at functional health care goals, such as those of mobility and physical activity within a social context. Interestingly, Houtrow, Kim, Chen, and Newacheck (2007), reported that parents of children with special healthcare needs received *more* anticipatory guidance from healthcare providers than their able-bodied peers because their disability-related health needs dominated healthcare visits, but that anticipatory guidance for children with physical disabilities lacked a focus on whole-person, preventive health promotion.

In the same manner of Houtrow, Kim, Chen, and Newacheck (2007), Rimmer, Roland, and Yamaki (2007), and Sawin, Brei, Buran, and Fastenau (2002), parents in this study reported that disability-related needs took precedence in their healthcare visits and, thus, became the primary focus for promoting health of their children with spina bifida. In this study, parents defined health promotion for their child with spina bifida as providing care management for disability-related spina bifida needs, and more specifically for maintaining bowel function.

Maintaining Bowel Function

Parents identified that maintaining bowel function was defined as health for their children with spina bifida. These parents focused on bowel function and continence as a way of maintaining health for their children because adequate bowel control and function allowed their children with spina bifida to feel better, eat better, and participate in physical activity on a daily basis. In contrast, Sawin and Thompson (2009) described bowel control for families and their children as a difficult, bothersome, and emotional experience. Parents from this study were different from the findings of Sawin and Thompson (2009). Parents in this study highlighted that bowel control was problematic, but additionally added that it was their marker of health and well-being for their children with spina bifida.

Buran, Sawin, Brei, and Fastenau (2004) reported that adolescents reported lower independence related to bowel and bladder care. In contrast, Blum, Resnick, Nelson, and St. Germaine (1991) reported that approximately half of the older adolescents in their study performed independent bladder or bowel care routines. As compared to Buran and colleagues (2004) and Blum and colleagues (1991), the parents in this study described their school-age children as having adequate self-care skills for their bladder and urologic needs, but not for bowel routines. Parents stated that their children's bladder care needs were met by the child rather than parents or other adults in their environment. This is of interest because health teaching and anticipatory guidance for these families had adequately provided knowledge and preparation to attain successful bladder management for their school-age children. However, bowel management goals had not been achieved for these school-age children in this study similar to the adolescents studied by Blum, Resnick, Nelson, and St. Germaine (1991). While this study was not specifically focused on bladder or bowel control or the level of a child's independence in performing bladder and bowel management skills, parents described their practices for their child's bowel control and their concepts of health were clearly focused on bowel management. Sawin and Thompson (2009) richly described the '*long and complicated journey*' parents experienced in attaining bowel continence and self-care for children with spina bifida. This study found that parents have the same struggle in helping their children with spina bifida achieve independent bowel control. Sawin and Thompson (2009) additionally reported that parents felt they were on their journey towards bowel control alone, that healthcare providers did not see bowel continence as a priority, or as a state that was not achievable. Compared to Sawin and Thompson (2009), most parents in this study did not feel that they were alone in their bowel control efforts. Instead, these parents demonstrated adequate knowledge about bowel control, support from their healthcare providers, and ongoing attention to attaining bowel control for their children. In addition, this study found that bowel function is the most prominent indicator of health for parents of children with spina bifida and that adequate bowel function represented successful health promotion practices to these parents.

Bowel function for children with spina bifida is a complex process of managing food, medications, and bowel routines (Sawin & Thompson, 2009). Parents in this study described that inadequate bowel function affected their child's health. Further, parents described how food and food management were closely related to adequate bowel function. This study also highlighted how parents focused on managing food to maintain adequate bowel function and health, preventing abdominal pain from trigger foods. Thus, these parents felt that maintaining bowel function was an essential health promotion practice for their children with spina bifida.

Healthcare Focus for Children with Spina Bifida

Ayyangar (2002) and Houtrow, Kim, Chen, and Newacheck (2007) reported that healthcare providers' time and energy is focused on managing obvious disability-related problems, rather than guiding children and their parents with health promotion and preventative teaching to avoid secondary disabilities. Parents in this study clearly identified that their healthcare providers' time and attention was directed to their child's spina bifida needs. Consequently, children with spina bifida are at-risk to miss traditional health promotion, primary care, and developmental assessment and teaching during their healthcare provider interactions (Houtrow et al., 2007). Similarly, Sawin, Brei, Buran, and Fastenau (2002) found parents described interactions with healthcare providers, the focus of care visits, and goal setting for their children with spina bifida to be disability-related care rather than focused on holistic health promotion care.

The goal of healthcare visits described by these parents was focused on successfully managing the physiologic, disease-related systems affected by spina bifida, and not about promoting health by preventing overweight and decreasing secondary disabilities (Jackson-Allen, 2004). Research is lacking on health promotion practices that parents employ for their children with physical disabilities (Antle, Mills, Steele, Kalnins, & Rossen, 2008). Although the risk of overweight for children with spina bifida has been identified in the literature, understanding about how parents incorporate health promotion as they care for their child's diagnosis of spina bifida has not been explored (Liou et al., 2005). Antle, Mills, Steele, Kalnins, and Rossen (2008) described health promotion efforts parents did for their children to prevent secondary conditions, but did not explore parents perceptions of health or health promotion practices for their children. Antle and colleagues (2008) interviewed families of children with physical disabilities including spina bifida and reported that parents in their study worked hard at health promotion by providing lifestyle information, advocating for social inclusion, and used family strategies to promote their child's independence yet conserved their child's energy for daily activities. Comparatively, this study explored health promotion in relation to parent perceptions of health for their children with spina bifida and practices they use to promote their child's ability to make healthy food choices and participate in physical activity to prevent overweight. Parents in this study described how they learned to promote health for their children with spina bifida based on the anticipatory guidance from their healthcare providers. Parents described the intensity and consistency of their healthcare providers' focus and teaching on their child's disability-specific needs. Thus, for these parents, health promotion involved managing their child's condition of spina bifida rather than more traditional health promotion practices related to healthy living and preventing disease.

Tong, Lowe, Sainsbury, and Craig (2008), reported that a focus on disability-related problems contributes to the medicalization of persons with chronic physical disabilities. Medicalization involves viewing a person's health as the function of their disability rather than their ability to function as a whole-person (Ayyangar, 2002; Tong et al., 2008). Parents in this study formed their health promotion beliefs as physiologic system-related spina bifida management and care, as opposed to whole-person focused care. Although this was not a study about parents' conceptualizations of health, the definition of health for these parents may be an example of medicalization whereby parents have learned to view their child's overall health through the diagnosis of spina bifida due to healthcare practitioner's constant and honed attention to the child's diagnosis and condition, rather than to their child's overall health, wellness, and social function.

Promoting Health by Reducing Secondary Conditions

Interestingly, parents' concepts of health promotion in this study did not relate to the prevention of secondary disabilities that they could avoid in their children, but were focused on disability-related conditions they expected to develop in their child with spina bifida. All the children in this study received care from multidisciplinary spina bifida clinics. These parents reported that the focus of their healthcare provider visits at the specialty-care spina bifida clinics was on the care for disability-specific systems, rather than on their child's health promotion needs to prevent the development of disease.

Promoting health by avoiding secondary conditions for parents and healthcare providers is a method of preventing disease and developing an optimal state of well-being for children (Glanz, Lewis, & Rimer, 1996). For children with spina bifida, the condition itself is becoming less of a threat to their state of well-being as compared to the development of secondary conditions (Simeonsson et al., 2002). Because children with spina bifida are living into adulthood, current threats are now related to secondary disabilities such as overweight, as well as managing other complications related to spina bifida (Rekate, 1991).

Parents in this study reported that their efforts to prevent and treat overweight were based on their children's social and physical environments. Patterson (1991), suggested that children with physical disabilities be assessed using a systems model focused on overall family functioning where child and parent outcomes are simultaneously considered. For example, Bronfenbrenner's (1979) socioecological developmental framework could explain how parents in this study were concerned with promoting their child's ability to be physically active with peers to meet the child's physical and social needs to interact in their environment. Children in this study needed their parent's presence to be physically active and parents wanted their children to be active. Thus, parents and children with spina bifida may be better served by use of an ecological systems model of healthcare in combination with specialty physiologic system-based care, to promote more holistic functioning in their environment (Jackson-Allen, 2004). In this study, parents' concepts of health of their children with spina bifida were influenced by their healthcare providers' focus on disability-related assessments. However, assessments of physical strength and endurance, engagement in physical activity, and barriers to peer and social relationships are assessments that support a broader view of function for these parents (Simeonsson et al., 2002). Similar to Sawin, Brei, Buran, and Fastenau (2002), parents in this study managed their child's ability to function in their social environment. Thus, a broader perspective that includes assessment of social and family functioning within their environment may improve health outcomes for parents and their children with spina bifida (Christian, 1998).

Secondary conditions and disabilities are, by definition, conditions that are preventable (Pope, 1992). Simeonsson, McMillen, and Huntington (2002) suggested the need to move from a medical model to a social model of care that includes focusing on reducing preventable secondary disabilities. Social models of care encourage healthcare providers to assess the holistic environment of the child as parents manage spina bifida. Examples of social model assessments include how a child interacts within their immediate environment and peers, the level of current physical activity and physical condition, and the child's ability to provide their own care. Social model assessments are focused on overall functioning in society rather than assessment of the function of physiologic systems, such as bowel, bladder, or neurological systems (Simeonsson et al., 2002).

Bronfenbrenner's ecological framework of human development (Bronfenbrenner, 1979) was the conceptual framework used to guide this study. This ecological framework describes the interrelationships among the child and family and their socio-cultural environment (Bronfenbrenner, 1979). Thus, interactions between parents and their child's healthcare providers at the spina bifida specialty clinic described one way that parents of children with spina bifida learned health promotion practices to prevent overweight.

Trajectory of Overweight as a Secondary Condition for Children with Spina Bifida

Parents in this study richly described their beliefs about the trajectory of development of overweight for their children with spina bifida. Overweight for children with spina bifida is a common complication in individuals with physical disabilities (Simeonsson et al., 2002), as well as for those with other physical disabilities (Liou et al., 2005). Typically, the development of overweight as a secondary condition occurs in children with spina bifida as they near adolescence and continues into adulthood (Dosa, Foley, Eckrich, Woodall-Ruff, & Liptak, 2009; Mita et al., 1993). Although, the parents in this study demonstrated knowledge of the risk of impending overweight for their children with spina bifida and managed their child's food to avoid overweight, all of the older children with spina bifida in this study were overweight or obese. Moreover, parents' health promotion efforts parents described were not successful in changing the trajectory of overweight in their children with spina bifida as they neared puberty.

Health risk assessments affect a person's trajectory of illnesses and secondary conditions (Corbin, 1998; DiClemente, Crosby, & Kegler, 2002). Parents in this study assessed *low* health risks related to food intake for their children with spina bifida. These parents reported that they perceived they were managing the quality of the food their children consumed (energy intake) and that their children received good nutrition to prevent overweight. Parents felt the risk of decreased physical activity was *low* for their *younger* children with spina bifida, as they displayed being active in their environment and the accommodations parents had made for them were sufficient. Yet, parents reported a *higher* health risk assessment related to physical activity for their *older* children with spina bifida. Parents explained that their older children became more sedentary as they reached puberty and were resistant to being physically active (energy output) resulting in overweight. Thus, parents' assessment of their older children's health risk was different than for younger children. Parents reported that they *did not anticipate* that their younger children with spina bifida would become overweight even though this was a consistent message from healthcare providers. Parents were confident that they could treat overweight if it should develop in the future. In addition, these parents reported that they did not know that their older children would become more sedentary (risk assessment). It is important to note from this trajectory description, while parents knew about the risk of impending overweight for their children with spina bifida from their healthcare providers, these parents perceived that (a) they were adequately treating their child's food consumption, (b) parents of younger children felt they could treat overweight should it develop, and (c) they did not anticipate, or were forewarned, that their older child would become more sedentary.

Mita, Akataki, Itoh, Ono, Ishida, and Oki (1993) found that younger children with spina bifida (< 6 years old) matched the estimated body fat of their nondisabled peers, but that 58% of the children over 6 years of age had increased percentages of body fat as compared to controls, suggesting a developmental effect was identified in the children with spina bifida in their study. Adolescents with spina bifida have an increased probability of developing overweight related to their inability to maintain adequate physical activity (Mita et al., 1993) and restricted social and peer relationships (Blum et al., 1991; Loomis, Javornisky, Burke, & Lindsay, 1997). Importantly, the trajectory experience for these parents, balancing energy intake and energy output to avoid overweight in their children, lacked guidance from healthcare providers about energy output and the protective effects of physical activity.

Healthcare providers, and nurses in particular, are key participants in how parents form their health beliefs and practices to create a supportive environment for raising their children with physical disabilities, such as spina bifida (Corbin, 1998). The model of trajectory for a chronic illness is not only a progression of the child's experience through the illness, but also an expression of nursing and healthcare knowledge, interaction, guidance, and intervention with parents and children within their environment (Corbin, 1998). In this study, the typical trajectory of the development of overweight for children with spina bifida was described by parents as (a) awareness of impending risk of overweight, (b) prevention messages from healthcare providers to avoid energy-dense, fatty food, (c) occurrence of developmental changes associated with puberty and the development of overweight, and (d) promotion of increased physical activity and restricting energy-dense, fatty food for sedentary, overweight older children with spina bifida. Trajectory in chronic illness has been primarily focused on managing the impending known experience of illnesses of chronic conditions for an individual and family, but needs to be updated to focus on health promotion (Corbin, 1998). Similarly, Simeonsson, McMillen, and Huntington (2002) also suggested that management of spina bifida be focused on whole-person environment interactions that promote assessment of risk for development of secondary conditions. These parents provided an accurate perception of the trajectory of overweight for their children. For parents of younger children, they anticipated their child's overweight status and physical activities to remain the same over time; thus, they did not anticipate changes in their child's future affecting their health risk of overweight. For parents of older children, they trajectory of their child's development of overweight was unanticipated and they described their current environment was complicated by a struggle to learn how to increase physical activity for their older children with spina bifida.

Pubertal Changes and Development of Sedentary Behavior

In this study, changes in physical activity occurred that parents did not anticipate when children reached puberty. As older children with spina bifida in this study reached puberty, their parents reported significant changes in their physical activity and desire to interact with others in their environment. Parents reported their child's increase in sedentary behavior promoted the development of overweight. Epstein, Paluch, Gordy, and Dorn (2000) found that sedentary behavior is more reinforcing than being physically active for children who are overweight and may also contribute to their development of overweight. Increased sedentary behavior may have contributed to overweight for the children in this study, but additional factors, such as changes in the child's functional ability to be physically active as these children with spina reached adult body size (Simeonsson et al., 2002), may have also promoted more sedentary behavior. Parents in this study described that their older children with spina bifida developed emotional barriers to being physically active, such as a fear of being dropped during transfers in and out of their wheelchairs and the need to minimize their physical differences to others as they were participating in activities. These additional barriers to being physically active for children with spina bifida have not been previously reported. For these older children, these barriers may have contributed to them becoming more sedentary and less physically active as they reached puberty.

Puberty represents the most rapid period of physical growth after the fetal and neonatal periods for all children (Styne & Cuttler, 2003). Developmental and physiologic changes occur during school-age and adolescent years for all children (Boyce & Shonkoff, 2003). School-age children use concrete thinking to assess their self-competence and they measure self-competence by what they can do (Dixon, 2003). The children in this study represented school-age and pre-adolescent ages of development as parents described their child's ability and behavior. A physical disability can interfere with the child's and adolescent's ability to form a concept of self as a physically-able person (Simeonsson & Rosenthal, 2001). As children with spina bifida in this study reached puberty, their parents identified that they were developing the ability to understand that they were physically different from their nondisabled peers, while *younger* children were unaware of their peer difference. Further, older children with spina bifida in this study were beginning to adopt behaviors that protected themselves from exposing their differences with peers, preferring to be with their parents when their differences were likely to be exposed, such as during physical activity. Most adolescents naturally desire to be like their peers, to be with their peers more than their parents (Irwin, 2003). However, older children with spina bifida in this study wanted to be with their peers, while at the same time needed their parents to help them hide their physical differences and minimize their physical differences from peers.

Anticipatory Guidance to Prevent Overweight for Children with Spina Bifida

Anticipatory guidance is a model of clinical practice that prepares families for future encounters and is a clinical responsibility of healthcare providers (Pridham, Hansen, & Conrad, 1979). Pridham and colleagues (1979) described factors of anticipatory guidance as prioritizing problems that need to be addressed, sensing signals that may indicate receptiveness to guidance, and assessing responses to open-ended questioning. Pridham and colleagues (1979) suggest that healthcare providers encourage conversations, shared goal-setting, and interventions to best prepare parents for anticipated developmental changes in their children.

Anticipatory guidance for parents of children with spina bifida in this study did not include knowledge about changes that occur when children reach puberty and adolescence. For example, older children in this study became more sedentary and resistant to participating in physical activity. Typically, older children and adolescents experience increased sedentary behavior and decreased physical activity when they reach puberty (Epstein et al., 2000). Thus, these children with spina bifida were similar to their nondisabled peers in this developmental pattern of becoming more sedentary. Important anticipatory guidance to include is the knowledge that adolescents are more rewarded by sedentary behavior (Epstein, Roemmich, Paluch, & Raynor, 2005), as well as the knowledge that children with physical disabilities may become more sedentary due to decreased physical function, as well as their developmental changes (Blum et al., 1991).

Sawin, Brei, Buran, and Fastenau (2002) reported that parents of children with spina bifida noted that the disability-specific anticipatory guidance they received provided them the knowledge to successfully care for their child's complex diagnosis. Similar to Sawin and colleagues (2002), parents of children with spina bifida in this study benefited from anticipatory guidance to promote successful management of many aspects of their child's spina bifida care. Even though aspects of anticipatory guidance were identified as valuable by parents in this study, they still reported that the anticipatory guidance they had received had not helped them feel competent in managing their child's changing behaviors related to physical activity. Specifically, these parents did not know how to manage their child's emotional and developmental barriers to physical activity, isolation from peers, and increased preference for sedentary behavior, and reluctance to join organized community activities to promote physical activity.

Helping parents learn the nuances of developmental changes is an appropriate goal of anticipatory guidance. Anticipatory guidance about these significant changes that may affect a child's level of physical activity and improve their future health promotion practices for children with spina bifida. Ultimately, either preventing or changing the development of overweight is an important goal of anticipatory guidance for these parents of children with spina bifida. However, the findings of this study indicated that although parents were provided with anticipatory guidance about the potential for children with spina bifida to become overweight, parents were not adequately prepared for the developmental and behavioral changes that decreased their child's ability and desire to be physically active as they reached puberty. Anticipatory guidance prepares individuals to optimally manage an impending healthcare concern or condition (Pridham et al., 1979). However, for these parents, their anticipatory guidance did not prepare them for the future changes in physical activity of increased sedentary behavior for their older children with spina bifida or the development of the trajectory of overweight.

Parenting Practices to Prevent Overweight as a Secondary Condition

The years prior to puberty are crucial for establishing health promotion processes for all children in the prevention of overweight. This time period represents formative years in the lives of children to develop optimal health and wellness practices (Bond & Burns, 1998), set patterns of physical activity (Dietz & Robinson, 2005), and provide an opportunity to teach and influence children to prevent overweight (Katz et al., 2005). Simeonsson, McMillen, and Huntington (2002) highlighted the importance of preventing secondary conditions such as overweight for children with physical disabilities by establishing a knowledge base of their natural history and epidemiology. Critical knowledge related to preventing overweight needs to include knowledge about how to manage food intake, as well as how to encourage and adapt physical activity to prevent the secondary condition of overweight for children with spina bifida (Rimmer et al., 2007).

Parents in this study knew that a secondary condition of overweight would have negative consequences for their children with spina bifida. These parents described their practices for preventing overweight in their children with spina bifida through food management and restriction more than encouraging physical activity. Parents viewed their younger children with spina bifida as having adequate physical activity; thus, they felt their practices to promote physical activity were adequate for their younger children. Younger children with spina bifida in this study were within normal weight, BMI-for-age, and physical activity ranges for their physical ability. Yet, as children with spina bifida became older and approached puberty, they preferred less physical activity, became more sedentary and increasingly overweight. Rimmer, Roland, and Yamaki (2007) also found sedentary behavior to be true for adolescents with physical disabilities. Interestingly, parents in this study reported trying to treat overweight with increased physical activity for their older children with spina bifida. Overweight for all adolescents is related to changes in physical activity in addition to their food intake patterns (Ritchie et al., 2005). In this study, parents reported they felt their older children were adequately managing food to avoid and that their children's overweight status was due to their increased sedentary behavior. Thus, overweight prevention for the older children with spina bifida in this study may have benefited from promoting adequate physical activity in addition to managing food.

Managing Food for Children with Spina Bifida

Overall, parents in this study focused on managing food to prevent overweight for their children with spina bifida in much the same manner that Ritchie, Welk, Styne, and Gerstein (2005) reported that parents of nondisabled children managed food by providing access to nutrient-dense and high-fiber foods and beverages during meals and snacks; restricting access to high-calorie, nutritive-poor, and energy-dense foods and beverages; and avoiding excessive use of food as reward. One notable difference reported by parents in this study was the consistent use of food restriction to control calorie consumption and prevent overweight in their children with spina bifida. Ritchie and colleagues (2005) and Birch and Davidson (2001) both suggested that to optimally develop healthy eating behaviors for children, parents should avoid using excessive food restriction. Parents in this study reported using food restriction as their primary intervention to control food consumption by their children with spina bifida. Similar to Ritchie and colleagues (2005) and Birch and Davidson (2001), food control and restriction was evident in these parents' description of promoting health through managing food. It is unknown whether or not restriction strategies of these parents were at appropriate or excessive levels.

As compared to Birch and Davidson (2001), the parents of children with spina bifida in this study reported restricting food to prevent overweight by avoiding energy-dense, fatty foods. Additionally, parents reported restricting trigger foods to prevent the negative effects of certain foods on their child's bowel function. Parents reported that poor bowel function and abdominal pain resulted from ingesting high fat and high carbohydrate foods that negatively affected their child's health. Thus, food restriction was complicated for these parents because they were trying to control bowel function, as well as to restrict intake of unwanted calories to prevent overweight.

Food was described by parents for its structural capacity to maintain bowel function by providing fiber-rich foods. While fiber improved their child's bowel function, when taken in pill form, fiber did not always improve their child's appetite. For children with spina bifida in this study, fiber administered in the form of medications (fiber pills and powders) frequently decreased their appetite, resulting in abdominal bloating and having excess flatulence. Sawin and Thompson (2009) reported similar perceptions about food as structure from parents of children with spina bifida in that diet changes and medications were their first-line interventions to establish effective bowel programs. Parents in this study identified the value of food for its nutritional benefit and they believed their children with spina bifida were getting adequate nutrition from the food they consumed. Their larger concerns about food were related to the structural effects of food related to bowel function rather than nutrition. For parents of children with spina bifida in this study, managing food was reported as being complicated by three disability-specific issues: (a) the need to restrict food consumption to control excess intake of calories and trigger foods, (b) managing food and fiber to promote adequate bowel function, and (c) monitoring food intake to help their children maintain energy throughout the day.

Parents in this study reported using food and fiber interventions as directed by their healthcare providers to maintain adequate bowel function. However, Sawin and Thompson (2009) reported that long-term food and fiber interventions were inadequate to address the complexities of bowel continence. Compared to the findings of Sawin and Thompson (2009), parents in this study reported that fiber intake helped their child's bowel control and function, but that they were frustrated with trying to teach their children about fiber content in food and the relationship of fiber to bowel function.

Teaching About Food

Parents reported teaching about food quality and portion control for meals and snacks as a way of facilitating the development of healthy food choices, as well as controlling caloric intake for their children with spina bifida. These parents reported that the healthy food choices they were teaching were working and that their children's food choices were enhanced by their physical presence. Fisher and Birch (1999) found that teaching health food choices for children without disabilities worked best while the children were in the presence of their parents but that children reverted to poor food choices when outside the influence of their parents. Comparatively, parents in this study reported that they felt their presence was required to help their children with spina bifida make good food choices but reported specific examples that their children still made good food choices, for the most part, even when they were not present.

Parents in this study reported barriers to teaching and monitoring healthy food choices consisted of times when their children spina bifida were not within parental control, such as when children were with older siblings or at school. Similarly to Fisher and Birch (1999), Brown, Ogden, Vögele, and Gibson (2007) also reported that nondisabled children were more likely to make poor food choices when they were outside of the influence of their parents. Additionally, parents in this study focused their teaching on helping their children with spina bifida make independent choices that facilitated their bowel function, as well as controlling excess caloric intake. For parents in this study, teaching their children with spina bifida about food choices also included how food can trigger abdominal pain and how their child felt throughout the day. Research is limited about how parents teach their children with spina bifida about how food affects how they feel through the day (e.g., causing pain, abdominal discomfort), or how parents facilitate their child's ability to make independent choices outside of their control. Sawin and Thompson (2009) reported that parents explained that their children with spina bifida frequently had reactive gastrointestinal systems that were triggered by certain foods, but did not report how these families worked with their children to help them make independent, self-directed, healthy choices to avoid foods when they were outside of their parents' control.

Parents in this study described clear goals for self-management in teaching their children with spina bifida about food so that their children would learn self-regulation over food choices, as well as how to make healthy food choices. Buran, Sawin, Brei, and Fastenau (2004) reported self-management skills for adolescents with spina bifida were inadequate, citing they still required moderate assistance from parents to make healthy choices and direct their own care. Although Buren and colleagues (2004) reported about the development of self-management skills, such as managing medications, making appointments, and developing household skills, they did not report specific findings about making healthy food choices as a component of self-management. In contrast, for parents in this study, making independent, healthy food choices to avoid energy- dense foods and trigger foods was reported as one of their primary goals of self-management for their children with spina bifida.

Monitoring and Restricting Food Intake

Parents in this study monitored and restricted food as their first line of defense for preventing overweight in their children with spina bifida. Monitoring and restricting is a common first line of defense for many parents, yet does not always have a positive effect or outcome for controlling overweight for children (Birch & Davidson, 2001; Gilman et al., 2000). From early in the child's life, parents in this study recalled an awareness that their children were at greater risk for overweight as compared to their able-bodied peers. More specifically, parents noted that they had been consistently taught to restrict energy-dense, fatty foods by their healthcare providers. Birch and Davidson (2001) reported that if parents perceived a risk for overweight in their child's environment, they would increase control through monitoring and restriction of the undesired food; yet, restriction and increased control could have a paradoxical effect of promoting overweight by increasing a child's desire for the forbidden food. Thus, increased control of food exerted by parents has been identified as a risk factor for promoting obesiogenic environments (Birch & Davidson, 2001). In contrast, Ogden, Reynolds, and Smith (2006) reported that increased monitoring also has beneficial effects on eating behaviors for children because parental control often includes promoting healthier behaviors in addition to monitoring and restricting food. In this study, parents reported that restricting food was a positive health benefit for their children with spina bifida, in that food restriction controlled their child's poor eating habits and helped develop healthy food choices. However, restricting and monitoring food is a complex parenting process with both positive and negative effects and is not consistently reported to promote obesiogenic environments.

Explaining opposing research on the effects of food control may be clarified by examining Baumrind's descriptions of parental control to understand mechanisms parents use to control food (Lederman et al., 2004). Secure, nurturing, supportive parents are reported to communicate standards (e.g., demandingness) to their child and model confident, self-controlled behaviors; thus, parents who combine warmth and rational, reasonable control (e.g., responsiveness) are more likely to be effective in promoting self-competence in their children (Baumrind, 1967, 1996, 2005). Warm and rational parents praise children for striving to meet their demands of behavior and judiciously use disapproval and restriction (Baumrind, 2005). Responsiveness balanced with demandingness are key concepts of Baumrind's theory of parental control that affect a child's behavior (Baumrind, 1996). In this study, parents reported that they were responsive to requests by their children with spina bifida for restricted food and felt they communicated their expectations for behavior appropriately to their children. Comparison of this report to either Ogden, Reynolds, and Smith (2006) or Birch and Davidson (2001) was difficult as neither study reported actual levels of responsiveness or demandingness in their studies of parent practices during food restriction.

Parents in this study reported they believed food restriction was a positive parental action in much the same way that Ogden and colleagues (2006) reported that monitoring and managing food choices promote healthy food choices in children. As stated previously, parents in this study reported using food restriction to control excess caloric intake to prevent overweight, adding that they felt food restriction was a health promotion process that was good for their children. Parents reported managing and monitoring food for controlling caloric intake and promoting their children's ability to make healthy food choices. Yet, despite monitoring and restricting food consumption, the older children with spina bifida in this study were overweight.

Monitoring and restricting food for these parents involved being present during snack and meal times. All the parents in this study reported that at least one parent was present when their child left for school in the morning and when they returned home from school, even though the majority of parents were employed outside the home. Parents stated they were not at home specifically to monitor food consumption, but had already accommodated their work schedules to be home when their children with spina bifida were home. These parents changed their schedules to assist their child with spina bifida on and off their school bus transportation and to monitor their other spina bifida management care needs. As Sawin and Thompson (2009) reported, their participants were also from two-parent families with parents mostly working outside of the home, but did not report if parents were home before and after school to assist their children with spina bifida. Buran, Sawin, Brei, and Fastenau (2004) reported that 69% of the children in their study were from two-parent families, yet most parents worked outside of their home. Neither of these two studies reported how available parents were for their children with spina bifida or if parents had accommodated their work schedules to be home before or after school. For parents in this study, an unanticipated benefit of being home with their children with spina bifida was that it facilitated parents' ability to manage food intake of their children with spina bifida.

Food restriction of energy-dense calories is problematic unless nutritive- and fiber-rich foods are substituted in diets because children experience feeling unsatisfied and hungry (Birch & Davidson, 2001). Food restriction to lower caloric intake is reported to be commonly misused unless it is paired with substituting nutritive-rich food offered to children to increase satiety (Gilman et al., 2000). Gilman, Rifas-Shiman, Frazier, Rockett, Camargo, Field, Berkey, and Colditz (2000) reported that restricting energy-dense food is a common food control employed by parents of nondisabled children who were focused on preventing overweight. Similar to research with nondisabled children, parents in this study more frequently reported using food restriction to control caloric intake, but did not report substituting with more nutritive-rich food. Nutritive-rich food substitution helps children learn that some foods will make them feel full for longer periods of time and that they do not have to decrease how much they eat, but *change* what they eat to promote satiety (Birch & Fisher, 1998).

Additionally, food restriction in early childhood also promotes poor self-regulation and self-control over food by children and is actually associated with increased intake of restricted foods (Birch & Davidson, 2001; Fisher & Birch, 1999). All of the parents in this study described that they focused on controlling food quantity and restricting energy-dense, fatty food as one of their early methods of preventing the development of overweight. These parents did not report they were aware of any future negative effects of food restriction on their children with spina bifida. Birch and Davidson (2001) and Hood, Moore, Sundarajan-Ramamurti, Singer, Cupples, and Ellison (2000) demonstrated that food restriction is, at best, misunderstood and possibly mismanaged by parents due to the paradoxical effect that food restriction has on children by triggering overeating, promoting an increased desire for restricted food, and undermining the development of the child's autonomy in making food choices. Additionally, Sibler, Shaer, and Atkins (1999) suggested that the future effects of food restriction may be related to the development of eating disorders. As compared to these researchers, parents in this study were unaware of any potential negative effect of their use of food restriction.

Sibler and colleagues (1999) called for food substitution rather than food restriction to promote children experiencing satiety from their diet, prevent feelings of hunger or being deprived of desired foods, prevent the development of poor food choices and future eating disorders. Parents in this study did not report learning about food substitution or that some food results in higher levels of satiety, thereby reducing children's calorie intake while also leaving them feeling full. Rather, parents in this study reported that they believed that food restriction would control their child's calorie intake.

Promoting Healthy Eating and Satiety

In this study, parents explained that they promoted healthy eating for their children with spina bifida by teaching and rewarding positive food choices that their children made to increase fiber and maintain adequate hydration in their diet. Parents reported that their healthcare providers taught them to increase fiber and maintain adequate hydration to promote bowel function; thus, they focused on teaching and rewarding their children for making these healthy choices. Paradoxically, promoting healthy food intake, just as restricting unhealthy food intake, may negatively contribute to poor food choice behaviors in children (Birch & Davidson, 2001). Birch and Davidson (2001) found that rewarding healthy food choices in nondisabled children had conflicting results, while increasing the child's intake of healthy food, rewarding healthy food can decrease the child's desire and increase their aversion to that same healthy food. Thus, parent rewards for healthy choices of nutritive- and fiber-rich foods or adequate intake of fluids has a potentially negative effect of increasing the child's aversion to the healthy food and fluid intake. Parents reported they felt that rewarding healthy eating had positive outcomes for their children and they did not see negative behavior as reported by Birch and Davidson (2001). It is possible that the parenting behaviors described by parents in this study promoted healthy eating behaviors in a highly responsive and appropriate manner of parental control as described by Baumrind (2005). Baumrind (2005) and Ogden, Reynolds, and Smith (2006) suggested that parental control behaviors that are highly responsive promote adaptation of healthy eating behaviors, rather than promoting aversion behaviors as reported by Birch and Davidson (2001).

Silber, Shaer, and Atkins (1999) suggested that parents receive teaching that nutritive- and fiber-rich foods promote satiety from their children's diet, as well as instructions to decrease intake of energy-dense foods. Comparatively, healthcare providers guided parents to encourage fiber intake through medications and food to promote bowel function. Parents in this study reported that fiber medications and fiber-rich foods were promoted in healthcare visits, but were promoted primarily for bowel function, not satiety. Parents in this study did not report that they used fiber in their child's diet to help their child develop healthy eating habits that promote satiety. Additionally, parents in this study reported that fiber in the form of medication often caused their children to feel uncomfortably full, causing an opposite goal of satiety as their children, if they felt bloated, were unable to eat food for sustenance. Similarly, Sawin and Thompson (2009) also reported that parents knew that fiber-rich diets were recommended for bowel function, and added that including fiber in their child's diet had inconsistent results, was problematic to their child's appetite, and, actually, not sufficient to deal with the lack of intestinal motility in their children with spina bifida. Parents in this study, and those described by Sawin and Thompson (2009), knew that fiber was associated with healthy bowel function; however, they did not report that fiber in food increased satiety or had other cardiovascular benefits for their children with spina bifida, as suggested by Silber and colleagues (1999). Teaching about the benefits of a fiber-rich diet is focused on promoting bowel motility, not on promoting satiety for children with spina bifida. Teaching about the need to increase intake of fiber-rich foods is further complicated by promoting the intake of fiber in medication form to solve overriding needs for these children with spina bifida to maintain adequate bowel motility.

Encouraging Physical Activity for Children with Spina Bifida

Physical activity was described as part of the daily lives of younger children with spina bifida in this study, with parents providing specific details about barriers and facilitators of play and physical activity. In contrast, parents of *older* children overwhelmingly reported that physical activity was not a part of their older child's life and they focused on promoting physical activity as a method to prevent and reduce overweight in their older children with spina bifida. Parents reported having few conversations with healthcare providers about the importance of physical activity to prevent or treat overweight for their children with spina bifida. Parents developed plans for increasing physical activity on their own without the assistance of healthcare providers. While parents in this study were able to recount consistent messages from their healthcare providers that were focused on preventing overweight by managing food intake, parents did not report conversations about the protective effects of being physically active to prevent overweight.

To date, few research studies have described how parents of children with spina bifida promote physical activity to prevent overweight (Liou et al., 2005; Rimmer et al., 2004). Most research on physical activity and physical disabilities has focused on physical barriers in the environment that decrease participation for children with physical disabilities (Rimmer et al., 2004). Parents in this study found additional barriers to physical activity to include the lack of holistic person-environment assessment and planning between parents and healthcare providers to help them encourage physical activity for their children with spina bifida. Parents in this study reported that the focus of their healthcare providers was to promote functional mobility by way of adapting braces and orthotics, and acquiring a wheelchair for their child with spina bifida to move about the environment more efficiently. Children with spina bifida are reported to require more energy to be mobile (Asher & Olson, 1983), explaining the rationale for healthcare providers to focus on assisting with mobility and ambulation to preserve energy and promote function. Yet, parents in this study were interested in assistance with a broader range of physical activities within their child's environment, such as active play and peer-related physical activities and socialization. Parents in this study struggled to keep their child active with peers and believed that peer-related physical activities afforded their children more benefits of being physically active within their natural environment.

However, parents of older children with spina bifida in this study were challenged to accommodate the physical and emotional barriers in their child's environment while encouraging participation in physical activity. Simeonsson, McMillen, and Huntington (2002) reported barriers to physical activity as gaps in the person-environment interaction that promote decreased mobility and increased inactivity in individuals with spina bifida. Simeonsson and colleagues (2002) described dimensions of accommodation, affordability, and acceptability to illustrate what hinders children with spina bifida and physical disabilities from being physically activity. Simeonsson and colleagues (2002) described how physical activity is affected by environmental and personal factors for children with spina bifida. They reported that factors such as limited parent and healthcare provider expectations, inaccessible facilities, fatigue, and parental overprotection contribute to overall decreased physical activity for children with spina bifida. Parents in this study described environmental and personal factors similar to Simeonsson and colleague's dimensions (2002), but added that their older children with spina bifida also displayed an increased desire or comfort to being in their wheelchairs and to not participate in physical activity.

Similarly, Epstein, Roemmich, Paluch, and Raynor (2005) reported that nondisabled adolescents developed an increasing preference to be sedentary, attributing this preference to adolescents being more rewarded by sedentary activities than by being physically active. As compared to Epstein and colleagues (2005), older children with spina bifida in this study displayed similar preferences for sedentary behaviors rather than physical activity. Additionally, parents of children with spina bifida in this study described that their children with spina bifida were beginning to recognize that their physical differences and physical abilities were different that their peers; thus, they were reluctant to participate in competitive physical activities. Parents reported that their children with spina bifida experienced difficulty moving in and out of their wheelchairs due to decreased physical functioning and larger body size as they grew older. Additionally, parents explained that their children with spina bifida wanted their parents to participate with them in physical activity rather than peers, because their parents were able to assist them bridge the gap in their physical abilities and minimize their differences from peers.

Anticipatory Guidance for Physical Activity

Studies of healthcare providers have described that they feel unsuited or ill-prepared to discuss how to motivate children to be more physically active and how to adapt personal and social environments for children with physical disabilities (Brawley, Rejeski, & King, 2003; Heath & Fentem, 1997; Messent, Cooke, & Long, 1999). Additionally, Simeonsson and colleagues (2002) reported that healthcare providers and parents may have limited expectations of a child's physical ability to participate in physical activities, which can interfere with effective anticipatory guidance about physical activity. Parents in this study reported that they created the environment for their child to be physically active by themselves, without encouragement, support, and teaching from their healthcare providers. Parents reported that healthcare providers focused on assessment and treatment of functional mobility, rather than focus on facilitating the child's participation in physical activities and matching the physical activity to their child's functional ability. Simeonsson and colleagues (2002) promoted a social model of assessment for children with physical disabilities to encompass assessment of activities, such as improving school participation or participation in family activities, such as chores at home. Because healthcare providers focused on disability-related system assessments, they missed opportunities to discuss how the child's physical disability impairs physical activity, affects their interactions within their immediate environment that may promote more physically activity, and engage siblings and peers to promote joining physical activities (Simeonsson et al., 2002).

Parents in this study did not receive anticipatory guidance that their child would become more sedentary at puberty. Younger children with spina bifida were active in their environment and parents reported that their children were within normal weight and physical activity ranges for their age. Yet, when older children in this study reached adolescence, they became sedentary, with increasing overweight, similar to children without physical disabilities (Epstein et al., 2005; Schneider & Brill, 2005). Epstein, Roemmich, Paluch, and Raynor (2005) investigated sedentary behavior in adolescents without disabilities and found that developmental changes were associated with being less physically active, with adolescents preferring to be sedentary as a common problems that contributed to them being overweight. Similarly, older children with spina bifida in this study experienced developmental changes at puberty with increased sedentary behavior and marked decreases in their overall physical activity levels. Thus, in anticipation of upcoming physical and developmental changes for children with spina bifida, important anticipatory guidance for parents needs to focus on encouraging physical activity before children reach adolescence to maintain physical activity and prevent overweight.

Hindering Physical Activity

Parents in this study reported similar factors of hindering physical activity for their children with spina bifida as compared to those reported by Simeonsson (2002) of accommodation, affordability, and acceptability. These parents reported additional hindrances to promoting physical activity in their personal beliefs. These parents reported they felt that forcing their child to play was “unnatural,” “uncomfortable,” and “bothersome.” These barriers or hindrances were similar to those identified by Borra and colleagues (2003) for parents of children without disabilities. Parents of children without disabilities reported similar anxiety about forcing their child to be physically active, anticipating that their children would become defensive if directed to be physically active, and parents wanted to know how to motivate their child to be more physically active. In comparison, parents of children with physical disabilities have also reported they find it difficult to tell their children to 'go play' due to the physical and emotional barriers in their environment (Blum et al., 1991). Children with physical disabilities choose to play, but their play is characterized by less physical activity and more sedentary activity than their nondisabled peers and parents feel compelled to push their children into physical activity (Rimmer et al., 2004). Indeed, similar to Rimmer, Roland, and Yamaki. (2004), parents in this study reported that their children faced barriers to being physically active in their neighborhoods and schools and that children were not as active as their able-bodied peers. Additionally, the parents in this study were reluctant to force their children with a physical disability to participate in physical activity similar to Borra and colleagues (2003) and Rimmer and colleagues (2004).

Facilitating Physical Activity

Most children are drawn into physical activity because physical activity is personally rewarding and they are engaged in physical activity with those around them, including siblings and children in their community (Ritchie et al., 2005). Once a child learns how to engage in a physical activity, either alone or with a peer or sibling, the physical activity becomes more internalized and self-directed (Epstein & Roemmich, 2001). Similar to Epstein and Roemmich (2001), parents in this study reported that their younger children with spina bifida found play and physical activity rewarding because it involved friends and siblings. Parents reported that their younger children were active for their age and physical ability and had access to physical activities. Even though parents reported their younger children with spina bifida were physically active, they reported that their children did not demonstrate play and physical activity naturally through their own experiences in their environment. Thus, parents had to facilitate play and physical activity for their younger children with spina bifida through monitoring and accommodation of the environment.

In this study, parents reported that their older children with spina bifida wanted their parents to participate in physical activity with them. Research on how internalized, self-directed physical activity for children with spina bifida develops is limited for comparison of this finding. Current physical activity research reports the barriers and facilitators to developing physical activity for children with spina bifida (Rimmer et al., 2004); however, research findings that parents are required to participate with their older children with physical disabilities has not been found. A benefit of parents participating with their children in physical activity was reported by Welk and colleagues (2003) in that physically active parents promoted more physical activity in their nondisabled children. However, Welk, Wood, and Morss (2003) reported parents and their children did not do the same activities or perform at the same level of physical activity or actually participate in physical activity with their children. Rather, they reported that physically active parents have children who are also more physically active. In contrast, parents in this study reported that their children with spina bifida benefited from doing physical activity with them not because they were modeling healthy physical activity, but because they were present to facilitate physical activity by helping their children with spina bifida be mobile and negotiate the physical environment.

Decreased Interest in Physical Activity and Developmental Issues

The decrease in physical activity during adolescence has been well-documented (Dietz & Robinson, 2005; Epstein et al., 2005). Parents in this study reported that once children neared or reached puberty, they desired to be less physically active and became more sedentary. Parents described difficulty with encouraging and engaging their older children with spina bifida in physical activity. This finding is similar to other research on physical activity and sedentary behavior of adolescents with and without physical disabilities. Epstein and colleagues (2005) reported that as children reach adolescence they desire less physical activity and take on more sedentary behaviors. It is important to note that adults with physical disabilities continue to be less physically active than their nondisabled peers (Heath & Fentem, 1997). In this study, all of the older children (≥10 years, 6 months old) had decreased interest and participation in physical activity and were already overweight or obese

There are multiple physical and developmental issues that affect an older child with spina bifida's ability to be physically active: (a) difficulty with mobility as their bodies grow, (b) an increased desire to be sedentary, (c) decreased ability to be active out of their wheelchairs, and (d) lack of appropriate adaptive outlets to be physically active (Rimmer et al., 2004). In this study, parents reported that their older children with spina bifida (≥10 years, 6 months) also worried about differences from their peers and felt embarrassment, anxiety, and fear, which decreased their desire to participate in physical activity. Parents in this study felt that their older child's fear and embarrassment contributed to them not wanting to be physically active as compared to when they were younger. Similarly, Rimmer, Roland, and Yamaki (2004) reported that adolescents with physical disabilities identified barriers to physical activity that included that adolescents felt self-conscious doing physical activity. Additionally, older children in this study would not participate in most physical activities unless their parent participated with them in the activities, such as swimming and bike riding. In contrast, Rimmer, Roland, and Yamaki (2004) reported that individuals with physical disabilities lacked the support of friends and family in their environment to help them access and participate in physical activity and recreation. Additionally, Rimmer, Roland, and Yamaki (2004) interviewed staff at fitness facilities and found that staff reported that if parents of older children with physical disabilities participated with their children, they were overprotective and became a barrier to participation. Thus, in comparison to the findings of Rimmer, Roland, and Yamaki (2004), the older children in this study required their parent to be present for them to be physically active; yet, parents reported that they felt their presence was a behavior of necessity, not overprotection.

Sawin, Brei, Buran, and Fastenau (2002) reported that adolescents with spina bifida struggled with independence, at one time needing their parents and at another time wanting to be independent of their parents. Parents in this study did not identify that they were overprotective or that their children with spina bifida experienced the effects of overprotection as a barrier to them being physically active. Rather, parents in this study felt their child wanted them to be with them during physical activities to ensure safety, help negotiate physical barriers, and to provide encouragement. Thus, parents' presence, even though required and desired by the older children in this study, could represent a struggle for independence for these children.

Awareness of Physical Differences and Decreased Mobility

During adolescence, children with spina bifida become increasingly aware of their physical differences from peers and are developing their identity as a person with a physical disability (Simeonsson & Rosenthal, 2001). Adolescents with spina bifida are more aware of their differences from peers, as compared to when they were younger (Feldman & Varni, 1985; Minihan, Fitch, & Must, 2007). As children with spina bifida near puberty, increased body size and physical function leads to increased time in their wheelchairs and marked decreases in mobility as compared to when they were younger (Marge, 1994; Simeonsson et al., 2002). And, indeed, adolescents with spina bifida choose predominantly passive physical activity with their peers, such as watching television or playing games, such as chess (Blum et al., 1991). Adolescents with physical disabilities are four and one-half times more likely to report that they participate in physical activity *only* once per week as compared to their able-bodied peers (Ludwig & Ebbeling, 2005). Additionally, Ludwig and Ebbeling (2005) suggested that an emphasis on competition and winning emphasizes physical differences may make it more difficult for adolescents with physical disabilities to feel they can successfully participate in physical activity. Parents in this study reported their older children with spina bifida had similar patterns of decreased physical activity and increased awareness of their physical differences from peers. These parents recognized that previous methods promoting mobility, such as scooting on the floor and transferring in and out of wheelchairs with assistance from others, was embarrassing to their older children, and highlighted their differences from peers. Growing awareness of physical differences for older children may explain why they chose to spend more time in their wheelchairs, less time transferring in and out of their wheelchair, and less time scooting on the floor. However, parents in this study were unsure of the reasons their children's chose to stay in their wheelchair, whether they were trying not to appear different, if they were embarrassed, if they resisted being competitive in physical activity, or if they were less able to move out of their wheelchair due to the larger body size.

Blum, Resnick, Nelson, and St. Germaine (1991) explained that ambulation is closely associated with social and peer interaction; thus, decreased mobility creates a another risk of setting children with physical disabilities apart from their peers. Younger children with spina bifida in this study were more mobile, while older children were less mobile and at-risk for social and peer isolation. In this study, parents identified additional mobility factors that influenced their older children with spina bifida being physically active, including (a) being afraid of participating in physical activities that were possibly unsafe, (b) needing parents or skilled helpers to assist with transfers and adapt physical activity, and (c) worrying about exposing their continence protection pads or being incontinent during the physical activity. Older children in this study were less mobile and more dependent upon their parents to be move about their environment. Additionally, Blum and colleagues (1991) identified that when adolescents with spina bifida and cerebral palsy were highly dependent upon their parents for personal care such as bowel programs and transfers, they also experienced overprotection and were at-risk for social and peer isolation. Similar to Blum and colleagues (1991), older children in this study had impaired mobility, requiring their parents to interface in their environment, and, thus were also likely to be at-risk of experiencing increased social and peer isolation. Parents in this study reported they were minimizing their child's risk factors associated with mobility such as safety, transfer assistance, incontinence, and peer differences, and were not intending to isolate or overprotect them.

Minimizing Differences

Parents in this study recognized that their older children with spina bifida were reluctant to have their physical differences evident to their peers or others in their environment. Thus, these parents acted as an interface between their child and their physical activities to decrease visibility of their physical differences to others. These parents felt they needed to minimize their child's differences to promote their children's engagement in physical activities. Parents minimized differences with anticipatory actions of accommodations during physical activity to help their children with spina bifida become physically active without others noticing their child's differences. The parents in this study were similar to those studied by Ray (2002), in that parents of children with special needs anticipated how their child would fit in the social world and minimized their child's differences by performing '*invisible*' parenting roles to '*pave the way*' for their child's acceptance by others. Miles and Holditch-Davis (1995) described parental roles of compensatory parenting in which parents learn early in their child's fragile life that parenting includes being a protective interface between their child and the outside world. Similar to both Miles and Holditch-Davis (1995) and Ray (2002), parents in this study identified parenting roles that extended their ability to protect their children with spina bifida into their school-age years. Parents in this study minimized their child's differences that could identify others' concerns so their children would not face adversity in making relationships. Ray (2002) described parents' recognition of the world as '*cruel*' and their instinct was to '*shelter*' their children; yet, parents recognized that their children needed social interaction, thus they worked to desensitize those around them by managing the environment to gain acceptance for their children. Similar to Ray (2002), parents in this study moderated the exposure of their children's differences to minimize the reactions from adults and peers in an effort to improve their child's acceptance by others. For example, parents in this study participated in swimming or biking with their older children to protect them from exposing their differences; they minimize their child's differences by quickly transferring, assisting, and covering their child's differences from peers and others.

In this study, parents also minimized their child's differences with peers by providing excuses for their child so that they could prevent peers from knowing that their child could not participate in group physical activities without the assistance of their parents. For example, parents made excuses of a previous appointment or other family activities for their child so they would not have to reveal to their peers they could not go biking or swimming without the help of their parent. Although parental interface may be a comfort to adolescents with spina bifida, it also promotes dependence upon their parents (Antle et al., 2008). While helping to minimize their child's differences from peers, parents in this study also recognized that their interfaces decreased their child's opportunity to be physically active with peers and decreased peer interaction, thereby preventing them from attaining skills of social competence and independence.

Parents in this study felt they had to interact in the environments for both their younger and older children to minimize their child's differences from others to successfully promote play for their children with spina bifida. Parents in this study did not anticipate or believe their interface and presence would put their children with spina bifida at-risk to be socially isolated or have limited physically active experiences with their peers. Feldman and Varni (1985) described that younger children with spina bifida do not see themselves as different from peers, despite their inability to move in the same way as their peers or that they were wearing bladder and bowel continence pads.

Similarly, *younger* children with spina bifida in this study engaged in physical activity despite their differences, because parents reported participating in the activity was more important than being left out. However, *older* children with spina bifida were choosing not to engage in physical activity to avoid others recognizing their differences that previously were not important to them. Similar to Feldman and Varni's conceptualizations of health and illness for children with spina bifida (1985), these older children were portrayed by parents as having an advanced understanding of their physical condition that they were now trying to hide from others. In comparison to the findings of Buran, Sawin, Brei, and Fastenau (2004), older children with spina bifida in this study were not engaging in the full range of activities necessary for successful participation in social skill development.

Dependence on Parents for Physical Activity

Dependence on families for physical activity is common for children with spina bifida (Loomis et al., 1997). Loomis, Javornisky, Burke, and Lindsay (2002) found that young adults with disabilities were dependent on families to help them with negotiating physical activity in their wheelchairs, even though they were community wheelchair ambulators independent of their families for transportation. Similarly, parents in this study reported that their children were dependent upon them to either teach other people how to assist their child or to be present to assist their children to be physically active. In this study, parents recognized that their children with spina bifida were dependent upon their physical presence; thus, parents remodeled their environment and revised their work schedules to be available to their children.

Older children with spina bifida ($\geq$10 years, 6 months) in this study were reported to be dependent upon their parents to be able to participate in physical activity. Parents described that their older children with spina bifida needed the support and physical presence of their parents in order to engage and maneuver in their environment. When older children in this study encountered barriers to physical activity and peer interaction, they relied upon their parents to adapt barriers in their environment. Additionally, parents reported their older children were more aware of how barriers highlighted their differences to peers.

Current research on the outcomes of parental presence is contradictory. Steele, Kalnins, Jutai, Stevens, Bortolussi, and Biggar (1996) reported that 68% of youth with physical disabilities felt overprotection by parents when they were present and that their parents presence prevented them from doing activities that they wanted to do. Conversely, others reported that parental presence and involvement was more comforting and not associated with overprotection outcomes for adolescents with physical disabilities (Ellis, Templin, Naar-King, & Frey, 2008). Parents in this study described how they were present to assist and encourage their older children with spina bifida to be physically active, not to overprotect them. For older children to be physically active, they relied upon parents to help them safely negotiate physical environments and accommodate for unknown needs. Additionally, parents of older children with spina bifida reported their children simply did not want to depend on others to perform necessary accommodations for them to be physically active; they were more comfortable with their parents than anyone else.

Normalization Activities by Parents to Encourage Physical Activity

Parents in this study anticipated that their child with spina bifida would be dependent on others when doing physical activities and worked on bridging that gap in their child's environment by finding skilled helpers. For example, normalization for parents of children with spina bifida in this study included how parents performed physical activities with their children and how they created skilled helpers in their environment to manage their child's dependence on them.

Normalization is a process whereby parents perform *invisible activities* to accommodate the special needs of their children (Antle et al., 2008). Deatrick, Knafl, and Walsh (1988) described normalization as a constant process that parents performed to accommodate for the physical and emotional needs of their children with disabilities. Accommodation is initiated from a practical necessity of providing solutions to problems of daily living for parents of children with disabilities (Deatrick, Knafl, & Murphy-Moore, 1999). Thus, in this study, normalization was achieved by these parents when they participated with their older children in physical activities. By participating with them in the same physical activity, their older children were less aware of their differences and experienced physical activity as normal as their parents could make it for them.

Normalization through the use of skilled helpers was identified by parents in this study as a practical need for their children with spina bifida to be physically active. Skilled helpers were required to accommodate their child's need to feel safe in doing physical activity when parents were not present. Skilled helpers had confidence and knowledge about how to transfer and move their child, and thus, children with spina bifida felt safe while participating in physical activity. In this study, parents reported that community coaches, school and church staff members were willing to become skilled helpers to help their children with spina bifida to participate in community-based physical activities.

The acceptance of skilled helpers was different for younger and older children with spina bifida in this study. While younger children did not notice a skilled helper was assisting them to be physically active, older children were aware that they required assistance. These parents reported that their older children preferred to have their parents assist them, and *not* a skilled helper. For parents of older children, the accommodation of skilled helpers was unsuccessful and their older children were once again dependent upon them to be present and anticipate their needs so they could participate in physical activity. Thus, further adaptation and accommodation was necessary to normalize their environment, as described by (Deatrick et al., 1999), as these children became older and more aware of themselves and their environment.

As compared to older children in this study, parents of younger children (<10 years, 6 months old) with spina bifida reported fewer barriers to participation in all physical activity, such as nonadapted community activities, school physical education, and disability-adapted recreation. While parents in this study reported their younger children were able to participate in most physical activity, they clarified that physical activities still needed to be assessed for any necessary adaption for their child to be able to safely participate. In this study, younger children were still dependent upon their parents to normalize situations, but parents were able to do so with the help of skilled helpers by quickly assessing the necessary accommodations their younger children with spina bifida may need to be physically active. Parents knew what was required to normalize physical activity for their children and relied upon skilled helpers as needed to assist their younger children with spina bifida when participating in physical activities.

Miles and Holditch-Davis (1995) defined compensatory parenting as actions of accommodating and avoiding situations that mothers used to direct the environment for their premature infants because of their child's fragility. Parents in this study continued to use compensatory parenting skills that they learned when their child with spina bifida was an infant. Parents were now using compensatory parenting to manage and accommodate their school-age child's environment. Skilled helpers may also be considered as compensatory parenting roles for the parents in this study. Additionally, parents described training skilled helpers in much the same way that Ray (2002) described how parents of children with special needs '*close ability gaps*' and '*pave the way*' for their children to interact within their environments. Skilled helpers reported from this study were a necessary requirement to close ability gaps for younger children with spina bifida and pave the way for these children to be physically active without their parents' presence. Important to these parents was that compensatory actions that skilled helpers provided their children in their absence were required for their children to be less dependent upon them. Parents also reported that younger children were more willing to let skilled helpers assist them, less aware of the actions of skilled helpers, and thus, more willing to engage in physical activities. Thus, parents were able to share their child's dependence upon themselves with others through using skilled helpers to easily accommodate the environment so their younger children could participate in physical activities.

Summary

This research focused on parents of children with spina bifida and provides further understanding of the practices that parents use to promote health for their children. Identifying parents' perceptions, beliefs, and practices that they used to promote health of their children with spina bifida, and describing how parents managed food and physical activity practices to prevent overweight contributes to a better understanding of the health promotion environment for children with spina bifida. Further, this information provides an explanation of the environmental factors that facilitate and hinder parents' efforts to promote the health of their children with spina bifida.

This study contributes to the growing body of literature on preventing overweight as a secondary disability for children with spina bifida. Importantly, parents defined their children's health as healthy bowel function, as well as managing the disability-related function of physiologic systems affected by spina bifida. Thus, parents' health promotion practices were directed at maintaining their child's bowel function and spina bifida care management, rather than more holistic health promotion practices focused on preventing disease. These results highlight parents' perceptions of their health promotion practices to manage food and promote physical activity for their children with spina bifida. Additionally, this study describes activities parents used to promote health and adapt the environment of children with spina bifida.

This study provides an understanding of how parents have utilized teaching and anticipatory guidance from their healthcare providers to manage and restrict food to prevent overweight for their children with spina bifida. Physical activity for children with spina bifida was complicated by an environment that hindered their free access to physical activities that they could engage in independently with their peers. Parents minimized their child's differences from their peers to encourage their continued participation in physical activity. Children with spina bifida depended upon their parents to normalize and adapt their environment so they could participate in physical activities. For older children, physical activity was restricted by their increased preference for sedentary behavior when they reached puberty. Despite the prevention measures of monitoring and restricting food and promoting physical activity, all older children in this study developed the secondary condition of overweight.

Overall, the results of this study contribute to providing a more complete description of parents' health promotion beliefs and practices for their children with spina bifida, primarily focused on maintaining bowel function and spina bifida care management. Further, this study contributes to understandings of parental practices related to managing food and promoting physical activity to prevent overweight in their children with spina bifida. Thus, promoting health for children with spina bifida is a complex process within an environment that must be adapted by parents to accommodate the child's physical disability.

Implications

Implications for Future Research

While qualitative research methods were invaluable in discovering unknown parental health promotion beliefs, values, and practices for children with spina bifida, quantitative research methods may be used to build upon and expand these findings. Future research needs to address the specific health promotion practices parents employ to promote the health of their children with spina bifida. Quantitative research methods may provide conclusions based on statistical significance through the investigation of health promotion variables for parents of children with spina bifida.

Although qualitative methods richly described these parent's beliefs about how they managed food, future research should explore variables related to food intake, physical activity, and the development of overweight for these children with spina bifida. Quantitative methods may be used to clarify how parents manage food for their children with spina bifida. Food consumption for children with spina bifida should be examined with food frequency questionnaires to measure the types of food and actual calories consumed, including the intake of fiber in foods and medications. Quantitative research should be conducted to measure the level and intensity of physical activity for children with spina bifida.

Future research should expand to include other children with spina bifida from other developmental age groups to determine whether or not health promotion patterns are similar to those described by these parents of school age children with spina bifida. Future research needs to investigate how feeling healthy is influenced by bowel function for children with spina bifida and the relationship between how maintaining healthy bowel function interacts with healthy eating patterns. Parents in this study clearly described how bowel function affects the health of their children and interacts with how they manage food. Future research needs to investigate interventions that promote bowel function for children with spina bifida through healthy eating practices. Future research needs to explore what factors promote child satiety, maintain energy and endurance, provide nutritive-rich foods, while minimizing the use of food restriction. Research focused on managing food for children with spina bifida needs to include bowel function as well as food interventions parents employ to avoid overweight because these problems are interrelated.

Future research should investigate food restriction and its relationship to developing negative food control behaviors for children with physical disabilities. Future research on food restriction should seek to describe the whole environment, including the level of restriction, the style of parenting, and the presence of other health promotion activities that parents use to control food that may have positive outcomes previously not identified in research.

Future research should expand to include other physical disabilities beyond spina bifida, to determine whether or not health promotion beliefs and activities that parents promote for their school-age children with other physical disabilities are similar. Further research needs to determine how to provide more holistic care and anticipatory guidance to parents of children with spina bifida to promote healthy lifestyle behaviors and reduce health risks, as well as continue to provide for the physiologic, disability-related system needs of these children.

Future research needs to explore ethnic and cultural variations in the use of food to prevent overweight, as well as how other ethnicities and cultures promote physical activity to prevent overweight for their children with physical disabilities. Cultural variations will provide more in-depth understanding of parents' health promotion practices for their children with spina bifida, including managing food and promoting physical activity to prevent overweight for their children with physical disabilities. Identifying cultural differences in beliefs, practices, and behavior patterns, as well as facilitators and barriers to health promotion efforts will inform and guide the development of more culturally-competent interventions for children with spina bifida and other physical disabilities.

The developmental changes of increasing sedentary behavior evidenced by the older children with spina bifida in this study are an important area for further exploration. Future research should investigate how developmental changes affect the ability and desire of children with physical disabilities to participate in physical activity. Intervention research is needed to test the effectiveness of strategies to decrease sedentary behaviors of children and adolescents with physical disabilities. Additionally, adapted physical activity and competitive sports for children with physical disabilities needs to be investigated to determine if current disability-related sports are indeed adapted and able to accommodate the needs of older children with physical disabilities to feel physically and emotionally safe and secure in these adapted environments.

Future research needs to continue to describe obesiogenic environments for children with physical disabilities. Research needs to provide parents and healthcare providers with knowledge about the associations between environmental variables that promote sedentary behaviors and poor feeding practices that ultimately support the development of overweight for children with physical disabilities. Future intervention research needs to provide parents and healthcare providers more accurate guidelines for clinical treatment to change obesiogenic environments and decrease overweight for children with physical disabilities.

Implications for Clinical Practice

Nurses and healthcare providers are in a unique and powerful position with parents to promote strategies to prevent the development of the secondary condition of overweight across the lifespan for children with spina bifida. Overweight and obesity is increasing for children with all types of physical disabilities and the findings from this research represent knowledge development in nursing. The relationship of overweight and spina bifida is the subject of the current research and provides essential knowledge for nurses to design interventions to change the course of overweight for these children. Identifying how parents' understand and employ practices to promote healthy lifestyles, define health for their children with spina bifida, manage food, and encourage physical activity to prevent overweight is an important knowledge base for developing clinically-based interventions to prevent or decrease overweight for children with spina bifida. Understanding the current environment of children with spina bifida related to promoting health to prevent the development of overweight will provide a sound basis upon which to develop effective nursing interventions.

Findings from this study will facilitate understanding of (a) the challenges faced by parents and their children with spina bifida related to promoting health, (b) how parents of children with spina bifida manage food to prevent overweight, and (c) how children with spina bifida choose to be physically active, characteristics of the school-age developmental age group. Knowledge from this study can be used to expand anticipatory guidance used by healthcare providers to enhance care of children with spina bifida. With increasing directives for nursing and healthcare providers to decrease secondary conditions such as overweight, the application of findings from this study could prove useful in development of interventions to improve health outcomes and prevent overweight for children with spina bifida.

Unanticipated findings from this study were that parents' view of health for children with spina bifida was based on bowel function and the effect of bowel function on how children feel on a day-to-day basis. The findings from this study may assist parents and healthcare providers to prioritize bowel function as the key indicator of the child's health. Bowel function was a high priority for these parents and reflected their children's health and functional status. Interdisciplinary teams need to provide anticipatory guidance to parents about the importance of adequate bowel function and its influence upon their child's life and ability to participate in activities on a daily basis. Early interventions to promote bowel function combined with food management to improve bowel continence influence the overall health and physical functioning for children with spina bifida. Promoting fiber intake with nutritive-rich diets and healthy eating is important health promotion teaching that promotes bowel function, in addition to providing protective effects against overweight and health in general. Advances in the care of children with spina bifida have made the future better; yet, children's day-to-day bowel function remains a constant frustration for parents and children, as well as a daily threat to the child's health status.

Important information gained from this study is that parents of children with spina bifida have health promotion beliefs for their children focused on maintaining the function of their child's disability-related systems, rather than a broader holistic perception of health. Knowledge from this study may assist healthcare providers to revise their current practice of assessment and intervention focused on the child's disability to include more holistic health promotion practices. Health promotion for parents of children with spina bifida is based on disease management as parents to care for their child's chronic physical disability. In contrast, promoting health is focused on lifestyle patterns and changes that decrease the risk of developing a secondary condition or disease, such as overweight. Healthcare for children with spina bifida revolves around assessment of their current disability function, but not an assessment of the risks of developing more sedentary behavior, other conditions such as overweight, or the health effects of these secondary conditions. Healthcare providers may use this knowledge to expand their focus from a systems-specific functional view to a more broad holistic perspective that includes providing health promotion assessment, teaching, and guidance for parents and children with spina bifida. It is imperative that assessment and teaching for parents and children with spina bifida be focused on promoting healthy lifestyle behaviors that can last into adulthood. A description of what parents of children with spina bifida believe about health promotion has been illustrated in this study as disease-specific rather than holistic in nature. Expanding the disease-specific approach to spina bifida care to the use of a more holistic approach toward spina bifida care and health within the confines of specialty-care clinics is a challenge for healthcare providers.

Preventing overweight is a balance of healthy eating versus energy output in a social environment of physical activity, play, and peer interaction for children with spina bifida. An important finding from this study is the knowledge that parents of children with spina bifida have modeled their strategies for overweight prevention from an environment influenced by their interactions with healthcare providers. Parents have employed teaching and anticipatory guidance from healthcare providers about managing food to reduce overweight for their children and they are open to more information about decreasing overweight for their children. Healthcare providers need to become more skilled at addressing assessment and intervention strategies to prevent overweight for children with spina bifida to include (a) the knowledge of encouraging food substitution, (b) minimizing the use of food restriction, (c) increasing satiety through nutritive- fiber-rich foods, and (d) promoting healthy eating goals more than restrictive eating practices to prevent overweight.

Current research informs nursing that when healthcare providers discuss overweight, the conversation is laden with a lack of understanding and this lack of skills creates barriers to effective interaction. If interactions between healthcare providers and parents are uncomfortable, unclear, or inaccurate, then the outcome will be less than desirable and ineffective in preventing overweight in children with spina bifida. Effective healthcare provider and parent interaction needs to promote quality clinical outcomes of reducing overweight for children with spina bifida. Healthcare providers caring for children with spina bifida need to have an understanding of parents' beliefs, practices, goals, and their environment to promote effective interventions. It is vital that healthcare providers communicate accurate information to parents through teaching and anticipatory guidance. Further, it is important that healthcare providers feel comfortable assessing and planning with parents to decrease overweight for their children. It is also important for healthcare providers to understand the trajectory of overweight for children with spina bifida, as well as the trajectory of becoming more sedentary as children reach puberty, in order to provide accurate health teaching and anticipatory guidance to parents.

Developing physical activity for children with spina bifida may be enhanced by findings from this study based on the perceptions that parents shared and current research. Parents in this study described ongoing assessment, planning, and anticipatory guidance by healthcare providers to promote physical activity. Current health promotion and intervention research suggests strategies for promoting physical activity for children with physical disabilities. However, healthcare providers need to teach parents physical activity strategies for children with spina bifida with equal attention that is given to strategies related to food management to prevent overweight. Healthcare providers need to become more skilled at promoting and adapting physical activity for children with spina bifida, with the knowledge that physical activity changes for children as they reach puberty due to changes in their body size, becoming more sedentary, and changing physical ability to interact in their environment. Healthcare providers also need to be aware that their own limited expectations of a child's physical abilities may affect how vigorously they encourage physical activity for children with physical disabilities. Nurses and healthcare providers are in unique positions to assist parents and children to adapt their environment to promote physical activity and teach about balancing energy intake with energy output for children with spina bifida to prevent overweight. Interventions focused on teaching about physical activity should include (a) assessing children's current level of participation in physical activity, (b) building upon small achievements in physical activity, (c) encouraging children to maintain adequate physical activity throughout childhood and with their peers, (d) helping parents identify their children's individual physical abilities and preferences, and (e) tailoring interventions to maintain the physical activity. These interventions may assist parents and their children with spina bifida to become more physically active as they progress from childhood to adolescence.

Physical activity for children with spina bifida in this study required time and attention by their parents. Healthcare providers may assess the efforts that parents employ for their children to be active and strategize with parents about using adapted recreation, as well as skilled helpers, in the community to help their children to be physically active. In this way, parents and children with spina bifida may become more accustomed to how they may use skilled helpers to keep their children as physically active as possible. Healthcare providers may also focus on physical activity as social activities necessary to help children with spina bifida develop self-competence as well as to develop physically. Maintaining physical function is an important goal of all parents of children with spina bifida; thus, strategizing with parents to promote physical activity at home and in the community is essential.

Promoting positive health outcomes requires healthcare providers to base their teaching and interventions on current research. To that end, this study improves understanding of the environment related to promoting health, managing food, and encouraging physical activity for children with spina bifida. Children with other physical disabilities who experience social and environmental barriers to being physically active may benefit from the experiences of these parents in promoting health for their children with spina bifida.

Obesiogenic environments are those that promote overweight. With increased interest in reducing the occurrence of overweight as a component of health promotion and decreasing secondary disabilities for children with spina bifida, this study contributes to knowledge about factors within obesiogenic environments. To create positive change in the development of overweight for children with spina bifida and to reduce the negative effects of overweight, it is imperative for healthcare providers to understand the interrelationships among the physical disability, environment, parenting, and the development of overweight. To this end, this study promotes a beginning understanding of the obesiogenic environment for children with spina bifida.

Knowledge from this research may be used for teachers and others involved in promoting healthy environments, including physical activity and healthy eating for children with spina bifida to improve the lives of children with physical disabilities. Schools and community recreation centers have goals of decreasing overweight for the children they serve. Thus, the findings of this study may be useful for others as they seek to enhance their environment and programs for children with physical disabilities by supporting (a) the promotion of healthy eating practices in schools and communities; (b) the development of skilled helpers to assist in physical activity; (c) providing safe and accessible physical activities; (d) promoting noncompetitive, adapted physical activities, such as yoga, weight training, and conditioning; (e) acknowledging that children with spina bifida want to minimize their differences from peers; and (f) promoting physical activity as an individual personal goal rather than a team competition. Increased understanding about the environment for children with physical disabilities includes knowledge of children's developmental stages, the barriers and facilitators of effective food management, and how to promote optimal physical activity for children with spina bifida. Using this understanding related to children with physical disabilities may prove to be more effective in decreasing overweight. Decreasing overweight will improve long-term health outcomes for children with spina bifida who are surviving into adulthood with longer lifespans than previous generations. Parents in this study were successful in incorporating complex healthcare needs into their daily lives, and the lives of their children with spina bifida. However, children with spina bifida are threatened with negative health outcomes of secondary conditions such as overweight that will lead to the development of other chronic conditions that will decrease their quality of life and their lifespan. Furthermore, although healthcare has improved the lives of children with spina bifida, these children are more threatened by behavioral lifestyle factors related to overweight than from the effects of their physical disability.

Nurses and healthcare providers are passionately interested in maximizing physical and social function and to promote healthy lifestyles for children with spina bifida. Increasing self-care skills, decreasing social isolation, and promoting self-competence are all interventions that nurses focus on throughout the lifespan of children with spina bifida. This study described how parents currently manage the environment for their child with spina bifida related to food and physical activity and described facilitators and barriers to preventing overweight through food and physical activity processes. Therefore, this study provides knowledge about how to improve health promotion efforts with a more holistic view of social and physical function for children with spina bifida.

Implications for Health Policy

Overweight is increasing for children with all types of physical disabilities and this study has implications for health policy at federal, state, and local levels. Facilitating healthy behaviors to prevent overweight for children with spina bifida is clearly a complex and multidimensional issue needing effective health policy for communities and schools. Nurses and healthcare providers are a trusted source of knowledge to inform health policy to promote healthy lifestyle development for children with spina bifida and should be sought as experts and consultants in health policy development at all levels. The health effects of overweight represents a substantial cost to the public and an even more substantial loss of optimal social and physical functioning for children with spina bifida. Health policymakers are faced with examining environmental barriers that promote overweight for all children, not just children with spina bifida. Understanding the current environment for children with spina bifida related to promoting health, managing food, and promoting physical activity provides health policy leaders knowledge upon which to achieve broader changes in food and physical activity environments that promote the development of overweight for children with spina bifida.

School and community policy needs to focus on the type of food that is available for children with physical disabilities. School food represents a large portion of dietary intake for all children. Children with physical disabilities, such as spina bifida, have specialty food requirements to help them maintain optimal physical functioning. Schools need to be designed to support healthy eating habits. School policy needs to include nutritional standards and limitations in offering energy-dense foods from any sources, especially those placed within schools by competitive food markets. School and community interventions focused on improving healthier food environments need to be provided support and funding to promote the health of children with physical disabilities, as well as other children.

School and community policymakers need to focus on evaluating facilitators and barriers to providing accessible, safe, and appropriate outlets for physical activity. School policy should promote physical activity as a life-long activity of developing personal endurance, strength, and muscle conditioning, more than competitive interaction with peers for children with physical disabilities. The needs of parents must be addressed in developing community and school physical activity programs. Children with physical disabilities represent a vulnerable population in which parents themselves have adapted their immediate environments to facilitate inclusion of their children who face barriers to being naturally included in all activities. Facilities provide adaptive recreation for children with physical disabilities by promoting inclusive physical activities for children with spina bifida. Recreation facilities may also improve their accommodations for children with physical disabilities by providing noncompetitive activities that promote endurance and strengthening. School and community policy needs to facilitate physical activity to assure that all children with physical disabilities have the ability to participate in physical activities and social activities as easily as their nondisabled peers. School environments should promote physical activity by having a policy of inclusion and accessibility for children with physical disabilities.

School and community buildings should be designed as accessible facilities that are in compliance with federal law. The codes and guidelines of the *American Disabilities Act, Public Law 101-336* (ADA) assure access and safety for all people with disabilities and are a requirement for all existing and new buildings. Existing buildings should be inspected and brought into compliance with ADA to optimize use of facilities by children with physical disabilities. ADA requirements should be followed for all new facility planning.

The *Individuals with Disabilities Education Act, Public Law 105-17* (IDEA) identifies the school's responsibility to include students with all disabilities into the general curriculum (including physical education, extracurricular, and nonacademic activities) with accommodations when necessary. Physical education policy should promote endurance and muscle strengthening over competition due to the physical differences in disabled and nondisabled children. Physical education policy should be reflective of the use of adapted physical activities and equipment for those with physical disabilities.

School facilities should promote social interaction, as well as physical access, for children with disabilities during times before and after school, during recess, and at lunch. Specific to promoting social interaction for younger children with physical disabilities, school environments may include walking paths within the current expanses of grassy areas to encourage children with alterations in mobility to freely move about the school and playground environments with their peers. Cafeterias should have tables that provide seating for children using wheelchairs, walkers, and crutches to join their nondisabled peers to promote social interaction during lunch time. School entrances, parking lots, and playgrounds should have adequate space for wheelchair access, be adapted and disability-accessible, and be consistently maintained.

School success represents a large component of personal success and self-competence for children with spina bifida; thus, school policy needs to develop goals related to how children may demonstrate success in their physical education curriculum. Examples of school physical education initiatives for children with physical disabilities includes adapting course goals to the child's ability and preferences, promoting physical strength or flexibility goals, using peer tutoring to help children participate in activities, or strategizing to improve mobility in the school. Health and physical education curricula in schools should include health promotion teaching related to healthy making food choices and engaging in physical activity.

Healthcare policymakers should focus their overall health goals for their children with physical disabilities to embrace holistic healthcare with the same attention they currently give to promoting excellent, state-of-the-art health care, focused on system-specific functioning. Healthcare policymakers should focus on health promotion and prevention of secondary disabilities, through detailed examination of health coverage and reimbursement for their children with physical disabilities to promote optimal physical and social functioning. Health policies that support the social and physical functioning of children with spina bifida will improve the quality of their lives. Further healthcare policy makers and administrators need to remember that children with physical disabilities will become adults who, while continuing to depend upon their communities to promote their optimal functioning, will also contribute and enrich their communities.

Limitations

The findings of this study are limited to the characteristics of the sample under study, parents of school-age children with spina bifida between the ages of 6 years to 11 years of age, living in a large metropolitan area within the State of Utah. Demographically, the children were representative of the state and region. Whether or not these findings reflect those in other geographic regions is unknown. The descriptions provided by these parents of children with spina bifida may not reflect those of other parents of children of similar or different physical disabilities. Additionally, these finding may not reflect those of children in other developmental stages or ages. The perceptions of parents of these children with spina bifida in this study may not be generalizable to other ethnic or cultural groups, or those of parents living in other geographic regions of the U.S. However, qualitative findings are not meant to be generalized to other samples or populations, but to provide rich description and understanding of a phenomenon (Morse, 1995).

Parents who agreed to participate in this study may have been more aware of the health risks of overweight for their children with spina bifida and more inclined to have adapted their environment to prevent overweight than other parents. All parents in this study received care at the spina bifida specialty-care clinics for their child's care. A limitation to this study is that parents focused on care at spina bifida clinics and did not report care from primary-care clinics. Specialty clinics are created to meet the multidisciplinary needs of children with spina bifida. These healthcare experiences may have served to increase the knowledge and skills of these parents, as opposed to parents who are only able to obtain healthcare for their children with spina bifida within non-specialty care clinics. Most children with spina bifida in the U.S. receive care at specialty-care clinics, even when they live at great geographical distances from the specialty care clinic. Thus, these findings are a description of the common experience of specialty-care clinic experiences for children with spina bifida.

The purposive sample of parents of children with spina bifida between the ages of 6 to 12 years old may have limited the experiences of parenting, and their descriptions of the environment, as parents had to recall earlier experiences in their child's lives and may have been unable to describe their children's environment accurately over time. Within the sample of school-age children, it was anticipated that children would not have reached puberty; however, most of the older children were nearing puberty and were beginning to attain adult body size. This may be a limitation of this study as reflected by the different physical activity patterns of younger and older children with spina bifida. Interviewing only the parents provided their perspectives and not those of their children, and this may have limited the description of their children's environment to the views and beliefs of parents.

APPENDIX A

IRB APPROVAL

IRB: IRB_00029188

Principal Investigator: Brenda Luther

Title: Parents Food and Physical Activity Choices to Prevent Overweight in Children with Spina Bifida

This New Study Application qualifies for an expedited review by a designated University of Utah IRB member as described in 45 CFR 46.110 and 21 CFR 56.110. The research involves one or more activities in Categories 5 and 7 (published in 63 FR 60364-60367). The designated IRB member has reviewed and approved your study as a Minimal risk study on 1/13/2009. Federal regulations and University of Utah IRB policy require this research protocol to be re-reviewed and re-approved within 1 year from the approval date.

Your study will expire on 1/12/2010. Any changes to this study must be submitted to the IRB prior to initiation via an amendment form.

APPROVED DOCUMENTS

Protocol Summary Protocol Summary

Informed Consent Document BLuther-consent-irb-12-28.doc

Surveys, etc. Semi-Structured Interview Questions and Recruitment Flyer

Grant Application American Nurses Foundation Sanofi Pasteur Scholar Award Letter and Proposal 2008

Other Documents Original Article: Baumrind's Parenting Typologies and Overweight for Children; Original Research: Age-Specific Activities that Support Transition to Adulthood for Children with Physical Disabilities;
PHONE SCRIPT.doc

APPENDIX B

RECRUITMENT FLYER

Your help in contacting parents of children between the years of 6 and 12 with spina bifida is requested. This research is being conducted to learn the activities parents use to guide and direct their children related to food and activity choice.

You only need to ask their permission for me to call them and collect a contact phone number from them. Also, please note their child's age on this form.

I would also appreciate if you let me know your name so I can record where the referrals for this study have come from.

Thank you for your help with this study. You may contact me at any time at (801) 364-5067.

Brenda Luther, MS, RN
PI
"Parent's Beliefs of Developing Health Promotion Beliefs for Children with Spina Bifida"

You have my permission to contact me to discuss if I am interested in participating in the following study:

"Parent's Beliefs of Developing Health Promotion Beliefs for Children with Spina Bifida"

Parent's Name	Contact Phone Number

Child's Date of Birth:
(MM/DD/YY)

Referring Provider Name

Please print all information clearly
Please fax to Brenda Luther 801-364-5067

APPENDIX C

PARENT CHILD DEMOGRAPHIC TOOL

	ID Number:____________
Parent Name:______________________	Age:________ ☐Male ☐Female Ht: _______ Wt:_________
Child Name:______________________	BIRTHDATE:________ ☐Male ☐Female Ht: _______ Wt:_________
Parent Race/Ethnicity	☐ White ☐Black/African American ☐Asian ☐Native ☐Hawaiian/Pacific Islander ☐American Indian/Alaskan Native ☐Other:_______
Child's Race/Ethnicity	☐ White ☐Black/African American ☐Asian ☐Native ☐Hawaiian/Pacific Islander ☐American Indian/Alaskan Native ☐Other:_______
Are you of the Hispanic/Latino culture?	☐ Yes ☐ No
Is your child of the Hispanic/Latino culture?	☐ Yes ☐ No
What is your Marital Status?	☐ Single ☐ Married or living with partner ☐ Divorced ☐ Separated ☐ Widowed
What is your level of Education?	☐ Some High School ☐ High School Graduate ☐ Trade, technical or vocational school ☐ Some College ☐ College Graduate ☐ Post-graduate degree
How many hours do you work outside your home for pay?	☐ Full-time (30 hours per week or more) ☐ Part-time (less than 30 hours per week) ☐ I do not work outside my home
What is your gross household income?	☐ Less than $29,000 ☐ $30, 000 to $59,999 ☐ $60,000 or more

APPENDIX D

CHART REVIEW TOOL

		ID Number:_____________
Indicate either Chart * or Parent report	☐ Chart * Review	☐ Parent Report
Level of child's lesion?	Level: ______	Level: ______
* All Chart review is to be conducted by the staff of the Institution, not the PI	☐ Chart * Review	☐ Parent Report
Does child require help with transfers?	Yes__ No __ How?:	Yes__ No __ How?:
Does child require help with being active?	Yes__ No __ How?:	Yes__ No __ How?:
Does child use any adaptive equipment?	Yes__ No __ What?:	Yes__ No __ What?:

APPENDIX E

SEMISTRUCTURED INTERVIEW QUESTIONS

"I am starting our interview with questions about health promotion for your child with spina bifida."

Health Questions

1. Tell me about health promotion activities that you do for your child with spina bifida.

"Now we are going to talk about food choices for your child with spina bifida."

Food Choices

1. Tell me about your experiences with food choices for your child with spina bifida.
    a. Describe anything that is helpful in making food choices.
    b. Describe any barriers to these food choices.
    c. Do these food choices differ from those of other family members? If so, explain.
    d. Tell me about any complaints about food choices from your child.
2. Tell me about any concerns you have about food choices for your child with SB?
3. Tell me about food choices for your child with SB?
    a. At school?
    b. With friends?
4. Explain how you learned about food choices.
5. Tell me about any concerns about your child with SB being overweight or underweight.

1. Tell me about physical activity choices for your child with spina bifida
    a. Describe who makes these physical activity choices.
    b. Explain whether or not these physical activity choices differ from other family members.
    c. Describe your child's energy and strength level for participation in physical activities.
2. Describe anything that facilitates physical activity for your child with SB.
    a. Tell me about any barriers to physical activity for your child with SB.
3. Tell me about any changes in your child's physical activities to prevent overweight or underweight.
4. Tell me about physical activities that your family and child with SB do together.
5. Tell me about how you received information about physical activity for your child with SB.
6. Tell me about any concerns about your child with SB participating in physical activity.

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