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A phenomenological inquiry into children's experiences and choices related to health and disease prevention

Juliann Marie Chavez
University of Tennessee

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To the Graduate Council:

I am submitting herewith a dissertation written by Juliann Marie Chavez entitled "A phenomenological inquiry into children's experiences and choices related to health and disease prevention." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Child and Family Studies.

Priscilla Blanton, Major Professor

We have read this dissertation and recommend its acceptance:

Accepted for the Council:

Carolyn R. Hodges

Vice Provost and Dean of the Graduate School

(Original signatures are on file with official student records.)

To the Graduate Council:

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Priscilla Blanton, Major Professor

We have read this dissertation
and recommend its acceptance:

Betsy Haughton

Julia Malia

Delores Smith

Accepted for the Council:

Carolyn R. Hodges, Vice Provost and
Dean of the Graduate School

(Original signatures are on file with official student records.)

A Phenomenological Inquiry Into Children's Experiences
and Choices Related to Health and Disease Prevention

A dissertation
Presented for the
Doctor of Philosophy
Degree
The University of Tennessee, Knoxville

Juliann Marie Walker Chavez
May 2009

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Accomplishments cannot be achieved without the love and support of family and friends.

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May we all learn from children and be inspired by what they have to say.

ABSTRACT

In this phenomenological study, 10 children who were diagnosed with insulin resistance and child overweight were interviewed. These interviews focused on how the children described their first experience as they learned about their risk factors for Type II diabetes and what prevention strategies they utilized. Each child interviewed, indicated that he or she experienced positive clinical outcomes, such as weight loss, weight maintenance, lower insulin levels, or decreased lipid profiles, all physiological markers for reducing risk factors for Type II diabetes. Children illustrated through narratives how they changed lifestyle habits, primarily in food selection and exercise. These changes were coping strategies that they utilized to lose weight and decrease insulin levels. Children spoke about the how changes in body composition also improved their self-confidence and self-esteem. The themes that emerged through the interviews included (a) positive lifestyle changes (b) social support and family (c) supportive friendships (d) psychosocial environment and (e) understanding self and developing resilience. The perspectives from each child have implications for future educational programming and initiatives regarding child overweight and disease and for providers who perform individual counseling.

PREFACE

INTRODUCTION

As the number of children who are overweight continues to grow, there are complications associated with overweight, such as insulin resistance, high serum cholesterol, and Type II diabetes, also increase. Health care professionals who work with children will continue to be challenged to identify effective interventions. Understanding the underlying factors that contribute to the issues related to child overweight and disease is important, as is understanding how to treat and motivate children and their families strategies how to improve health and well-being.

Finding methods that encourage lifestyle changes that reduce the risk of Type II diabetes is beneficial to preserving the health of future generations. Behavioral treatment programs for families have shown some success over the long term (Epstein, Roehmich, & Raynor, 2001) and behavioral interventions in disease states continue to evolve. Recent emphasis on the behavioral change component included in the treatment of pediatric obesity continue to evolve. In many instances, families know what they should do, but they do not have the knowledge or support to change behaviors (Epstein et al., 2001). The use of behavioral change models and understanding what may influence a child to become motivated to change lifestyle habits are critical to health care professionals and others who work with children who are overweight and who are diagnosed with associated medical complications.

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CHAPTER ONE

Child Overweight and Secondary Complications

The prevalence of child overweight and obesity in adolescents and younger children has doubled in the past decade. Recent data from the Centers for Disease Control and Prevention (CDC) indicate that children younger than five years across all ethnic groups have had significant increases in overweight (Committee on Nutrition, 2003).

“Between the 1960’s and 1988-1994, the prevalence among 6-11 year old children increased from 4% to 11%. During this same period the prevalence among 12-19 year olds increased from 5% to 11%. Overweight children often become overweight adults, and overweight in adults is a health risk” (Ogden, Flegal, Carroll, & Johnson, 2002, p. 1728).

In 2007, an expert committee comprised of scientists, researchers, and clinicians from 15 professional organizations met and revised recommendations on the approaches to prevention, assessment, and treatment of child overweight (Barlow & the Expert Committee, 2007). The committee concluded that a child over the age of 10 years who is between the 85th and 94th percentile for Body Mass Index (BMI) for age and gender and with a family history of cardiovascular disease and/or diabetes should be screened for secondary complications (See Figure 1 and Table 1).

Complications associated with child overweight can be numerous. Physical parameters related to overweight are cardiovascular risk factors, such as hypertension, sleep apnea, orthopedic problems (joint pain, arthritis), insulin resistance, and impaired glucose intolerance (Dietz, 1998; Ogden et al., 2002). Body Mass Index (BMI) has been the main predictor of the

Table 1. Identification, Assessment, Prevention, and Treatment Recommendations for Child Overweight and Obesity.

Identification: Calculate and Plot BMI			
	BMI 5 th -84 th Percentile	BMI 85 th -94 th Percentile	BMI \geq 95 th Percentile
Assessment			
Medical Risk	Obtain child history and exam Evaluate child growth pattern Obtain Parent and Family Medical History	Obtain child history and exam Evaluate child growth pattern Obtain Parent and Family Medical History Request Lab as needed	Obtain child history and exam Evaluate child growth pattern Obtain Parent and Family Medical History Request Labs
Behavioral Risk			
Attitudes	Screen Sedentary Activities Eating Habits Physical Activity	Screen Sedentary Activities Eating Habits Physical Activity	Screen Sedentary Activities Eating Habits Physical Activity
Prevention	Assess Family and Patient Concern/Motivation	Assess Family and Patient Concern/Motivation	Assess Family and Patient Concern/Motivation
Target Behavior	Identify behaviors Praise if no current problem behaviors	Identify behaviors Praise if no current problem behaviors	Identify behaviors Praise if no current problem behaviors
Patient and Family Counseling	Review Risks for Disease Uses Behavioral Change as Model	Review Risks for Disease Uses Behavioral Change as Model	Review Risks for Disease Uses Behavioral Change as Model
Intervention/ Treatment		If Health risks are present Implement stages of treatment based on Age and BMI*	Implement stages of treatment * based on Age and BMI

(Modified from Figure 1. Universal assessment of obesity risks and steps to prevention and treatment. Barlow & Expert Committee 2007). p. S169.

* Stages of Treatment are described on pages S181-S186.

Medical Assessment And Screening According To BMI Category

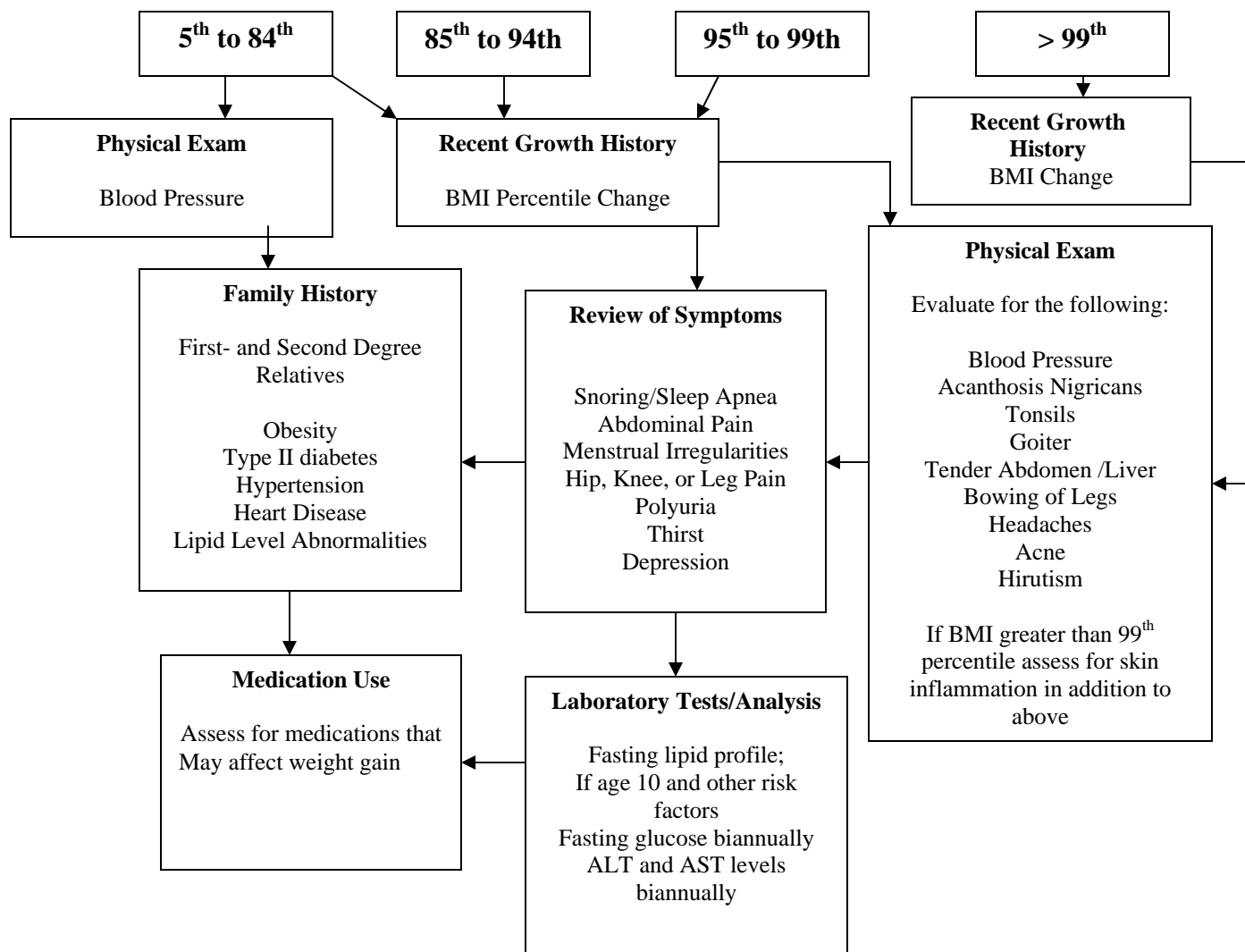


Figure 1. Medical Assessment And Screening According To BMI Category

An algorithm used for medical assessment and screening of children according to BMI category. Children in all BMI categories should be evaluated for changes in BMI percentiles, physical exam, family medical history, and medication use. For children in the three BMI categories; 85th–94th, 95th–99th, and greater than the 99th percentile, review of symptoms, laboratory tests, and a detailed physical exam is recommended.

variance in insulin sensitivity, insulin resistance, and high blood pressure. In insulin-resistant individuals, the response of tissue cells is limited, interfering with the ability to respond to insulin activity, and the pancreas compensates by secreting more insulin (Cruz, Shaibia, Weigensberg, Sruijt, Ball, & Goran, 2005). Higher insulin levels in the blood stream lead to an increase in the production of fat, thus increasing weight gain over a short period of time. Insulin resistance and/or hyperinsulinemia combined with a higher percentage of trunkal fat (central adiposity) increase diabetes and cardiovascular risk factors (Committee on Nutrition, 2003). Currently a 20-fold increase in the incidence of Type 2 diabetes in children is estimated. In a study that investigated weight, height, BMI, and glucose tolerance for children ages 4-10 years, the researchers concluded that there was a 20.5% incidence of impaired glucose tolerance (Cruz et al., 2005). When a child's BMI is greater than 30 kg/m^2 , one should expect to find high blood pressure, dyslipidemia or coronary heart disease, and insulin resistance, if there also exists a family history of Type 2 diabetes in a first-degree relative (Rao, 2001). Early evidence indicates that the pathogenesis of Type 2 diabetes in youth is likely to be similar to that of adults but occurs within a more accelerated time course (Cruz et al.). Because insulin resistance often precedes by years the development of other consequences of overweight, identifying and treating the insulin resistant syndrome is encouraged (Cruz et al.).

Rationale for the Study

In the year 2000, the Knox County Health department conducted a screening on BMI for children in kindergarten through 10th grade (East Tennessee Two Step, 2003). Results revealed that on average 25% of the children screened were found to be overweight or at risk for overweight. The number of children referred to the pediatric endocrinologist at the East

Tennessee Children's Hospital increased from 25 per year in 1996 to 25 per month in 2004. The problems associated with childhood overweight are worrisome, and intervention methods are overwhelmingly needed, especially in our local area, East Tennessee.

A growing concern among health care providers is the treatment and management of child overweight. Working with a child who is overweight begins with proper identification of the child's weight status in proportion to height and growth. In addition, knowledge of assessment of complications associated with overweight is important. Studies recently published evaluated physicians' knowledge and beliefs based on the 1998 Expert Guidelines (Dietz, 1998). Findings revealed that physicians who are more aware of the expert committee recommendations are more likely to have a positive attitude regarding their ability to counsel obese children (Beno, Hinchman, Kibbe, & Townsbridge, 2005). In addition to reviewing knowledge of and adherence to the expert committee guidelines, Barlow and Dietz (2000) identified seven common barriers that existed when pediatricians and other clinicians treated child overweight. Physicians have reported that lack of patient motivation, patient non-compliance, and absence of effective obesity treatment programs were ranked among the most common barriers when working with children who are overweight and their families. Perrin, Flowers, Garrett, and Ammerman (2005) studied practice-based barriers and physicians' self-efficacy in obesity management and found that self-efficacy was lower for physicians who reported problems with non-MD staff reimbursement, lack of an on-site dietitian, or lack of patient education materials.

The methods that physicians use to communicate with parents and children regarding the risks of child overweight are not as well researched. Little is known about what educational materials are utilized during office visits. Fifty percent of pediatricians in one study (Barlow &

Dietz, 2000) reported talking about issues of weight and growth with all children, and they discussed maintaining a healthy weight with children ages 13 to 18 years. The pediatricians indicated that discussing weight loss and achieving adequate nutrient intake for growth (i.e., energy balance) was complicated to explain to both parents and children.

Communication in private practice office settings for other childhood-related issues has been researched to a greater extent. Childhood vaccine risks are deemed important by parent groups and considered a hallmark for standard of practice with professional organizations. In one study (Davis, Fredrickson, Arnold, Cross, Humiston, Green, & Joseph, 2000), it was found that physicians were likely to discuss the materials but not likely to distribute materials regarding vaccine risks. Nurses were more likely to discuss materials and give materials to parents. Physicians indicated that patient education is not “billable,” which leads to less interest and priority in spending time communicating or giving counseling. In reference to child overweight, most pediatricians requested better counseling tools and efforts to engage patients in discussions concerning weight management (Barlow & Dietz, 2000).

In March 2004, a convenience sample of pediatricians, family practice physicians, and emergency medicine pediatricians in the database of East Tennessee Children’s Hospital ($N = 229$) participated in a survey modified from an original survey conducted in 2000 by the International Life Sciences Institute and U.S. Maternal and Health Child Bureau (Barlow & Dietz, 2000). Specific aims of that survey were to determine at a local level (a) what resources pediatricians, family practitioners, and emergency physicians used to address children who were overweight, (b) what barriers existed for the effectiveness of managing child overweight, (c) what resources had been beneficial in the community and clinical office settings, and (d) barriers

that existed when counseling or referring patients for additional intervention. The most frequent barriers reported were lack of patient motivation, parent involvement, reimbursement, and lack of resources for programs. Physicians also indicated that a need in the community is desired to increase awareness regarding the complications of child overweight. Physicians also noted time is a constraining factor, as was non-reimbursement for services of physicians and their staff and the lack of on-site ancillary services, such as registered dietitians and patient education materials - all contribute to the difficulty they experienced in effectively addressing the problems of child overweight (East Tennessee Children's Hospital Prescription for Healthy Kids Grant Report, 2004). Physicians in the study who reported spending less time talking to patients were also more likely to experience resistance from families or patients regarding desire for weight loss or feeling that controlling weight gain was essential. As one physician described, "I speak until I am blue in the face, and still these patients and families do nothing to change their habits that lead to weight gain" (East Tennessee Children's Hospital Prescription Healthy Kids Grant Report, 2004).

In a similar study conducted by International Life Sciences Institute, physicians described a societal environment as a barrier to successful obesity management because of the ubiquitous exposure to high fat food and soft drinks. The same physicians also reported needing guidance in behavioral management strategies, parenting techniques, and how to help families deal with conflicts (Barlow & Dietz, 2000). Understanding how the child works through the process of becoming healthier and what methods and resources are valuable to each child and family will improve how practitioners and other health care providers work with families and their overweight children.

Substantive Frame and Purpose of the Study

Understanding Disease: Children's Concepts of Illness

How children understand what an illness is and the causes and cures of illness and disease has been found to be consistent with the three major stages of Piaget's theories on cognitive development (Bibace & Walsh, 1980, p. 912). Bibace and Walsh interviewed 72 children, ages 4 years, 7 years, and 11 years, to determine if the children's understanding of disease and what causes and cures a specific disease (e.g., a cold) were consistent with the stages of causal reasoning. The researchers reported that the ability to understand disease occurred when children were able to differentiate between their own needs as opposed to what others may think or say about them. These cognitive processes and qualitative differences in thinking occurred more frequently at about age 11 years (Bibace & Walsh). The child's personal control increases with development and in turn is influenced by the child's ability to understand the concepts related to disease prevention and management of his or her own illness (Bibace & Walsh). Thus, children's understanding of a disease is directly related to how clear the concepts related to the cause and effects of disease is explained and the child's cognitive ability (Matza, Swensen, Flood, Secnik, & Leidy, 2004).

If the child and family are expected to be the primary managers of a child's health and the prevention of disease, then self-regulation is of great importance (Clark & Gong, 2000). Clark and Gong defined self-regulation as "the process of observing, making judgments, and reacting realistically to efforts related to managing tasks or goals" (p. 573). The perception of the ability to manage and the confidence that lies in the individual are crucial to changing behaviors and one's self-efficacy (Clark & Gong).

Purpose of the Study and Research Questions

The purpose of this study was to describe the experiences and understandings associated with lifestyle changes made by overweight, insulin-resistant children. These children had been identified and followed by a team of dietitians and pediatric endocrinologists. The main qualitative approach incorporated in this study was phenomenological inquiry. The use of phenomenological inquiry allows each child to tell his/her own story. Using the phenomenological approach allows the individual to share his or her point of view as related to a specific experience (Creswell, 2007).

The interest was in how the child perceived his or her health. Do children attach different meanings to the word *healthy*? Family messages are important and only recently have been examined in research on child overweight. The effects of family and support have been studied in adults but have not been the focus of much research with the pediatric population. Also, in the overweight child population and those children with disease, few studies have been conducted that emphasize qualitative inquiry. The focus of the present study was the child's understandings and descriptions of his or her experiences about what changes in lifestyle occur when working toward disease prevention and reducing risk factors for diabetes and other related complications associated with child overweight.

Research Questions

Some research questions that guided the design of this study were the following:

1. How do overweight children understand concepts of weight and health?
2. What does it mean to them to be healthy?

3. To what extent have children focused on weight loss or making changes in their lifestyles?
4. What influences in the environment have affected choices?
5. What perceptions do overweight children have about themselves?
6. What were the hardest or most challenging changes made?
7. How has their family context affected their health?
8. What advice would children give to other children their age who are trying to work at being healthier?

Theoretical Perspectives

Several theoretical perspectives provided anchor points for this study. Among these perspectives were phenomenology, symbolic interactional theory, theories related to family stress and family functioning, and behavioral change theories.

Phenomenology

In the phenomenological approach, it is crucial for individuals to share their own experiences and point of view (Taylor & Bogdan, 1984). In phenomenology, reductive reasoning is used instead of deductive reasoning, which is more common in other methods of research. Dahl and Boss (2005) referred to reductive reasoning to peeling away the layers of skin from the onion; getting to the “what it is” instead of “what it is not” (p. 69). The child’s perceptions and experiences that are constructed throughout the process of achieving improved clinical outcomes are difficult to obtain through surveys and other quantitative methods of inquiry. Interviewing children using phenomenological methods allows the researcher to capture descriptions of how each individual child has worked toward his or her own goals and the process of these

experiences. As the researcher interviews each participant and engages in dialogue with the participant, he or she continues to employ reductive reasoning (Dahl & Boss, 2005).

The task of the researcher is to capture the participant's own interpretation. According to Moustakas (1994), the process of recalling one's actions allows one to reflect on and come to an understanding of one's own meaning. The descriptions that children share about their actions and how their parents and peers have responded to them might be important if more effective interventions are to be developed. In the phenomenological approach, the human experience is "an inherent structural property of the person who lived the experience and not by the outside observer" (Creswell, 1998, p. 86). The lenses of symbolic interaction and family stress theory provide concepts that frame human experiences in ways that are relevant to phenomenology.

Symbolic Interaction Theory

Meanings of events, how people act toward various events, and internal self-reflection are some of the main assumptions of symbolic interaction (White & Klein, 1996). Humans are motivated to create meanings and make sense of their world. Actors think and act in accordance with how they perceive and construct meanings for their experiences. When a person understands he or she has a disease or a problem that may lead to disease or impact his or her own person, one of the first steps taken is problem solving. The way the problem is defined influences what solutions may follow, and the process of how constructing meaning with the event for children takes place in the family context. The family's ability to change and evaluate lifestyles influences patterns of behaviors that undergird the social construction of new roles and relationships for the overweight child. How children elaborate on how family members become

involved, encourage change, or motivate each other toward change will contribute to how social interaction influences outcomes in this population.

Health and Behavior Change Theories

Patterns of human behavior play a central role in the maintenance of health and prevention of disease. Growing evidence has suggested that effective programs to change individual health behavior require a multi-faceted approach to helping people adopt, change, and maintain behavior. Offering only strategies for establishing and maintaining healthy behaviors for children and adolescents might be quite ineffective for changing maladaptive eating behaviors (Jeffery et al., 2000). Models of behavioral change that have focused on both the child and significant others in their environment have been developed to promote healthy behaviors and to facilitate effective coping with illness.

The Health Belief Model is one of the earliest theoretical models developed for understanding health behaviors. The Health Belief Model incorporates elements of both operant conditioning and cognitive theory. “Cognitive social-learning theory proposes that reinforcements are not the sole determinants of behavior, but behavior changes with observation of others” (Institute of Medicine, 2001, p.186). According to cognitive social-learning theory, the most necessary prerequisite for behavioral change is a person’s perceived level of self-efficacy. Furthermore, people can feel susceptible to an illness and expect to benefit if they change a behavior only if they perceive that their environment encourages such change (Institute of Medicine, 2001).

Family Stress Theory

Changes in family equilibrium can be experienced as either positive or negative, but changes do create family stress. The changes or events that impact the family may be a result of an individual's stressor that brings about change for all members of the family or an event that affects the whole family at the same time (Boss, 2002). The contextual model for family stress includes both external and internal factors that may impact a family's response to a stressor. Families who perceive child overweight as a problem for the family are more likely to recognize that consequences related to child overweight can be long-term and chronic. The family's meaning or perception of the event or situation is important but should be considered along with other variables (Boss). Wake et al., (2002) found in their study of parents' perceptions of child health and child weight status that a low percentage of parents had concerns about general health if the child was overweight or obese, compared to parents of normal and underweight children. Although, parents of overweight or obese male children indicated poorer health on seven of twelve sub-scales related to psychosocial and physical health as compared to parent report of concern on only two sub-scales for females. A follow-up study was conducted by Williams, Wake, Hesketh, Maher, and Waters (2005) comparing child health reports to parent health reports of the child. Williams and his colleagues' (2005) found that overweight and obese children reported lower scores for physical and social functioning but not for emotional and school functioning as compared to normal weight children. They noted that if parents and children are not concerned with general health status when a child is overweight or obese, then few will seek change to improve health and prevent further complications that are associated with increased weight (Williams et al., 2005, p. 76).

According to Boss' (2002) Contextual Model of Family Stress, children who experience health problems often affect the family's structural, psychological, and philosophical contexts. External factors include processes embedded in culture, history, economy, development, and heredity. External factors are considered events that occur in the family's environment and are a result of previous attitudes, values and beliefs, or periods of time. Internal contextual factors are defined as elements that may be controlled or changed by the family (Boss, 2002, p. 44). Internal contextual factors include the family's ability to control what can be changed. These are categorized into three dimensions; structural, includes boundaries and roles, the psychological, how the family will deal with the problem, and the philosophical or values and beliefs of the family (Boss, 2002, pp. 44-45).

Applying concepts from family stress theory could improve current interventions for child overweight if they are utilized to inform assessment during the initial stages of intervention. Important concepts that require evaluation by clinicians include (a) identifying family demands, such as family strain, daily hassles, normative and non-normative stressors; (b) understanding the family's capabilities, the family's resources, and coping behaviors; (c) determining internal contextual factors, such as how they view themselves as a family and how capable they believe their family is for creating change; (d) the family's context in terms of both protective and risk factors; and (e) aspects of their family's resilience (Barlow & Expert Committee, 2007; Patterson, 1988).

Terms and Definitions

Body Mass Index (BMI): A measurement associated with body fatness. Body Mass Index (BMI) is a number calculated from a person's weight in kilograms divided by height in meters squared.

BMI provides a reliable indicator of body fatness for most people and is used to screen for weight categories that may lead to health problems.

Child Obesity: A Body Mass Index (BMI) for age, gender, and weight status that is at or above the 95th percentile using the Center for Disease Control and Prevention (CDC) BMI chart that is based on the 2007 Expert Committee Guidelines (Barlow and the Expert Committee, 2007).

Child Overweight: A Body Mass Index (BMI) for age, gender, and weight status that falls between the 85th percentile and below the 95th percentile using the Centers for Disease Control and Prevention (CDC) BMI chart that is based on the 2007 Expert Committee Guidelines (Barlow and the Expert Committee, 2007).

Insulin Resistance (IR): The cells or receptor sites of the cells resist the action of insulin to bind with glucose in the bloodstream; therefore glucose cannot enter the cells, thereby stimulating more insulin to be produced by the pancreas. This results in a continual state of increased insulin production and glucose in the bloodstream and increases excess fat accumulation in the body.

Lifestyle Changes: Changes in levels of stress, physical activity, nutritional intake, sleep patterns, and habits related to smoking and alcohol consumption.

Secondary Manifestations: Complications that are associated with being overweight or obese that place a person at higher risk. These include, but are not limited to, hypertension, impaired glucose tolerance or diabetes, hyperlipidemia, heart disease, shortness of breath, sleep apnea, orthopedic injuries, and insulin resistance.

CHAPTER TWO

LITERATURE REVIEW

Adolescents' Physical And Psychological Growth

Between the ages of 9 to 18 years marks the time when a child typically begins the process of physical pubertal changes. During puberty, many physical and psychological changes occur. In pubescence, growth in height occurs at the most rapid rate in the lifespan. Most children will obtain 15% of their adult height and 45% of their total skeletal mass. Children typically grow about two to three inches per year and gain about three to seven pounds per inch until they begin their peak growth spurt (Spear, 2002). Peak growth varies among boys and girls and is associated with sexual maturity development. For girls, menarche follows peak height velocity. The average age that girls in the U.S. begin menarche is 12 1/2 years. For girls who begin menarche early (i.e. before 11 years of age), many will have a later growth spurt as compared to girls who start menarche at a later age (Spear). Most girls will grow about two to three inches after menses has normalized.

Hormonal changes also affect growth. In girls, female sex hormones promote fat accumulation. For females, the increase in fat accumulation prior to the increase in height often is worrisome to both the child and the parents (Spear, 2002). Males produce more testosterone and anabolic adrenal hormones, creating increased muscle mass, skeletal mass, and red blood cells during puberty. Boys' peak height typically occurs in conjunction with peak weight. Lean body mass will double between the ages of 10 to 17 years. In boys, the first sign of puberty is enlargement of the testes along with the presence of facial hair and voice changes. If the signs of

puberty are not established by the age of 14 1/2 years and 13 years, for boys and girls respectively, then puberty is considered delayed. (Spear, 2002)

A child's growth typically is analyzed and reviewed at each child's annual well check-up visit. Height and weight are plotted on growth charts, and separate growth charts are established for males and females for ages 2 to 20 years (Centers for Disease Control and Prevention, 2000). Typically children will follow the same percentiles for height and weight from birth, but slight variations usually occur during puberty. For example, if a child plots at the 25th percentile for height and the 50th percentile for weight at age 3 years, we would expect the child to be at or between the 25th to 50th percentile for height and at or between the 25th to 50th percentile for weight at 13 years. Following the same percentile on a growth chart is referred to as tracking or following the growth curve. If children are not routinely seeing a pediatrician for well-child visits, then growth is not followed, and deviations from normal will not be identified. If these visits are delayed, problems with excess weight gain and/or delayed stature would not be recognized and may promote the chances of future complications.

Body Mass Index (BMI) is a measurement that is calculated using height and weight and correlates with the percent of body fat or body fatness. A recommended BMI for children is between the 10th to the 84th percentile for age and gender using the CDC BMI chart. Body fatness also may be determined in children using skin-fold calipers and waist circumference (Spear, 2002). Testing body fat is not a routine clinical measurement because of the rapid changes that occur in fat and muscle development. Recommendations from the expert committee on the prevention, assessment, and treatment of child overweight and obesity included the

measurement of waist circumference as opposed to skin-fold measurements when screening for secondary complications in addition to BMI (Barlow and the Expert Committee, 2007).

Because growth occurs very rapidly during adolescence and there is an accelerated accumulation of skeletal mass and muscle mass, and production of hormones, nutritional needs are also of importance. During this period of growth, strict dieting and sporadic eating may hinder growth and affect total nutrient needs. The child's body has greater need for certain nutrients such as calcium, iron, and zinc, as well as calories and protein. Therefore, it is important, when advising children about nutrition and physical activity, that an appropriate amount of calories and nutrients is suggested to support overall growth and development. (Spear, 2002)

Physical activity is also important during these years. Physical activity supports skeletal and muscle mass development and provides the child the ability to establish lifelong healthy habits. Most children between the ages of 10-16 years require at least 30 to 45 minutes of moderate physical activity four to five times per week (Steinbeck, 2001). Unfortunately, many children, especially at the age of 13 to 14 years, stop participating in sports or after school physical activities, leading to a sedentary lifestyle and possible weight gain. Finding methods of activity that adolescents can participate in and enjoy is of importance.

Psychological Development in Adolescence

Along with physical development, adolescence is the time when there are many cognitive and emotional changes that occur. Cognitive growth occurs as children develop different ways of thinking. David Elkind has stated, "Adolescents' are described as thinking about others and what others are thinking and feeling about them" (as cited in Sturdevant & Spear, 2002, p.). During

this transition, the child moves from the concrete thinking, seeing things as black and white, to formal operations or abstract patterns of thinking. In abstract or formal operations, the adolescent is able to solve problems and think hypothetically (Sturdevant & Spear, 2002).

Identity formation also occurs in adolescence. As adolescents change in both physical growth and maturity, they also experience psychological changes. James Marcia's identity status model evaluates adolescents as they learn to be unique and separate individuals (Meeus, Iedema, Helsen, & Volleberg, 1999). Meeus, Iedema, Helsen, and Volleberg explained that the identity status model "fails to be a theory but is a descriptive system for developing identity" (p. 419). Children solve the identity crisis by making choices regarding their future. The core variables to solving the crisis and making choices are the crisis itself and commitment to themselves (Meuss et al., 1999). Higher self-esteem and autonomy are associated with the moratorium (i.e., trying out different roles and finding out who you are) and achievement (i.e., becoming committed to an identity) (Meeus et al.).

There are other theoretical perspectives that suggest that parents and peers encourage and influence independence. Steinberg and Morris (2001) found that the child's relationships with his or her parents are more influential when related to a child achieving identity. Authoritative parenting styles lessen the effect of negative peer influence, whereas peers influence children in less cohesive families more. Peers influence most adolescents because they admire peers and respect their opinions. Participation in cliques and groups with structured activities also are associated with achieving identity. Eccless, Barber, Stone, and Hunt (2003) found in a group of adolescents that the association between risky behavior and participation in extracurricular activities was mediated by mechanisms associated with identity formation, peer group

membership, and attachment to non-familial adults (p. 866). Peers' influence on children's behaviors is of interest when studying adolescents with disease or other physiological complications that require self-management of disease as peers may influence coping behaviors and self-management behaviors.

Madan-Swain, Brown, Foster Vega, Byars, Rodenberger, Bell, and Lambert (2000) examined if adolescents who had survived cancer treatments differed in identity formation in comparison to adolescents without illness. Previous studies (Manne, Jacobsen, Gorfinkle, Gerstein, & Redd, 1993; Safyer, Hauser, Jacobson, Bliss, Herskowitz, Wolfsdorf, & Wertlieb, 1993) had found that often families of children who have illness become more restrictive and that these restrictions impede successful identity development. However, Madan-Swain and colleagues (2000) using the Extended Objective Measure of Ego Identity Status-2 (EOMEIS-2) found that there were no differences between the cancer survivors and their healthy counterparts in attainment of identity status. Differences were found with family functioning and stress, and these were associated with identity foreclosure status. They attributed this to restrictive parenting styles. No significant associations were found for peer emotional support and identity, but peer support was found to be positive factor that was considered essential to the survivors (Madan-Swain et al., 2000). Identity formation and figuring out "who I am" is much of what occurs during adolescence. Sturdevant and Spear (2002) referenced the work of Erik Erikson and Richard Jessor when they said, "Adolescence is a time that testing and risk taking behaviors happen for the child to figure out who he or she is. Experimenting with roles and attempts to determine where they excel are methods adolescents use to establish self-confidence and competence" (pp. S30-S31).

How children develop self-efficacy and self-regulation often occurs as children move from middle childhood to adolescence. This process of psychological development is interchanging and may not always transpire in a continuous pattern (Crain, 2005). As Crain (2005) described Piaget's stance on moral reasoning, he emphasizes that biological maturation and environment play a role in development, but stresses that Piagetians believe that learning is from internal and spontaneous interest (p. 215). Crain discussed Bandura's theories and other social learning theorists views on modeling and behavior, and stresses that as children become more socialized, they also develop their own standards of how to evaluate their actions and expectations (p. 206). The ability to set a standard for the "self" is considered a precursor for developing self-efficacy, and peers are more likely to influence adolescents as they are able to set standards that are attainable and more realistic than adults (pp. 201-206). The child's cognitive ability in conjunction with moral reasoning and environmental influences are important to examine in children with disease, as they contribute to how effective the individual can change behaviors. How these developmental shifts influence self-efficacy and self-regulation of health also contribute to a greater understanding of facilitating behavioral change and behavioral change theories. Understanding the child's stage of cognitive thinking and identity development facilitates effective counseling techniques and interventions with adolescents.

Child Overweight, Insulin Resistance, and Other Complications

Recently, an expert panel made adjustments in the terminology and definitions associated with the clinical diagnosis of child overweight and obesity (Barlow & Expert Committee, 2007). The BMI cutoff points presented by the 1998 Expert Committee Recommendations (Barlow & Dietz, 1998) have not changed, but the terms associated with these cutoff points did change with

the 2007 recommendations. If a child has a BMI between the 85th to 94th percentile for BMI, he or she is considered *overweight* as compared to *at risk for overweight*, and if a child is greater than or equal to the 95th percentile for BMI, that child is now classified as *obese* as compared to *overweight*. The 2007 Expert Committee did emphasize that, for older adolescents who have a BMI greater than or equal to 30 mm/kg², a child is considered at risk for medical complications and that further aggressive intervention and treatment is advised (Barlow & Expert Committee, 2007, p. S167). BMI continues to be the best measure to classify a child's weight and height status, and BMI correlates with percent body fatness. A higher BMI is associated with increased risk for secondary complications associated with overweight as well as future morbidity (Barlow & Expert Committee, 2007).

Medical Risk Factors and Child Overweight

Medical assessment for the obese child includes reviewing data and identifying possible factors related to morbidity. Parental obesity and a family history of diseases that are associated with increased risk factors for obesity are reasons for secondary screenings. For a child, cardiovascular disease, Type II diabetes, and/or insulin resistance in the first or second generation combined with being obese or overweight increases the probability of significant development of the same diseases. Screening for cardiovascular diseases, such as high blood pressure and abnormal lipid panels, are two of the main indicators of problems related to child overweight.

Endocrine problems in children, such as insulin resistance, Type II diabetes, polycystic ovarian syndrome, and liver problems, are all indicators that increased fatness is affecting the body's metabolism and systems. Other problems associated with overweight in children are sleep

disorders, respiratory problems, orthopedic issues, and psychiatric disorders. Descriptions of the problems associated with child overweight are described previously in Table 1 (Barlow & Expert Committee, 2007).

Insulin Resistance, Hyperlipidemia, and Development of Type II Diabetes

Insulin resistance is found in 60% of Americans, and about 25% of people are born with the propensity to develop insulin resistance, although most develop insulin resistance as a result of poor nutrition and inactivity (Hart, 2004, p. 6). In a multi-ethnic clinic-based cohort study (Cali, Savoye, & Caprio, 2008) that included 761 obese and non-diabetic youth, 25% of the children and 21% of the adolescents were found to be insulin resistant. The children with insulin resistance were followed over a 2-year period, and those who increased weight subsequently developed Type II diabetes (Cali, Savoye, & Caprio).

For children, obesity, or an energy imbalance caused by the body being unable to cope with an increase in kilocalorie intake relative to energy expenditure, is a major contributor to the increase in insulin resistance. Insulin resistance (IR) or increased production of insulin in the bloodstream is an independent risk factor for arteriosclerosis and Type II diabetes (Cali, Savoye, & Caprio, 2008). “In the early stages of Type II diabetes, IR is countered by a state of hyperinsulinemia, that is created by increasing production of insulin from the beta cells in the pancreas” (Hart, 2004; Martyn, Maseo, & Yasuhara, 2008). The cells or receptor sites of the cells resist the action of insulin to bind with the glucose in the bloodstream; therefore, the glucose cannot enter the cells. As more insulin enters the bloodstream, there is an increase in the levels of fat, causing the body to store excess fat. Increased fat storage results in increased amount of cholesterol in the bloodstream as well as the beta cells failing after time, altering glucose

metabolism and increasing the likelihood of hyperglycemic conditions, which results in the development of Type II diabetes (Cali, Savoye, & Caprio, 2008; Martyn, Maseo, & Yashuhara, 2008).

Figure 2 illustrates what occurs in the regulation of glucose. When food is digested and broken down into its component nutrients, the glucose produced combines with insulin from the pancreas to enter the cells through receptor sites. If the pancreas is unable to excrete enough insulin or if the insulin is not able to accept signaling from the receptor sites, then the sugar or energy is blocked and the liver, muscle, and fat cells are unable to metabolize glucose to produce energy (Hart, 2004). Adipose tissue, muscle tissue, liver, brain, and pancreatic beta cells are all involved in the pathways of making glucose, converted from food sources into energy. Adipose tissue is critical to metabolism. In adipocytes (fat cells), glucose is stored as lipid. Insulin inhibits the production of lipid or fat in adipocytes for energy (Shaluel & Kahn, 2001, p. 803). Increased amount of fat or adipose tissue is associated with increased concentrations of free fatty acids. The link between free fatty acids and insulin resistance involves the accumulation of triglycerides and other fatty acid metabolites in the muscle and liver. Increased free fatty acids are associated with cardiovascular risk factors, insulin resistance, and hypertension. When the body needs more energy, the fat or adipose tissue is stimulated, which increases available free fatty acids and blood glucose is spared as energy for brain function (Boden & Shulman, 2002; Sahliel & Kahn, 2001). Because the glucose is not taken up by the muscle, it is metabolized to lipid, resulting in fat storage and weight gain (Hart, 2004; Shaluel & Kahn, 2001). As the beta cells of the pancreas try to compensate for the insulin resistance by producing more

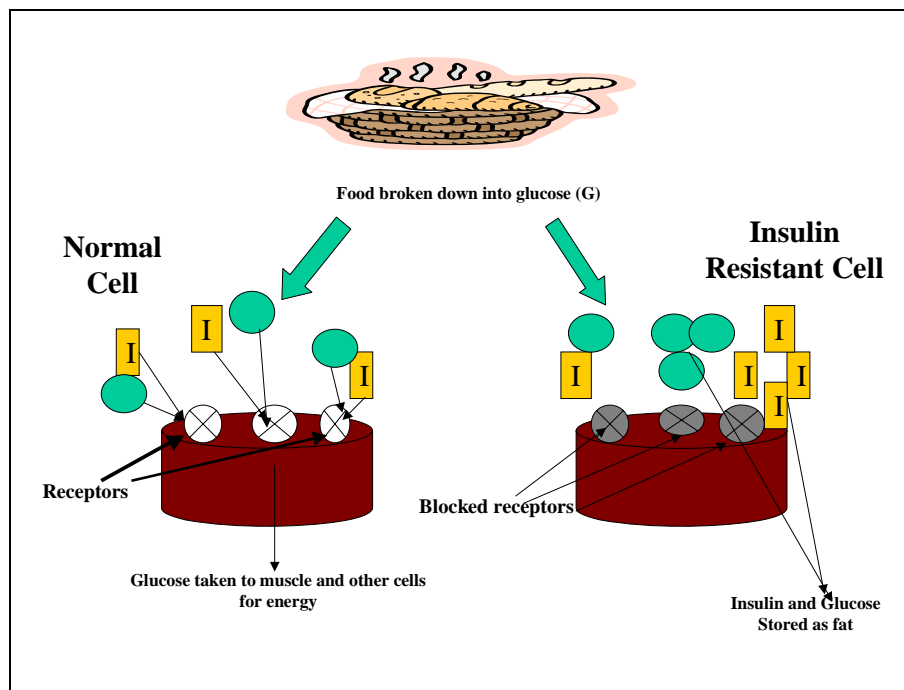


Figure 2. Diagram of the Action of Glucose and Insulin Entering the Cell in a Normal Cell and in a Cell of a Body with Insulin Resistance.

In normal metabolism, glucose and insulin enter the cell for energy through receptors in the cell wall. In an insulin resistant cell, the receptors are resistant or partially blocked causing insulin and glucose to build up in the bloodstream, reduce glucose uptake in the muscle and increase production from the liver, creating excess fat accumulation.

Reproduced and modified from Hart, C. (2004). Presentation for the American Indigenous Mental Health Institute Conference. Handout. pp. 5-6.

insulin, they eventually fail, raising blood glucose levels further, which creates a cycle that induces the development of Type II diabetes (Clark, 2008).

Puberty is a vulnerable time at which hormonal changes along with the natural ability for the body to accumulate fat and increase the chances of a child becoming overweight or obese. A genetic predisposition associated with environmental factors that lead to poor eating and sedentary activities can create an imbalance that leads to Insulin Resistance and then to Type II diabetes (Hannon, Roa, & Arslania, 2005, p. 474). For pubescent females, the occurrence of polycystic ovarian syndrome (PCOS) is associated with increased weight gain and insulin resistance. PCOS is an inherited syndrome and is accompanied by obesity, excess facial and body hair, acne, irregular menstrual cycles, and enlarged ovaries with cysts. The long-term effects, if not diagnosed and treated, may be loss of ovaries, depression, heart problems, and diabetes (Cali, Savoye, & Caprio, 2008; Chang, Liu, Xiao, & Yu, 2007).

Medicines known as *biguanides* (e.g., Glucophage & Metformin) are used frequently to help with the absorption of carbohydrates, particularly glucose, and to help the body use insulin more efficiently. If used in conjunction with limiting carbohydrate intake and exercising, the *biguanides* are effective in reducing serum insulin levels. The medicines are not without side effects. The most common side effects reported are diarrhea, nausea, and poor taste (Cali, Savoye, & Caprio, 2008; Martyn, Maseo, & Yusuhara, 2008). The non-pharmacological management of insulin resistance is to encourage moderate exercise for 30 minutes a day, increase dietary fiber, and work toward reducing weight to a desirable level (Rao, 2001).

Diabetes and Pre-Diabetes in Youth: Reversing the Cycle

Adult studies have shown that pre-diabetes and insulin resistance can be reversed. Programs, which emphasize lifestyle changes that encourage physical activity, nutrition education, behavioral modification, and weight reduction or stabilizing body weight have shown positive clinical outcomes (Epstein, Roehmich, & Raynor, 2001; Reinehr, Kriess, Kapellien, & Andler, 2004). Weight loss recommendations for children are different than those for adults (Foster, 2005). Because children continue to grow and develop throughout childhood and adolescence, strict weight loss diets (i.e., insufficient calories) may hinder a child's physical development. Suggesting that a child under the age of 7 years lose weight would be advised only if the child exceeds the 95th percentile for BMI for age and gender and has developed secondary complications such as a high insulin level. In the event a physician recommends weight loss, the weight loss should be modest and at a gradual rate so that growth and development are not impaired (Barlow & Dietz, 1998). The components of most weight loss programs emphasize modifying the environment of the child. Modifications should begin within the family environment. Modifying the household environment includes reducing access to high fat foods, purchasing healthier foods, cooking healthier meals and reducing sedentary activities while substituting other activities that include moving (Epstein, Roehmich, & Raynor, 2001).

Traditionally, weight loss goals were based on reaching an ideal weight as defined by height and weight charts. More recently, reductions in the measurements of body fat and waist circumference were found to be related to improvement in conditions such as Type II diabetes and high blood pressure (Foster, 2005). Weight loss is not always essential to decreasing insulin levels; dietary changes coupled with increased activity may normalize insulin levels in the

absence of weight loss. In one study, weight loss of 15% in adult women was associated with significant decreases in insulin levels. A decrease in insulin levels is associated with a lower risk for developing Type II diabetes in children (Cali, Savoye, & Caprio, 2008). Individuals who have decreased body fat over 3-6 years have countered the effects of high insulin levels, thus reducing the occurrence of Type II diabetes (Clark, 2008).

Several studies recently have been conducted to understand the effects of behavioral and lifestyle changes in insulin-resistant youth. Reinehr, Kriess, Kapellien, and Andler (2004) followed 57 obese children, ages 9-12 years, who participated in a 1-year multidisciplinary weight management program. The outpatient program was based on increasing physical activity, maintaining a low-fat diet, and incorporating behavioral therapy, which consisted of individual psychological counseling sessions with the child and his or her family (Reinehr et al., 2004). The results showed that children who reduced their BMI score by equal to or greater than 0.5 kg/m^2 improved their cardiovascular risk factors and reduced insulin levels. Physiological changes observed in children (i.e., reduced BMI and insulin levels) that occurred as a result of a program that encouraged weight loss through physical activity and energy restriction support findings from adult studies on the effects of weight and/or fat loss and improved metabolic risk factors (Reinehr et al., 2004).

Chang, Lui, Zhao, Li, and Yu (2007) conducted an experimental study that included 49 obese 12-14 year old Chinese children. Children were assigned to two groups: a control group and a fitness group. Each group received nutrition education on how to follow a low fat, high fiber diet, but the fitness group also participated in a structured exercise program for 9 months. Insulin resistance, measured using the Homeostatic Model Assessment for Insulin Sensitivity

(HOMA-IR), fasting glucose levels, serum lipids, and anthropometric measurements were taken at baseline and every 3 months for 1-year. After the 9-month intervention, the experimental or fitness group decreased insulin HOMA-IR by 48.5%, and the average BMI was 0.6 kg/m² lower than baseline, whereas the control group had no changes in HOMA-IR and BMI was 0.5 kg/m² greater than baseline. At 12 months, both groups had increased BMI and waist circumferences, and HOMA-IR had increased to baseline levels or above baseline levels, demonstrating that while a sustained exercise program can improve metabolic risk factors for obese children, adhering to such a program or exercise regime is imperative to improving health over time (Chang et al., 2007).

Similar improvements in insulin also were found in a study that focused primarily on dietary changes (Cummings, Henes, Kolasa, Ollson, & Collier, 2008). Cummings et al. examined the influence of restricting dietary carbohydrates, mainly sweetened beverages, in the diet of 45 children, ages 5-18 years, followed in a community-based treatment program titled KIDPOWER. After the 12-week program was followed, decreases in HOMA-IR and BMI z-scores were found in the overweight children who had decreased their intake of sweetened beverages. The authors of the study stressed that confounding factors may have affected results of both the BMI and HOMA-IR because patterns of physical activity and other dietary modifications were not monitored but also are emphasized in the KIDPOWER lifestyle program (Cummings et al.).

Demonstrating that changes in diet, activity, and lifestyle patterns are effective in reducing and reversing the insulin pathway and other metabolic risk factors associated with child overweight and obesity has been supported (Chang et al., 2007; Cummings et al., 2008). Finding

the additional variables that are important in assisting families and children to adhere to lifestyle changes across time appears to be a next significant step.

Behavioral Approaches to Intervention and Treatment

Human behavior plays a central role in the maintenance of health and prevention of disease. Growing evidence suggests that effective programs to change individual health behavior require a multi-faceted approach to helping people adopt, change, and maintain behavior.

“The combination of sound physiological and behavioral theories should form the basis of prevention intervention design. In addition, an ecologic approach that takes into consideration the dynamic interactions of personal, social, and environmental factors would best promote the long-term adoption of healthful behaviors in a supportive, meaningful, and personally enjoyable context ” (Huang & Goran, 2003, pp. 42 - 45).

Using only one approach for establishing healthy habits in children and adolescents may not be as effective. Models of behavioral change have been developed to identify strategies to promote healthy behavior, as well as to facilitate how individuals cope with illness (Jeffery, Drewnowski, Epstein, Stunkard, Wilson, & Hill, 2000).

Prochaska, DiClemente, and Norcross (1992) emphasized how the stages of change model can be effective when applied to health behaviors. The stages of change are categorized as follows: (a) The first stage is the pre-contemplation stage, when a person is in this stage they are unaware that behaviors need to be changed or ambivalent; (b) in the contemplation stage, individuals express changing a behavior, therefore he or she is thinking about making plans for change; (c) the third stage is the ready or preparation stage, in which a person feels he or she has the ability to change a behavior and changing behavior appears feasible; (d) the action phase is

when the individual is taking steps toward changing the behavior; and (e) the maintenance phase occurs when a person is able to continue to adapt, problem solve, and stay motivated (Prochaska, DiClemente, & Norcross, 1992; Rosal, Ebbeling, Lofgren, Ockene, Ockene, & Hebert, 2001). Of importance, the stages of change model depicts that individuals can move from one stage to another, but the stages are not linear and individuals may cycle back and forth to prior stages.

Behavioral change often is predicted by a person's level of motivation (Butler, Rollnick, & Scott, 1996). Practitioners using the stages of change approach for counseling have found that when a person is in the pre-contemplation stage of change and/or ambivalent to change, the goal is to move the individual to the contemplation stage or a state where they consider change as a possibility. When an individual reaches the contemplation stage it is important that perceived self-efficacy increases, otherwise the level of motivation may reverse because of fears, previous failures, or lack of environmental support (Rosal et al., 2001, pp. 333-334). The action stage is the stage where most people need intensive support and follow-up. At this stage, researchers find that individuals are more motivated to make changes when they use self-reports (e.g., diaries of intake or exercise routine), methods to problem solve or make decisions regarding set-backs, and focus on specific goals (Rosal et al., 2001; Schwimmer, 2006, cited in Sothorn, Gordon, & von Almen, 2006). The problem has been that most providers assume that the patient or client is in the action phase of the stages of change when they discuss guidelines or recommendations for lifestyle changes, when in fact they may be in the pre-contemplation or other stages, requiring different types of provider strategies (Rosal, et al., 2001, p. 332). Having an understanding of each individual's stage of change category can help practitioners approach the individual, so that they guide him or her to the next level or stage of change.

Recent efforts in health care counseling have focused on motivational interviewing. The methods clinicians use when interacting with patients often drive the desire for motivation or resistance to change (Butler, Rollnick, & Scott, 1996). Ambivalence to change is often a reason individuals are more resistant (Resnicow, Davis & Rollnick, 2006). Motivational interviewing techniques engage the client to take the lead in decision making and to work through the ambivalence, encouraging individuals to make their own appraisals (Resnicow, Davis, & Rollnick, 2006). One of the problems with research conducted in settings that incorporated motivational interviewing as part of a child overweight program was that counselors did not feel competent using the technique, resulting in inconsistent methods and inconclusive outcomes (Butler, Rollnick, & Scott, 1996).

What may make one person more motivated and compliant to follow a particular program is of interest and continues to challenge facilitators of weight loss and weight management treatment programs. Burke, Steenkiste, Music, and Styn (2008) surveyed 100 adults about their previous experience with weight loss programs, their preferences regarding the type of treatment, and the barriers that occurred during the time they were involved in a program. Using Bandura's social learning theory as an anchor, Burke et al. hypothesized that there would be a relationship between the number of attempts to lose weight and self-efficacy. Most (95%) of the individuals surveyed indicated that they preferred to attempt to lose weight on their own or with a structured program but had difficulty staying with a diet or activity program. The respondents also reported that they used food as a reward, did not know how to control what they ate when hungry, and needed more motivating strategies to eat healthy (p. 640). An individual's lack of confidence regarding the power to initiate change in his or her diet and activity coupled with an inability to

maintain changes concurs with Bandura's theory of self-efficacy (Burke et al.). Motivation to change is facilitated by a high level of self-efficacy, but low levels of self-efficacy are related to limitations in how individuals perceive their ability, their knowledge of the problem, the resources available to them, and environmental support (Rosal et al., 2001).

Researchers who examined self-efficacy theory in the context of diabetes management found that the incidence and severity of complications were reduced when individuals believed they were capable of self-management and were supported by family and other support groups (Brown, 1990; Brown, 1992; Hampson, Skinner, Hart, Storey, Gage, Foxcroft, Kimber, Cradock, & McEvilly, 2000). Thus, believing in one's capacity to change is enhanced by this belief being supported by significant others. Psychological interventions that included facilitation of coping skills and peer support seemed to result in greater success in improving metabolic control (stabilizing glucose levels, reducing serum insulin) as compared to interventions that only focused on educational approaches (Skinner, Carey, Cradock, Daly, Davies, Doherty, Heller, Khunti, & Oliver, 2007).

Family Relationships, Social Support, and Children with Disease

Raising parental awareness about the risk factors associated with child overweight in clinical settings is encouraged to reduce the rate of child obesity. Early interventions can prevent secondary complications associated with child overweight. Although clinical interventions may not change all risk factors, they can influence patients' adaptations (Ludwig, 2003).

Family relationships can influence the capacity for self-regulation of emotional and psychological processes. Family members often influence important contextual factors that affect health-related behaviors and family-focused approaches can maximize the effectiveness of

interventions (Institute of Medicine, 2001, pp. 11-12). Relationships provide an ownership of the disease not only for the person diagnosed, but also for the individuals who are part of the family system. Family focused interventions help families work together on the management of behaviors that are consistent with their beliefs and with the lifestyle of the family (Institute of Medicine, 2001, p. 220).

Golan , Kaufman, and Shahar (2006) found that targeting parents and emphasizing the “parent-only” approach have resulted in better outcomes in programs designed for overweight children. Using a parenting intervention approach increased parents’ ability to incorporate a different parenting style in response to food and activity behaviors, and these changes improved clinical outcomes and attrition rates (Golan , Kaufman, & Shahar).

Family functioning can be an important variable related to persistent patterns of increased weight among children. In a study that investigated family functioning and child weight status, absence of family mealtimes was significantly associated with children being classified as overweight. Family rituals such as “cleaning the plate” are control-oriented feeding practices, which have been related also to child overweight (Rhee, Lumeng, Appugliese, Kaciroti, & Bradley, 2006). Fisher and Birch (1999) suggested that children in highly controlled feeding environments often have difficulty with self-regulation, which is related to increased weight and body mass.

Family relationships and interactions can determine the capacity for self-regulation in the emotional, physical, and psychological realms (Institute of Medicine, 2001, p. 11).

Researchers investigating parental appraisals and disease management in a group of children with insulin-dependent diabetes found that when maternal involvement emphasized approval

combined with encouraging the child to become actively involved in the day-to-day issues, the child reported positively on adherence to disease management and quality of life (Wiebe, Berg, Korbel, Palmer, Beveredge, Upchurch, Lindsay, Swinyard, & Donaldson, 2005). These perceptions also were suggested to enhance personal levels of self-efficacy, autonomy, and motivation. It was concluded that “appraised collaboration” could be the key ingredient in the success of interventions that incorporate a parent-child team (Wiebe et al., 2005, pp. 168-169).

Social Support and Children with Health Complications

It has been found that adolescents from supportive and strongly cohesive families have better outcomes associated with achieving weight loss, metabolic control, and adherence to medical advice (Skinner, John, & Hampson, 2000). Especially for children who are chronically ill, family characteristics are important. Glasgow and Anderson (1995) suggested that, for adolescents, along with a strong family support system, peer support may have a greater impact on metabolic control and adjustment to illness and disease management than family support. Skinner, John, and Hampson (2000) examined whether social support and personal models are predictors of self-care and well-being in a group of adolescents with Type I diabetes. Personal model constructs are grounded in the general theory of cognition and are derived from past experiences of individuals. Personal models include (a) previous personal experiences; (b) patients’ beliefs that self-management will help control disease and prevent complications; and (c) emotional aspects of dealing with disease, such as how serious they consider their disease and how much they worry about current and future complications (p. 248). Personal models of beliefs about disease and ability to self-manage for adolescents with diabetes may mediate the relationship of peer support and dietary intake (Skinner, John and Hampson).

Adolescents also need a supportive peer group that supports the daily activities associated with self-management with Type I diabetes. In one study, the more the adolescent perceived others observed or questioned his or her blood sugar testing or insulin injections, the more likely the adolescent experienced a decreased sense of well-being (Lightfoot, Wright, & Sloper, 1999). Researchers tested self-efficacy theory in support of diabetes management for those individuals with Type II diabetes, concluding that the incidence and severity of complications were reduced when personal models of beliefs about management were supported by family and other support groups (Brown, 1990; Hampson et al, 2000). Peer support in the form of helping with medical issues and protecting when bullied were important factors also for children with disease (Lightfoot, Wright & Sloper, 1999).

Parenting presents its own challenges. Parents' philosophical, psychological, and structural contexts may impact situations that encourage habits leading to increased food consumption, less activity, and eventually weight problems. Mothers who are working to improve their own self-esteem or provide for the family may be overwhelmed by dual roles. Mothers who are traditionally responsible for meals and children's activities may not be as attentive or have adequate time to prepare nutritious meals, encourage physical activity, or supervise at-home activities (Anderson, Butcher, & Levine, 2003). The Baby-Boomer generation is also a generation that is more likely to be "sandwiched" (Blanton, 2003). Families may be taking care of elderly parents or grandparents in addition to raising children of their own, and such situations involve additional stressors that create change and may lead to unnoticed unhealthy behaviors.

In a study with minority children, Germann, Kirschenbaum, and Rich (2007) found that these families often experience extensive stress. In programs for child overweight that have been developed for minority groups, researchers found that, if the mothers self-monitored their behaviors such as mothers changing types of foods purchased and preparing healthier meals, then their children were more likely to self-regulate. The mediators for these behavioral changes were associated with emotional stability, degree of conflict in the family, and intellectual functioning.

Emotional Concerns and Impact of Health Problems

Children who have poor health often have been found to have lower self-esteem, suffer from depression, and have lower quality of life (Schwimmer, Burwinkle, & Varni, 2003). During adolescence and pre-adolescence, changes in hormonal activity, pubertal development and body image also may affect self-esteem and quality of life for children. Low self-esteem and depression have been associated with overweight status (Brown, McMahon, Biro, Crawford, Schreiber, Similio, Waclawiw, & Striegel-Moore, 1997). Physical appearance and peer acceptance additionally impact self-esteem and depression (Brown et al., 1997). Children who are overweight often have difficulty in breathing, and walking and limitations with exercise. A reduction in the ability to participate in daily activities may create fewer opportunities for social activities and friendship.

Health-related quality of life (HRQOL) measures an individual's physical, social, and emotional well-being, incorporating as well their perception of health-efficacy (Testa & Simonson, 1996). Schwimmer, Burwinkle, and Varni (2003) investigated HRQOL by comparing a group of children classified as "severely obese" and a group of children diagnosed with cancer and found that the severely obese children had lower HRQOL scores compared to the children

diagnosed with cancer. Several factors may have influenced the HRQOL scores. Determining which factors (e.g., self-esteem, social support, life event changes, or health beliefs) within the HRQOL measurement are affected is important when developing treatment plans.

Friedlander, Larkin, Rosen, Palermo, and Redline (2003) compared underweight, normal weight, at-risk for overweight, and overweight children using physical and psychosocial measurements. They found lower scores for psychosocial health (self-esteem, emotional distress) in children whose weight was considered overweight or underweight (Friedlander et al.). They also found that parents of overweight children reported more emotional distress and less personal time as a consequence of the child having more psychosocial issues, such as poorer school performance, greater aggression, and more immature behavior. Parental teasing and emphasis on dieting combined with comments from peers are additional factors that have contributed to poorer self-esteem and depression in children (Phares, Steinberg, & Thompson, 2003).

Teasing about weight is one of the most common issues affecting a child's emotional development that is associated with child overweight. Teasing may occur at school and in the home and may lead to beliefs and attitudes about one's appearance, self-worth, relationships with the opposite sex, and poor satisfaction with body (Borra, Kelly, Shirreffs, Neville, & Geiger, 2003; Phares, Steinberg & Thompson, 2003). Phares, Steinberg, and Thompson (2003) measured self-worth and psychological functioning in a group of preadolescent boys and girls, finding that girls were more concerned about body image than boys. The association of girls' concern about body image was related to global self-worth, teasing, depression, peer influences, and a history of family eating problems (Phares, Steinberg, & Thompson, 2003).

Recently, the relationship of psychosocial influences, body image, body dissatisfaction, and attitudes about health has been of greater interest. Finding patterns of the differences in attitudes among cultures, genders, or age groups may influence the direction of health care messages. Perceptions of health and body image seem to vary across cultures. Differences in self-esteem were found when self-esteem was compared among Black and White girls (Brown et al., 1997). Brown and colleagues found that White girls at the age of 9 years had lower scores for both social acceptance and physical appearance. Subsequently, Fallon and colleagues (2005) found that, among Black and White overweight adolescents, White adolescents considered their weight to impact quality of life to a greater extent. The White adolescents who reported experiencing higher levels of distress and lower psychosocial functioning as compared to Black adolescents also reported more problems with physical functioning (Fallon et al.).

For some children, psychosocial issues are not as salient as the physical issues related to increased weight. In two separate studies, (Fallon et al., 2005; Tanofsky-Kraff et al., 2005) groups of overweight children who were assessed for eating disturbances, self-esteem, body image, and physical issues, and were not found to have significant differences in psychosocial issues. However, children did report more physical issues related to overweight states. In Tanofsky-Kraff et al.'s (2005) an exploratory study, overweight children reported more concerns with weight, physical ability, and problems with eating, but did not differ from normal weight children on measurements of depression and self-esteem. In comparing these groups of children it appears that physical complications and perceived self-image were greater concerns than self-esteem and psychosocial issues. Possible differences in attitudes may be related to parental involvement. Including parental perceptions of a child's self-esteem along with the child's

perception is a need for future research and insight in the relationships that may exist between family members, home influences, or support mechanisms.

The inclusion of parents in studies measuring HRQOL also provides insight into the health services utilized. This process is of importance as it provides a means of determining attrition rates for attending and pursuing interventions aimed at those children at risk for disease or overweight. Investigating parents' perceived benefits of health-related care and need for intervention is important when examining children's health. Parents have reported confusion concerning their child's weight status and whether or not aggressive intervention should be pursued. Physicians may indicate that a child will "out grow" his or her weight or parents may be concerned that children will develop poor body image or dissatisfaction if too much emphasis is placed on diet and exercise (Borra, Kelly, Shirreffs, Neville, & Geiger 2003).

The differences in health efficacy, psychosocial issues, and possible physical limitations in children at risk for certain diseases are not always indicated in studies with children (Wiley, Stein, Saelens, Mockus, Matt, Hayde-Wade, Welch, Schechtman, Thompson, & Epstein, 2007). Insulin resistance is a clinical indicator and precursor in the development of Type II diabetes. Intervention programs for children having high insulin levels are limited, and these children are often encouraged by physicians to lose weight. Several reviews and meta-analyses have demonstrated the effectiveness of educational approaches aimed at increasing knowledge, control, and self-efficacy among patients with diabetes (Cruz et al., 2005; Institute of Medicine, 2001). Recommendations from reviews of programs suggest that particular individuals in periods of developmental transition are the best populations to target, with recent interest focusing on the "tween" population (Hamre, 2004).

Role of the Physician Office and Barriers to Educational Approaches

Because pediatricians and other health care providers working in traditional office settings are those on the forefront of addressing the problems associated with child overweight, child obesity, and other health care problems, it is important that the assessment of the child and messages for lifestyle changes provided are understood. Recent studies (e.g., Waldrop, 2005) have found that physicians struggle to find the time and the resources to address the issue of child overweight. A second concern of physicians is that 88% felt that they would be unable to help the family and individual achieve success (Waldrop). In 2007, the Expert Committee addressed these concerns of medical doctors. The Committee devised a chronic care model as a resource for doctor offices, clinics, and communities to collaborate and monitor progress of goals set by families and doctors to both prevent and treat the overweight child. A 15-minute Obesity Prevention protocol summarizes topics and provides communication tools to encourage self-management and motivate patients toward lifestyle goals (Barlow & Expert Committee, 2007, pp. S170-S173).

Many physicians report that they often encounter families and children who are reluctant to change and have many barriers that may prevent behavioral changes (Ward-Begnoche & Speaker, 2006). Recognizing these barriers and providing possible solutions are optimal. The most common barrier is the family's acceptance of the child's weight status. Parents may see their child as strong and thick and in addition a heavier weight in some cultures is associated with better health (Ward-Begnoche & Speaker). Parental obesity also is associated with child obesity and with less activity among children (Ward-Begnoche & Speaker).

Other common barriers are personal and socio-cultural in nature. Personal barriers include psychosocial problems, such as increased anxiety and hopelessness, which may lead to overeating and bingeing. Limited knowledge or obtaining incorrect information also may be a barrier. Parents or children may have been told there was no problem or that “the child will outgrow the weight issue” by one physician, and another more aggressive physician may request additional tests to ensure no other problems related to increased weight exist (Borra, Kelly, Sheriffs, Neville, & Constance, 2003). Socio-cultural barriers are linked to poor access to healthy foods, lack of safe neighborhoods to play, parents not knowing methods to set limits on television viewing, and the presence of other behaviors that lead to weight gain. These are presented as issues that need further investigation (Ward-Begnoche & Speaker, 2006).

Summary

The prevalence of child overweight and obesity in adolescents and younger children has doubled in the past decade. Recent data from the Centers for Disease Control and Prevention (CDC) indicate that children younger than 5 years across all ethnic groups have had significant increases in overweight (Committee on Nutrition, 2003). The health problems and diseases associated with childhood overweight are worrisome, and related health care costs have tripled. Insulin resistance, elevated serum cholesterol, high blood pressure, and Type II diabetes are among the primary risk factors and diseases developing in children who are overweight. Effective intervention methods are needed for this group of children.

Weight loss and exercise programs have shown some success in reducing risk factors and helping children achieve metabolic control. However, long-term maintenance of health efficacy is not as promising. Recent studies have shown that using the stages of change in practice along

with motivational interviewing with child overweight programs shows promise. The Health Belief Model and the Transtheoretical Model for the stages of change often incorporate social learning theory and the socio-ecological model as approaches in both individual and group intervention settings and programs (Theory at a Glance, 2000).

The significance of support systems, resources available, parents, friends, and physicians cannot be over-emphasized. Understanding the influence of these support systems and the impact they may have in relation to children's process of preventing disease is of interest. Motivational interviewing has begun to replace traditional interviewing in nutritional counseling as well as general pediatric counseling and is an area worth exploring. What a doctor in the office setting says that is effective in the adult settings may not be as influential in pediatric settings; this question merits further investigation (Glasgow & Anderson, 1995). How influential parents can be, especially during their child's teen years, is of great interest. The voice of the child becomes imperative when discussing intervention programs for children and families. Children provide great insight and have excellent ideas. Using their words and exploring their experiences with becoming healthier will contribute to research and theory and enhance current programs, community classes on wellness, development and dissemination of school-based curricula, community projects, and vocational programs.

CHAPTER THREE

METHODS

The purpose of this study was to describe the experiences and understandings associated with lifestyle changes made by overweight, insulin-resistant children. These children have been identified and followed by a team of dietitians and pediatric endocrinologists since March 2004. The main qualitative approach incorporated in this study was phenomenological inquiry. Phenomenological methodology allowed children to tell their story about specific behaviors and experiences. It incorporates in-depth interviewing allowing children to relate in detail their experiences and motives for behavior choice. Children's experiences and their thoughts about their own health status and motives for behavioral health choices will contribute to the research literature in the fields of both child development and health. The information acquired using the phenomenological method also will contribute to a needed richer understanding of children's perceptions of their self-efficacy as related to their own health. The objective of this study was to capture the essence of how children perceived their health and themselves after they had made successful lifestyle changes.

Phenomenological Methodology for this Study

For this study, the phenomenological method of inquiry provided the researcher with the opportunity to understand the perspectives of each child. In phenomenology, it is important to label the perspective of the participant so that what is said represents what each participant portrays at that specific time and place and in the participant's context (Dahl & Boss, 2005, p. 64). The researcher accepts assumptions that are imperative when embracing phenomenological inquiry. Dahl and Boss (2005) emphasized that seven assumptions undergird phenomenological

inquiry; they are categorized into aspects of understanding the “How we know,” “What we need to know,” and “How we locate ourselves in the research process” (pp. 65-68).

The “How we know” is based on taking for granted that

1. Knowledge is socially constructed. Therefore, the child will tell you what he or she knows and understands in the context and in his or her words.
2. Objects, events, and situations mean different things. Thus, children may describe a similar or same event in many different ways.
3. Art and science can be intertwined. The narratives and stories children share will enrich research as well as provide an experimental understanding of their processes of behavior change.

The “What we need to know” assumes that

1. The everyday world is known to be just as important as when a major event occurs. Discussing scenarios that are common to everyday life is important to research and what becomes known.
2. The language of everyday life is meaningful and salient in depicting what naturally occurs in each individual’s environment and surroundings.

“Where we locate ourselves in the research process” is the third set of assumptions to influence researchers:

1. The researcher is not separate from the phenomena. Subjectivity is expected and recognized. The researcher is to be trusted to be open about his or her values and beliefs.

2. The researcher and the participant are both equal and share common ground. Each will gain from the experience with phenomenological methods of inquiry.

Phenomenology is an approach to qualitative inquiry that allows the individual being interviewed to share his or her lived experiences and sense of the significance of these experiences. The phenomenological approach assumes that the researcher is not separate from the phenomenon being studied. Because the researcher is not separated from the phenomenon being studied, researchers are able to treat experiences and behaviors as an integral part of a single whole (Creswell, 1998). Incorporating the phenomenological approach in studies with children will help provide better insight about how they experience lifestyle changes that are related to health management and may provide a better understanding of how they understand the experience of becoming healthier.

Identification and Recruitment of Participants

From March 2004 through December 2005, the Department of Endocrinology at East Tennessee Children's Hospital (ETCH) referred over 400 children who had high insulin levels and were overweight for nutritional intervention. Each child who had insulin resistance or a secondary complication associated with being overweight and his or her family was scheduled to attend a class on nutrition and fitness. Classes were conducted on a monthly basis and focused on disease prevention, dietary recommendations, and methods for how to incorporate strategies to enhance physical fitness into daily routines. Referral forms were sent to the Department of Food and Nutrition at ETCH for a dietitian to review. The information included on each referral form sent to the dietitian included the child's height, weight, prescribed medications, lab results, clinical diagnoses, and physician notes. The dietitian reviewed this information to construct an

individualized meal plan for each child. The day prior to the class, each individual's family was notified as a reminder that they were scheduled to attend the class.

Data on each individual child were taken from the physician encounter forms and kept in a separate database that included all class referrals. Permission for the ability to review the child's personal health information for evaluating health care services was included in the privacy notice and acknowledged by a parent or guardian when they signed the Health Insurance Privacy Protection Agreement (HIPPA) form at the initial visit to the endocrine clinic. Every 6 to 12 months the dietitian / principal investigator determined if outcome data were available for children referred to classes. Data was available only for those children who returned to see the physician. Outcome data was reviewed to identify the physical measurements (i.e., height, weight, BMI, insulin level, blood pressure, and cholesterol profiles) that may have changed since the child was initially seen and referred to the nutrition and fitness class.

For the present study, the children who were referred to the classes from March 2004 through December 2005 were sampled. Specific criteria established for inclusion as a study participant were determined based on clinical outcomes that represented changes toward reducing risk factors that are related to the development of Type II diabetes. The clinical results of laboratory values were located in the hospital's computerized medical record, along with the date the individual returned to see the physician. To meet criteria for inclusion in this study, at least one of the following physical outcomes had occurred based on changes from baseline levels to those obtained at the last physician visit.

1. A reduction in serum insulin level by 50% of baseline levels or a current insulin level within the normal range that occurred 6-18 months after the initial physician visit.

2. A reduction in weight by 10% that occurred 6-18 months after the initial physician visit.
3. Maintaining or lowering of Body Mass Index 6-18 months after the initial physician visit.
4. A reduction in serum cholesterol, triglyceride, or low-density lipoprotein level 6-18 months after the initial physician visit.

Finally, all interviews were conducted with children between the ages of 9-16 years. This age range was chosen because it represented the average age range of the referral population and possibly would provide differences in experiences as well as differences in cognitive and physical development.

For all children who met the inclusion criteria, the parents or guardian were sent a letter describing the study and the interview process (Appendix A). The letter stated that the researcher would contact the individual by telephone approximately one week after the letter was sent. Phone calls were made to determine if the child expressed willingness and interest to participate in the study and if the parent agreed to the child's participation in the study. If both the parent and child agreed, then a time for the interview was arranged. Letters were mailed out to 31 potential participants in three waves. The additional waves of letters sent in case some of the children and/or parents declined to participate, the child and parent were unable to be reached, or the child was over the age criterion and/or was not currently being followed by the pediatric endocrinologist. The day prior to the interview, a phone call by the researcher was made verifying the time and place of the interview.

Interview Procedures

The University of Tennessee Institutional Review Board approved the research using Form B in conjunction with approval from East Tennessee Children's Hospital Institutional Review Board. Final approval from both institutions was granted on April 30, 2008. Prior to conducting interviews, the principal investigator participated in a bracketing interview with Dr. Priscilla Blanton, who is well accomplished in bracketing procedures. The purpose of the bracketing interview was to assist the interviewer/principal investigator in recognizing preconceived biases and assumptions about what children may experience and consider healthy changes in lifestyles. Bracketing is an interview process that encourages the researcher to set aside his or her own ideas in order for the perspectives and the voices of the informants to be understood. Bracketing begins with a researcher's accounts and descriptions of his/her own personal experience with the phenomena. Additionally, bracketing assists the researcher in understanding his or her role in the interview procedures as well as grasping how the child perceives his or her initial experience with the phenomenon of interest. The bracketing interview was audio taped, and I, the principal investigator, reviewed and noted feelings and impressions about the interview. What I learned was that much of what I thought about the questions and my idea of health was based on personal choices and experiences as well as what I had investigated or read in the scientific literature or heard in scientific and didactic lectures. When asked about what I thought children might say to questions, my responses were somewhat uniformed because I had only experienced what was reported on paper. Additionally, my experiences with children in this age group are only at one point in time, or on one occasion and therefore, to predict how they may respond to specific questions and the phenomena could only be based on what I would consider as typical age-appropriate answer.

Parents and children came to ETCH for interviews at a time that was convenient for them. The principal investigator greeted the parent and child at the Information Desk and escorted them to the area where the interview occurred. All interviews took place in a small conference room located in the medical library at ETCH. The child's parents remained in this area during the interview. All other parents or family members who accompanied the child were asked to wait in the main library area while the interview took place. The parents were welcome to utilize the library resources during the interview if desired.

Prior to the interview, written informed consents were obtained from the parent and any child over 14 years old (Appendices B and C). Children ages 9-13 signed an informed assent agreement (Appendix D). The principal investigator asked the parent and child to read the informed consent as appropriate. After the child and parent read the consent forms, the principal investigator reviewed each section to ensure understanding of the consent form and to obtain signatures. For children ages 9-13 years, the principal investigator read the informed assent to the child, had him or her acknowledge understanding, and then obtained signatures indicating that the child agreed to proceed with the interview.

Interviewing children may incur other risks, therefore specific risks and protection measures were in place. During interviews with children, potentially some children might not want to answer questions, might have become nervous, or might have decided that they did not feel like participating. Therefore, the principal investigator was flexible, changing the flow of the interview process based on age and cognitive ability of the child (examples may be found in Appendix E: Sample Assent and Procedures). To prepare the child for the interview an icebreaker (e.g., drawing a picture) was utilized at the beginning of the session. The children also were informed that the

interview would stop at anytime if the child felt uncomfortable. The principal investigator operated under the guidelines of the Health Insurance Protection Privacy Act. Along with the parental consent form, parents also were asked to sign a Health Insurance Protection Privacy Agreement for Research that concurred with the federal privacy regulations and access to participant's personal health information (Appendix F). The Health Insurance Protection Privacy Agreement for Research complemented the acknowledgment for disclosure of personal health information that was obtained by the endocrinology office when the child was seen by an endocrinologist at ETCH.

To gain experience with using phenomenology and the methodology at work in an interview process. The principal investigator conducted two pilot interviews in May 2004, the pilot interviews were conducted with a 12-year female and a 16-year old male who had been seen by the principal investigator for individual counseling at least once in the 2 years prior to the interview. The individuals did not have secondary complications associated with weight, but were overweight at the initial appointment. At the time of the interview both children had lost weight, but were still classified as overweight. Results of the pilot interviews are found in Appendix G.

Prior to beginning the interview, the child was reminded that the information would be kept confidential and was asked to provide a code name to be used during the interview. Each child's audiotape and transcription file was coded with a numeric code that matched the code in the patient nutrition class database. To protect confidentiality, the name of the child was coded on each transcript with a common name (e.g., Jane) and filed separately from medical information and data.

To begin the interview, the principal investigator asked the children to remember the scenario of the first visit with the endocrinologist and then asked if he or she could begin to tell the story about what he or she remembered at the visit and what they were told about his or her health.

Throughout the interview some of the following questions were asked. These questions or statements helped guide the children as they described the changes they had made after the first visit.

What does “being healthy” mean to you?

Tell me about any changes you made to become healthier.

How did you decide what to do?

What meanings do the changes have for you now?

Where did you go for information and help?

How do you feel you have changed?

What challenges did you face in making these changes?

What advice would you give to children your age who are trying to be healthier?

What advice would you give to physicians and other professionals about talking to children who are with insulin resistance?

The way the question or topic was presented varied and often was altered based on the flow of the conversation, the child’s grade level, or understanding of the question.

The interviews took place between May 2008 through August 2008. The time of the interviews ranged from 45 minutes to 125 minutes. After each interview, the child received a gift card that was equal to \$25.00 in value for participating.

Data Management and Analysis

The methodological procedures as described by Moustakas (1994) and Caelli (2004) were followed for data management and analysis. These are categorized as memoing, transcribing, textural descriptions, and structural descriptions. Memoing by the principal investigator was

achieved when I made field notes after each interview and wrote reflections about the experience of the interview. These descriptive notes were filed into a text document. Each audio taped interview then was transcribed by the principal investigator and read through several times to obtain an idea of the overall feeling of the interview. Transcriptions of the interviews and information from physician notes were compared and categorized by code name into separate data files. Triangulation is a strategy used in data analysis when more than one source of data are used to confirm information. Inclusion of encounter form notes from both the physician and the dietitian contributed to validating the information obtained in the interview. These notes were compared to determine if the information in the interview and outcomes reported by the child complemented what was documented in the endocrine medical record. By utilizing all sources of documentation, a more complete picture was provided and helped create credibility or trustworthiness to the data (Sprenkle & Percy, 2005). All files pertaining to each individual interview were created, gathered, and organized in a separate file by transcription number, referral database code number, and code name.

Once the transcriptions were complete and field notes filed, the significant statements each individual stated were categorized as a description of an event, construct, a topic, idea and/or meaning. The similar ideas and/or meanings then emerged into what is called “*textural descriptions*” or verbatim examples of the experiences the child described. Similar themes that emerged from each transcription were copied from the transcription file and organized by subject and context into a labeled text document file (as a *Microsoft Word* document) by theme name. Structural descriptions that evolved followed the textural description. Structural descriptions often depict the “how” aspect of the changes as described by the children (Moustakas, 1994). The themes that emerged were read and analyzed to compare what was said and described to literature cited.

The doctoral dissertation chair, Dr. Priscilla Blanton, reviewed the audiotapes and transcriptions to verify emergent themes.

Sample Population

The children recruited for interviews came from the list of referrals to the nutrition and fitness class from March 2004 through December 2005. There were 458 children referred during that time period. From the 458 referrals, 125 (27 %) children returned to follow up with the endocrinologist in the last 18-24 months. All outcome data were reviewed for the 125 individuals who followed up with the physician. After all of the outcome data were reviewed for the 125 individuals who returned to the physician, six general categories were developed to determine if those individuals would meet participant selection criteria. These categories included the following:

1. Children who met the inclusion criteria (31 of 125, or 24.8%).
2. Children who were not in the selected age range (15 of 125, or 12.0%) ‘
3. Children who did not meet inclusion criteria (41 of 125, or 32.8%).
4. Missing data (pre or post labs) in medical computerized charts prevented analyzing outcomes; therefore these individuals were excluded from recruitment for interviews (24 of 125, or 19.2%). (Note: Although doctors may have ordered labs, it appeared that sometimes the patient did not have those labs drawn after the visit per laboratory record. Additionally, labs are not ordered at each visit and ordered only if needed based on clinical signs or past history.

5. Child had returned, but outcomes were either unchanged for most criteria or the last evaluation by physician was January 2005 (12 of 125 or 9.6%), and these children were excluded.
6. There were two children (2 of 125 or 1.6%) who were not able to participate based on current developmental and/or mental status and therefore were excluded.

The age range of the children referred to the classes in 2004 through 2005 was 5 to 20 years, and the average age was 12.65 years. Gender distribution was 39% males and 61% females. Family living arrangements are of importance when children are making lifestyle changes. The majority of the total number of children referred to classes lived with both parents (60%). Joint custody was arranged in 7% of the children's households, and 23% of the children referred resided in a single, adult-headed household.

From the number who returned for follow-up 31 children (25%) met the inclusion criteria established for participating in interviews. Eleven children agreed to interviews, one interview obtained did was not in-depth, and therefore not included in analysis for this study. The following lists reasons other 20 interviews were not obtain:

1. Six children could not be contacted or did not return phone calls after five attempts.
2. Five children were not interested.
3. Eight children were not in the age range, either under 9 years or over 17 years.
4. One letter was returned and a forward or new address was not available.

All children interviewed had been referred to the Nutrition and Fitness class for education on disease prevention, nutritional guidelines for high insulin, and increased physical activity goals.

The information about the child's living situation and family size were provided by the child during the interview and not included in the physician chart notes. Eight of the 10 children attended the class from March 2004 through December 2005. With the exception of one child, all of the children interviewed were living in a two-parent household, seven children lived with biological parents. Two children lived with their biological mother and stepfather. Two were an only child, two children had four siblings at home, and the other five children had at least one sibling at home. One child had older siblings who lived away from home.

Table 2 depicts the descriptive data for the referral population, the follow-up population, the sample population available to recruit, and the children who participated in interviews. Additional physiological data for each participant will be described later.

Table 2: Data for Children Referred to Classes and Participants in Study

	Referral Population	Individuals Returned for Follow-Up	Participants Meeting Inclusion Criteria	Study participants
Number of Children	458	125	31	10
Age Range	5 –20 years	5-17 years	10-20 years	11y 11m-16y 10 m
Gender Distribution	39 % male 61 % female	47 % males 53 % females	33% male 67% female	20% male 80% female
Body Mass Index Average	37.0	33.9	30.6	26.6
Insulin Level Range Normal: 0-17	10.7-113.0 Average: 34.42	2.3-49.2 Average: 23.76	2.3-37.9 Average: 17.1	2.3-37.9 Average: 16.9

Table 2: Comparison of children in the referral population, follow-up population, participants for recruitment and study participants. Chart portrays the number in each group, age range, gender distribution, and Body Mass Index Average for each group. Insulin values are baselines values for referral population. Other groups' insulin values are the range of results and averages for each group based on the last level obtained.

CHAPTER FOUR

RESULTS

Demographic and Physiological Data for Participants

Ten children participated in interviews. Ages of children at their first encounter when they saw the physician ranged from 9 years 3 months to 13 years 5 months. At the time of the interview, the children's ages ranged from 11 years 11 months to 16 years 10 months. Two children were male (20%) and eight female (80%). Seven children were Caucasian, and three children were African American/Black. Children had visits with the physician every 6-12 months; on average three visits for each child occurred with the physician in the last 4 years. Two children had not seen the endocrinologist in the past year.

Outcome Data

The physiological changes (height for age, weight for age, BMI, insulin levels, and lipid profiles) are all variables that, if decreased, are associated with reducing the risk of developing Type II diabetes. All of the children interviewed except one had decreased insulin levels since baseline, and 6 of the 10 participants (60%) at the time of the interview had a serum insulin level within the normal range. Figure 3 shows the changes in insulin levels over the 2-4 year period for each participant (all names are pseudonyms). Changes in serum lipid profiles (total cholesterol, lipoprotein density levels [LDL], high density lipoprotein levels [HDL], and triglycerides) are shown in Figure 4. All children had positive outcomes in their lipid profile panels; to be more specific, each child had reduced triglycerides, and several had increased High Density Lipoproteins (HDL) from baseline. These changes reflect a better balancing of diet and exercise.

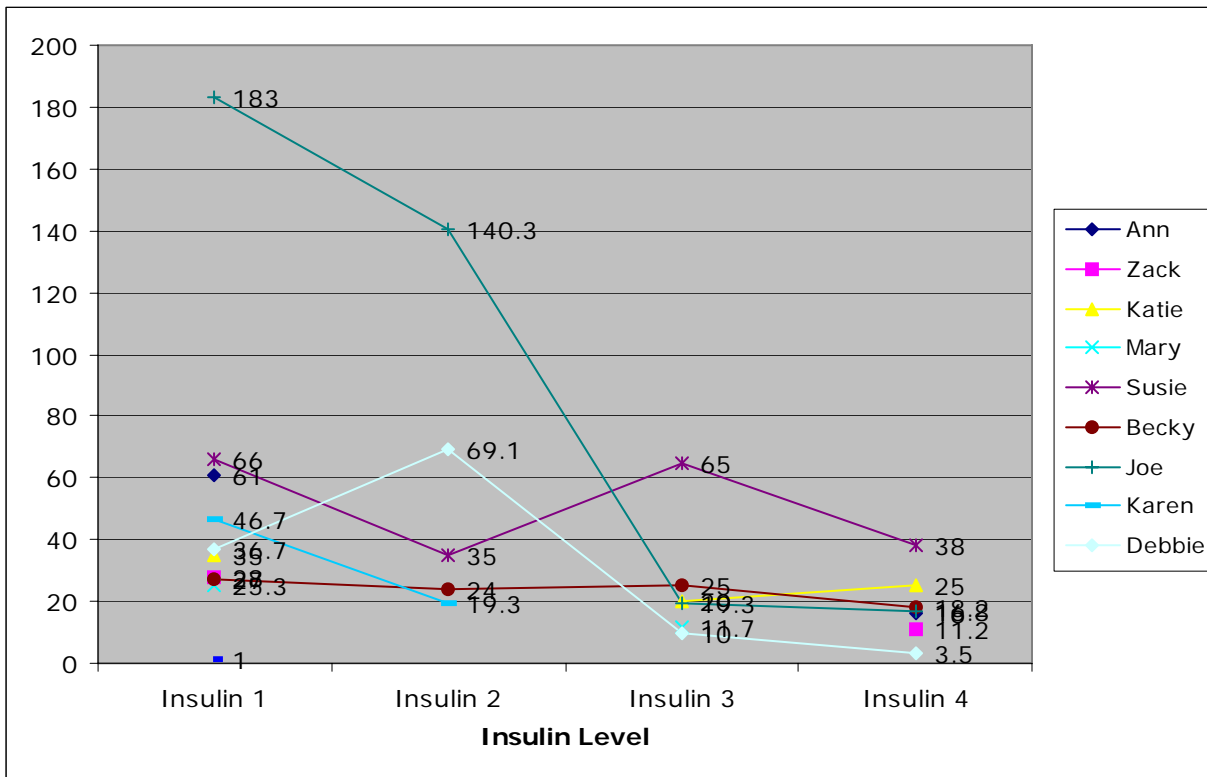


Figure 3. Insulin Level Changes for Participants

Participants’ results of insulin level changes are depicted using color coded lines. The values at each point are the insulin level (normal range 0-17 mg/dl). Insulin-1 is the baseline level. Insulin-2, Insulin-3, and Insulin-4 are values that show second, third and fourth results, respectively.

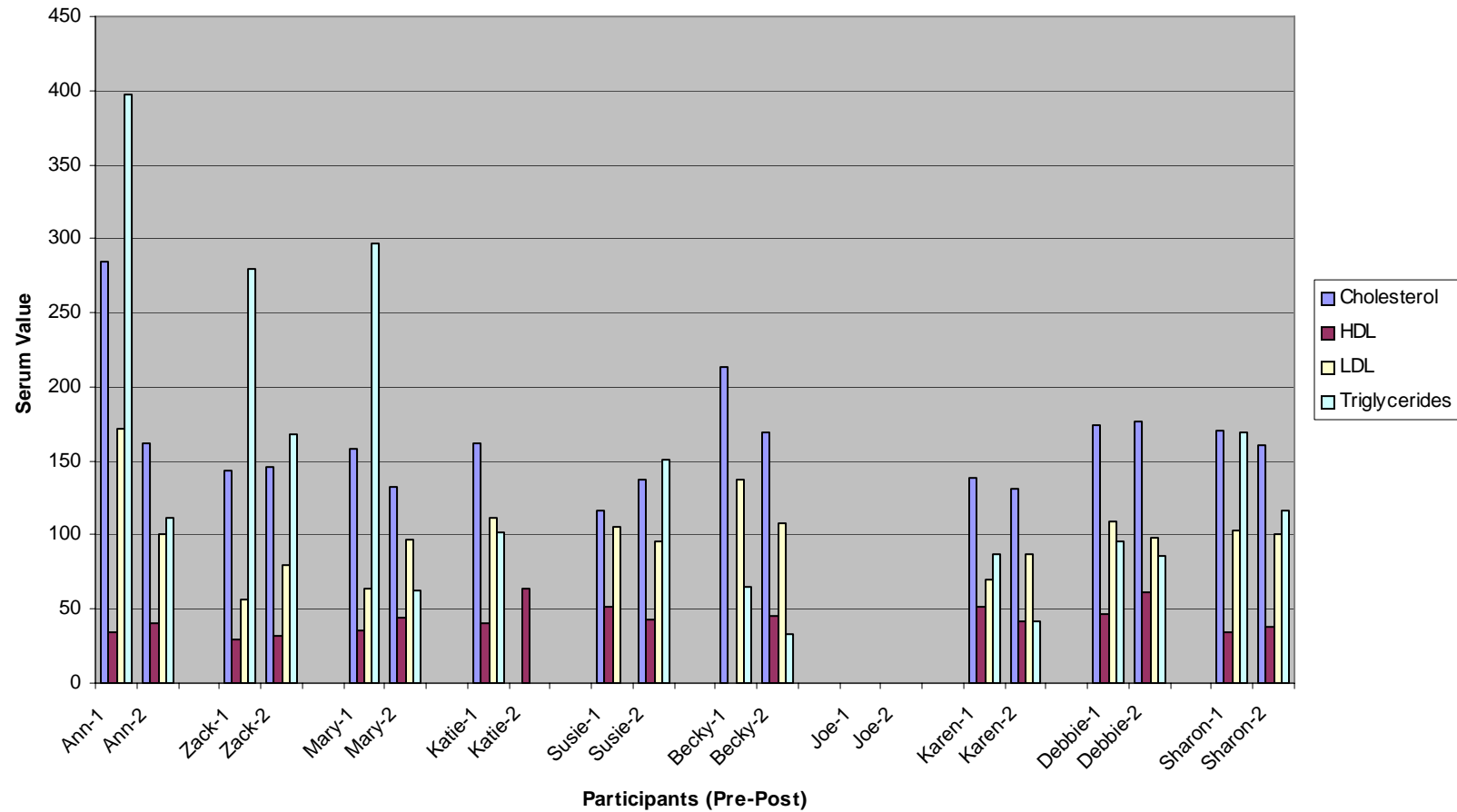


Figure 4. Bar Chart Representing Lipid Profile Changes

The bar chart shows the changes in total cholesterol, high-density lipoprotein levels, low-density lipoprotein levels, and triglycerides for each individual interviewed.

The boys' and girls' growth charts are represented in Figures 5 and 6, respectively, and show the changes in both height and weight for the participants interviewed, by gender. Each child continued to follow his or her growth pattern for height. Females over 14 years had stabilized growth in stature. Weight for age graphs for gender show the patterns for those who lost weight. Of importance is that Sharon's initial weight (279 pounds, indicated by navy) and Karen's weight, 240 pounds, indicated by orange) are located in the height area of the growth chart as the highest weight on the chart is 230 pounds. The Body Mass Index (BMI) charts (Figures 7 and 8) show the changes in BMI over the past 2-4 years by gender. Most children (7/10) reduced BMI levels, one child had a BMI that stabilized, and two children had BMI's that increased. The interpretation of the child's BMI needs to be compared with changes in both weight and height. All children followed their percentile curve for height. Body Mass Index did not change as much for those children who either gained weight at a slower rate and whose height steadily increased as compared to those children who lost weight and continued to grow in height.

One of physiological changes associated with increased insulin or insulin resistance is the presence of Acanthosis Nigricans (AN). The striation or appearance of black or gray rings on the neck (a description of AN) was evident in 7 of the 10 children (70%) at baseline according to the physician's documentation. Two children had significant AN at their first encounter. Five children had reduced color in the skin or showed no signs of AN at the last visit, indicating reduction in insulin. Physicians had prescribed medications that are intended to increase the production of insulin, allowing the body to use insulin more efficiently and slow the absorption of carbohydrates. Over the past 3 years, three children had reduced the amount of medicine

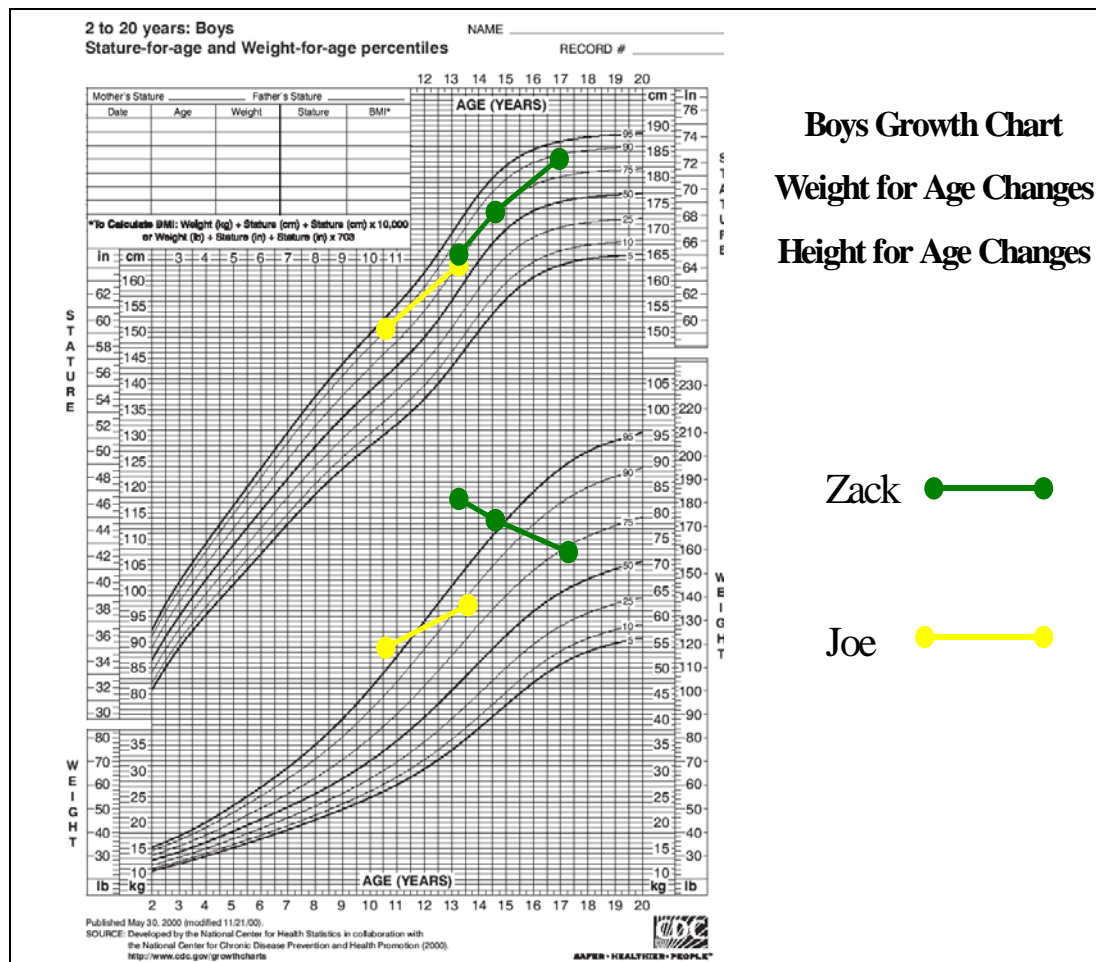


Figure 5. Male Study Participants Height and Weight Growth Chart

The male growth chart includes weight for age percentile and a height for age percentile curve.

Initially, each of the boys plotted above the 95th percentile for weight/age and now are at or below the 90th percentile for weight/age.

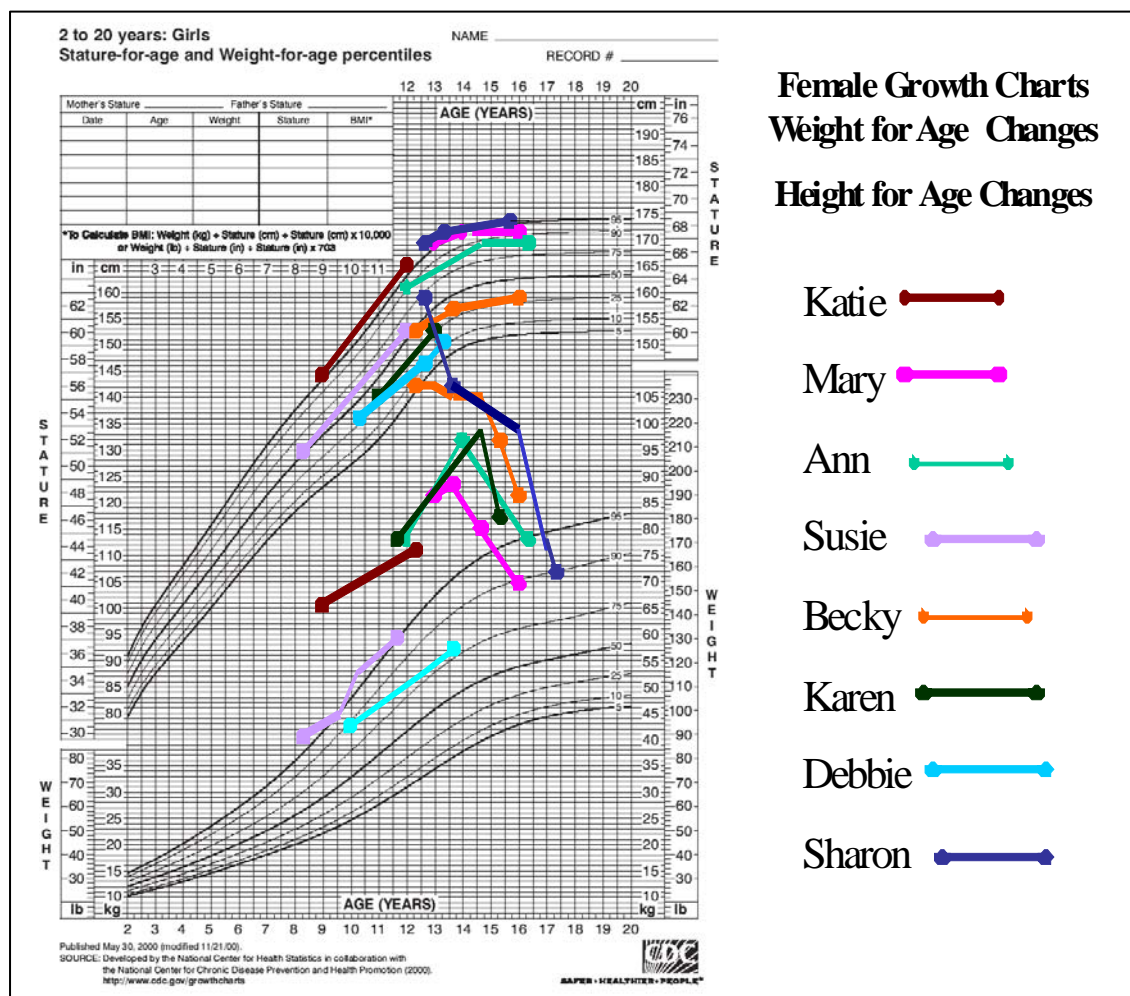


Figure 6. Female Study Participants Height and Weight Charts

All children followed their percentile curve for height. Body Mass Index did not change as much for those children who either gained weight at a slower rate and whose height steadily increased as compared to those children who lost weight and continued to grow in height.

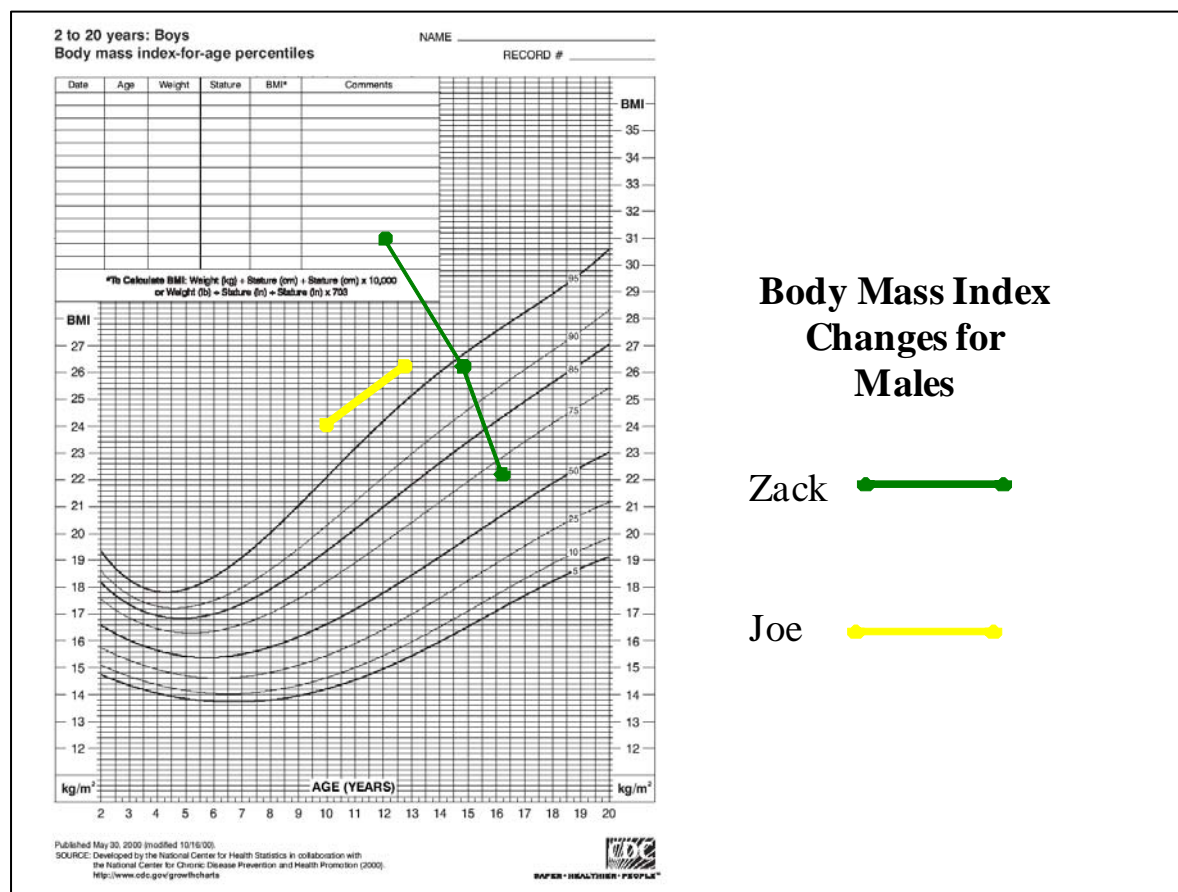


Figure 7. Body Mass Index Changes for Males

As Zack grew in height and lost weight his BMI decreased. Joe continues to grow slowly in height, although dropped his percentile in BMI. He has experienced a steady weight gain over years. Joe's BMI continues to follow the same linear path.

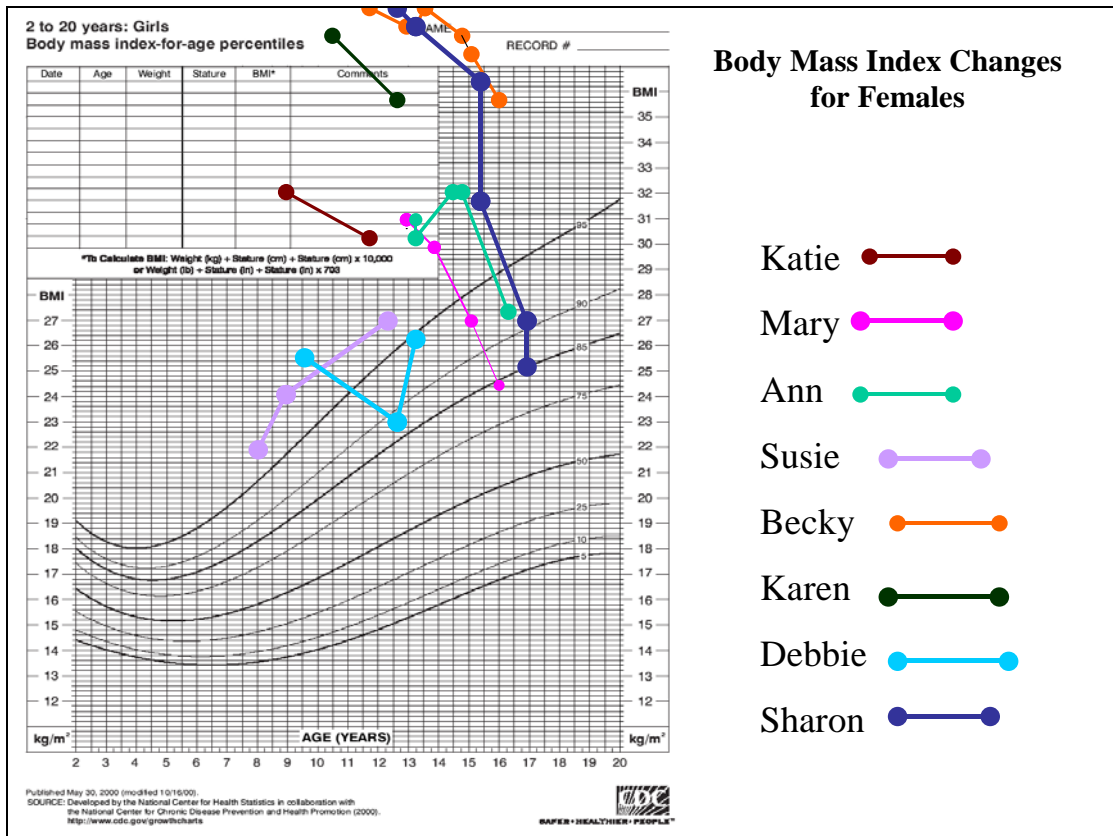


Figure 8. Body Mass Index Changes for Females

With the exception of two females, all others have reduced BMI over the past 2-3 years. Four of the eight girls are now under the 95th percentile for BMI for age, while the other four have reduced BMI from the initial BMI percentile. The most dramatic change in BMI was observed for Sharon whose BMI was 41.5 and current BMI is 25.7, and was a progressive decrease over 4 years. Becky whose BMI was 44.9 reduced to a current BMI of 35.2. The other children have decreased BMI or fell below their initial percentile range, although Susie has stayed at her percentile for BMI. Of interest is that all of the children under 14 years do not have as dramatic changes in BMI. It appears that more of the changes in weight occur between 13-15 years possible when pubescence is set and the growth rate slows.

needed, and three children were taken off medications. The change in the appearance of striations or reduction of the presence of Acanthosis Nigricans and a prescription to decrease or stop usage of medication are signs associated with weight loss and/or insulin levels decreasing or are within the normal range.

Biographical Sketch of Participants

Zack

At the time of the interview, Zack was a 16 year, 3 month old White male. He was diagnosed with insulin resistance at age 13. He was taken to the Emergency Room after an episode as he described as possible low blood sugar while playing football. He lives with his mom. His parents were divorced shortly before his diagnosis. He felt that the diagnosis of high insulin was a way to help himself. He described being healthy as eating less meat, watching portion sizes, and walking a lot. During the past 3 years, he has focused on changing the type of foods he eats and getting more activity. He would like to start Tai Chi or Karate as a means to get into better shape because he would like to resume playing football in high school next year. He feels he is mature for his age and would like to pursue a career that involves helping others. During the interview, he focused on how to overcome obstacles and how this has made him a stronger individual.

Katie

When Katie was interviewed, she was a 12 year 11 month White female. She was first seen in 2005 and was diagnosed with insulin resistance at age 9 years, 4 months. She lives with her parents and four siblings (three are older and one is younger). One older sister was identified as insulin resistant at the same time as Katie. Katie describes healthy changes as limiting junk

food, not eating out very often, and being more physically active. Katie exhibited a very outgoing and bubbly personality during the interview. She attributed her maintaining lifestyle changes to improved self-image and confidence. She discussed how exercise has helped her feel so much better about herself, both physically and emotionally. Her hobbies include talking to her boyfriend of 4 months, hanging out with friends, and creating her My Space web page.

Mary

Mary is a 16 year 9 month White female who was first seen in 2005 and diagnosed with insulin resistance and overweight at age 13 years, 2 months. Her younger sister was also diagnosed with the same condition. She lives with her biological parents and four siblings. Mary is very honest about her experiences and shared her excitement in the changes she has made and what they have meant to her. She was very happy to report she no longer needs that “stellar” medicine as she has normal insulin levels and has lost weight. She discussed how she became healthier by cutting back on junk foods, especially Twinkies, and exercising 4-5 times per week. She also stressed how important her support system was in the process of making changes related to eating less often and getting more activity each day.

Mary is very involved with her horse and will be getting another horse in 2008. She said she is hoping to find a job so she will have money to buy gas so she can drive. She was excited to talk about her boyfriend, being organized for school, and the possibility of going to college.

Ann

Ann is a 16 year 5 month White female who was diagnosed with abnormal thyroid and insulin resistance at age 11 years. Ann lives with her biological parents. Ann is very active in community groups and enjoys volunteering. Ann provided detailed and rich narratives during her

interview. Ann shared her memories about a period of depression and loss of friendships. She elaborated on how ‘mean’ people can be towards those who are overweight. She also discussed at length the challenges of battling both weight and health issues as a result of the “yo-yo” affect, either adhering to a plan or not making diet and exercise a routine.

Ann expressed how much better she feels about herself now and the importance of understanding the potential problems associated with diabetes. She feels she is at her best health ever. Her idea of healthy is to have a healthy lifestyle, limit fast foods, and take small steps to make changes.

Susie

At the time of the interview Susie, a Black female, was 2 weeks shy of 12 years. She was diagnosed at age 8 years, 2 months with high insulin levels, overweight, and Acanthosis Nicgricans. Susie lives with her parents and has four older siblings, all of whom live away from home. Susie’s mom was diagnosed with Type II diabetes shortly before Susie’s own clinical signs of pre-diabetes were noted. She likes art and is looking forward to starting middle school. She is hoping to be on the basketball or baseball team. She also likes swimming and says she is a “water baby”. Her idea of healthy is to feel good about oneself, eat right, and be active.

During the interview, she emphasized the importance of taking care of herself and becoming more aware of the problems with diabetes. Susie shared many stories about the experiences of individuals around her who either had Type I or Type II diabetes. She is very good at telling stories and would like to be a spokesperson. She also feels that she could be a person who helps others in dealing with a disease like diabetes. She feels she has many goals that may lead to careers in design, law, or public speaking when she grows up.

Becky

At the time of the interview, Becky was a 16 year, 6 month Black female. She was diagnosed at age 13 years with a high insulin level, overweight, and Acanthosis Nigricans. She lives with her parents and a younger sister who is 13 years old. She plays tennis and would love to go to Wimbledon some day. Her idea of healthy is to just feel good and eat the right foods. She also stated that it is important to wake up and feel good; it is good to sleep and to get exercise each day.

Throughout the interview, she emphasized preventing further disease and how that motivated her to stick to a plan and never give up. She was happy to report how the changes in her weight and insulin have allowed her to feel better about herself. She loves to go shopping now and enjoys the compliments from those who have known her since her initial diagnosis.

Joe

When Joe was interviewed, he was a 12-year old White male. He lived with his parents and older brother who was 14 years old. Joe was diagnosed with insulin resistance and overweight at the age of 10 years. He was not very sure about his first experience at the physician's office; he just knew he was told he was pre-diabetic. Since that time, he has focused on eating better and getting exercise at home. His parents started *Weight Watchers*, and this has helped because, as he says, "the junk is out of the house."

His idea of healthy is to eat right, exercise, and to not sit around at home and play video games. Joe is on a wrestling team at his school. He likes to play frisbee football at recess with friends and basketball at home with his dad. He would like to try jujitsu, a form of karate. He stated that he likes school and is hoping he grows more in height in the next couple of years.

Karen

At the time of the interview, Karen was a 14 year old, 5 month Black female. She was diagnosed at age 11 years with insulin resistance and overweight. She lives with her mother and her stepfather. Her step-father was recently diagnosed with Type II diabetes. She has a younger brother whom she mentioned in her interview; no other siblings were mentioned. She is also very close to her grandmother and aunt; they accompanied her to the interview.

Karen likes to workout at the YMCA and walk to the park with friends. She emphasized that exercise or activity should just be fun. Her idea of healthy is to be in good shape, eat right, and drink plenty of water. She discussed how her grandmother and aunt have encouraged her to stay healthy. She also discussed how people at school could be complicated and make things harder on someone who is overweight. She feels she has done her best at overcoming those obstacles and tries to stay in shape, watch what she eats, and feel good.

Debbie

Debbie is a 13-year-old White female who lives with her mom, stepfather, and a younger brother. She has four other siblings who live with her father, but she does not get to see him very often because he lives far away. She enjoys playing with friends in the neighborhood, and she enjoys cheerleading. Her idea of being healthy is trying to live your life better.

Debbie discussed her diagnosis very nonchalantly. She found that the changes she has made were somewhat difficult, but the hardest was giving up sweets. She also stated that “she doesn’t have that big of a story” and that having high insulin is controllable.

Sharon

Sharon was a 16 year 10 month White female at the time of the interview. She lives with her biological parents and frequently stayed with her aunt, uncle, and grandmother over the past 4 years. Her grandmother recently passed away, and Sharon is still dealing with the emotions surrounding her loss at times. She was seen initially in 2004 at the age of 12 years and since has lost 100 pounds, no longer requires two of the medications she was prescribed, and her insulin levels have normalized. She is very proud of those accomplishments and produced a smile (something she said she does not do very often). She described herself as a private person. She has friends whom she can trust, has strong faith with God, and loves working with the special needs group at her school. She feels encouragement every time she works with special needs students. Her idea of healthy is to eat three meals a day, exercise, get sleep, and like oneself. During her interview, she focused on being determined and making exercise and eating right a priority. She stressed to never give up. She is in honors classes at school and wishes to study psychology in college. Her goal this year is to continue to lose more weight and go to Senior Prom.

Development of Themes and Constructs

The children described their experiences in terms of how they made lifestyle changes that led to decreasing insulin levels, reducing weight, and preventing disease. The narratives that most children shared reflected a strong sense of pride about their accomplishments and how each participant developed improved self-image and a greater sense of maturity. As the children spoke about the process of how they learned about their health problems, several themes emerged from their narratives. Initially, the children were asked to recall their first visit to the

pediatric endocrinologist and discuss how they remembered when their symptoms were identified and a diagnosis of the problem was given. These descriptions provided a contextual richness for the themes that emerged subsequently from their narratives. The themes that emerged were (a) positive lifestyle changes, (b) social support and family, (c) supportive friendships, (d) psychosocial environment, and (e) understanding self and developing resilience. Children added to each discussion their goals for maintaining future health and what advice they would give to others.

Several children were still at an age where they were continuing to grow physically but were continuing to have some difficulty losing weight. All the children had positive outcomes with at least one variable associated with decreasing a risk factor for Type II diabetes. All 10 children were very positive about how they thought they would continue to improve or maintain their health and well-being.

At the beginning of each interview, each child was asked if he or she could remember the first time he or she went to see the endocrinologist at East Tennessee Children's Hospital (ETCH). Each child described the first encounter they experienced. A child's first visit to the endocrinologist most often occurred as a referral from the child's primary pediatrician or family doctor. There are several clinical indicators that may appear as symptoms for pre-diabetes or Type I or Type II diabetes that require further evaluation by an endocrine specialist. The referral often is a result of changes in weight (i.e. weight gain over the recommended amount for growth or deviating from the child's normal growth pattern), presence of Acanthosis Nigricans (i.e., darkened area of the neck), or abnormal blood work (specifically high triglycerides, cholesterol, insulin, or thyroid).

Each child described the first encounter with the endocrinologist, sharing his or her own impression of what occurred. They spoke of feelings related to hearing the diagnosis, and how they understood the problem and risk factors related to pre-diabetes. During the interviews, children discussed feelings of fear and anxiety, coupled with their understanding of what it meant to be told they have a disease. Some remembered the symptoms of the disease. Others experienced thankfulness and found some relief in having that a diagnosis for issues or problems they had for years.

Identifying Symptoms and Diagnosis of Problem

Several children were somewhat ambiguous about their first visit with the endocrinologist, but they were all aware of the final diagnosis. Joe, age 12 years, recalled his first visit: “Ok, the first time that I went I had a blood test done which took forever [slightly moaned]” Interviewer asks “And do you remember what they were testing?” and Joe responded, “Forgot, uhh . . . Except I do know that I am insulin resistant.” Susie, age 11 years, 11 months, seemed to have a similar recollection of her experience. She stated,

Um, I remember that she told me that I could have diabetes and that I needed to go get tested and that’s all that I remember. And then, like I remember, like every 2 hours getting -having needles in my arm. I think they were seeing if eventually I might have diabetes, but she didn’t know all the specifics. That’s all I know.

Other children were able to provide more details about why they went to see an endocrinologist. Katie and Mary explained the symptoms (e.g., weight gain) and signs (e.g., acanthosis nigricans) of insulin resistance. Katie, age 13, shared her description of when she saw first her family practice physician.

Ok-um, in like 3rd grade, that's when I started like gaining weight, you know. It was like a lot of weight, and you could tell you know. And I think that it was like in 4th grade that I first got diagnosed. My mom took my older sister to the doctor, and he was like looking at her neck, and she had that you know that gray stuff on the back of her neck. And he was like, "I think you should get that checked out because it's probably a problem." And then she looked at me and she looked at my brother and my little sister. And I was the only one that had it, other than my older sister. So in the middle of 4th grade year, I started going to the doctor here.

Mary, age 16, Katie's sister, described her recollection.

Well, the first time I went is to my family doctor was because I had pneumonia. And I had to go back for a check-up. And it was like my neck, whatever you get, with what we had you get like black around your neck from the excess insulin, and it comes up there behind your ears. Somewhere else, I can't remember where and he noticed it and referred us to Dr. XXX, and we ended up going to her either 10 or 11 months later, basically.

For several children, the first visit to the endocrinologist involved more than just knowing they had a disease. Children recalled the emotions associated with the disease and diagnosis and how they felt after being told about what was happening in their bodies. Susie described her anxiety as follows:

I was really scared. ... I was really, really scared. I really worried about-on my mom's side of the family. My mom's cousin who has a brother, he went completely blind, was in the wheel chair-legs off--arm about to be cut off if it doesn't-if he can't get any more feeling. I was really scared that possibly one day that could be me.

Mary's description of her emotions was slightly more dramatic.

Oh, I was pretty traumatized. I don't want to lie to you. It just seemed like a lot to take on because I was-I can't remember how old, either 13 or 14. Because you hear about it, but you know how you hear things and you start to think about it. And it was, I don't know, I thought of it a lot worse than it was. I thought, Oh, I'm going to become a full-blown diabetic and end up getting my feet cut off. So I was already really nervous.

Zack's story of his first encounter was not a typical doctor office visit, and he described the events that led him to the emergency room and his reactions. He did not truly understand what had happened or what was happening but reacted based on those around him. He described the scenario in this way:

Actually, if you want to hear, well, the amazing part of this was that was 4 years ago that they figured all this out. And before all this happened was when I was playing football. And before all this happened, trying to keep up with my teammates, and then I collapsed. I was going up and down a hill, and I had kind of bad asthma back then, and so you know, I was kind of used to it. And I took an inhaler, but the inhaler did not work. And then I came to the hospital, and they took my blood, and they kept me in there almost all night long and came back, and the results were this. And it was really hard, and all I can think about this was that probably things are getting hard for a reason, either to change yourself or change somebody else or, [Pause] help somebody. I think it was a doctor. I can't remember all the details; I didn't know what to think. I kind of remember what I was thinking at the time. I remember that I heard all that [pause], and I just kind of listened. It affected my mom, and she was crying, so I kind of figured it was pretty bad. So, I just wanted to make it so she wouldn't

cry no more, and so I tried to make it better. I hate to see people sad, and I love helping people.

For two of the females interviewed, the first visit made each realize that change was ahead and that past experiences of what they had been dealing with had come to fruition. Sharon, age 16, expressed her fear from 4 years before--of news she knew was eventually coming.

Ok, I remember I was kind of scared because I didn't know what to expect. Because I knew I was overweight and everything. And I knew that I was going to have to lose weight, and it kind of scared me that I was going to have to lose weight. To lose so much weight because, to be honest, I really hated to exercise. I mean really I did. Sometimes I wish I didn't have to do it all the time, but I knew that, if I was going to lose the weight and get healthier, I had to do something. And it wasn't just about exercising, I mean I had to change my lifestyle; I had to eat healthier too. And he, well, he told me that there were several things that I could still eat that I really do like, but it's hard that I can't eat a lot of the things that I like, like noodles. I love noodles.

Although Sharon was anxious about changes, Ann, age 16, was glad a diagnosis was finalized. She shared her thoughts of that first meeting.

That was . . . that was years ago. Well, I mean I'm not that old. I mean I'm in 11th grade now, and I was like probably like in 4th or 5th grade when I found out I had a problem with my thyroid. And, um, I remember the first time coming to the doctor, and I thought nothing was wrong with me. I just thought I overate. I mean, you know, I didn't think anything was really horribly wrong with me. And then we came because it was my grandma who was like,

“You should go get her blood checked and tested and check her out just to see what was going on.” So we came, and we got blood-work, and I remember my mom called me and told me that my levels were just “out the ceiling,” like I remember, I think. I don’t remember what the exact number was, but it was like I don’t remember if it was my cholesterol or my insulin, but it was really high. I think it was like 600-it was scary-like very scary, and so we went. And of course, it was a long time ago so it’s not the same way that I remember it, not detailed, but she just told me that I was going to have to take a pill (Synthroid) for the rest of my life. I mean I was just excited that there was something that I had a reason why like I couldn’t lose weight.

The memories of the first visit and the descriptions of what the endocrinologist discussed were more detailed with older children as compared to the younger children. After describing the first encounter, each child described what occurred in the 3 or 4 years that followed that first visit.

Positive Lifestyle Changes

Changes in Eating: “So I had to start eating healthier.”

As children left out of the physician office and returned to their own environments, the suggestions and advice regarding diet and activity given by the physicians became the focus of reality. These changes in lifestyle can be difficult and challenging, and often individuals do not know where to begin. Further, individuals may not be ready to make so many changes that seem so overwhelming. Susie, age 12, discussed how she contemplated choices:

Well, I felt like I when I go to school you know like ice cream, strawberry milk. It hurts cause I know, you know you don’t need to eat this. But, I have money, so why not get it? But then I have to sit down and think about, do you want to be in the same situation

everybody else is in? It's hard to start off young, and you have to change this whole thing all around. And a lot of cries and talks and meetings with the nutrition things and the computer stuff. It was rough. It was a rough 2 to 3 years. I got past it, and I know where I am now, I know where I need to be, I know where I need to stay. So I'm really not bummed out about them trying to eat candy and stuff in front of me all the time because I know I can have it like once a week or something, every 7 days, yeah.

For many children, they experienced similar problems with the school cafeteria choices, friends' comments, and boredom. Each of these elements can play a key role in inhibiting choices. Karen, age 14, and Katie, age 13, relayed how they confronted those temptations.

Karen stated:

I was like, no, I'm going to eat a salad or something' cause once I started eating salads when I was in 6th grade and then I quit in my 8th grade year. I started eating salads at school, and they were like "Are you going on a diet?" and I was like, "No, I just want to eat this" because I didn't want no pizza or other things not cooked right.

Katie described what happens when she is bored.

There are some days where I'm like, oh, my gosh, I would really love to have some ice cream right now. But then I think I don't really need it and what's the point in eating it? you know. . . If I'm just bored and I want something to eat, then I'll be just like forget it. But if I'm like actually hungry and want a little snack, then I'll get a granola bar or an apple or something cause I like apples.

Creating the eating habits to become healthier often requires enlisting the help of parents and other people around the child. Some children were able to accomplish changed habits on

their own, and they presented a picture as if it happened overnight, like Zack and Sharon, both age 16. Zack stated,

Honestly, I just kind of slid right through it. Because I figured it was going to be. Pretty much my diet changed to be just different, like I pretty much quit eating meat and just chicken. I eat bacon maybe once a week because my mom will make breakfast once a week and it's really good!

Sharon thought about the process ahead of time and planned how she would make the changes. She described her first steps that involved making changes.

Well, the first thing I started to do was buy healthier foods because I figured it wasn't going to do any good to start a workout regimen and eat unhealthy because it would just contradict what I was trying to do. And so I started buying, well, at first, before I came here, I was told I would have to be on a low fat diet. And when I came here it was a "low carb" diet. And so all the low fat stuff I had, I had to get rid of that, like peanut butter. Well, peanut butter doesn't have that much in it, and I'm not that big of a fan of it. So I just went and I had to buy all the low carb stuff that I could find and cut down on the, you know, noodles and stuff like that, that are highly carbonated. And it wasn't a year or so ago that I found the noodles that only have 5 net carbs. And so I can have those every once in a while, but not like regular noodles.

Most people making dietary and activity changes need the help of others. Two of the children interviewed described how their families changed and how parents became involved in the process. Mary, age 16, described the changes in the household purchases and mealtimes.

We stopped eating a lot of junk food and stopped going out to restaurants' cause used to, we would like, if my mom didn't feel like cooking, we would just order pizza, you know, or whatever the easy thing was. And now my mom cooks dinner almost every night and don't go out to eat that much. We eat a lot healthier, like we don't eat chips and stuff like that, and we eat a lot healthier now.

Katie, age 13, stated,

"I used to never eat breakfast and then my mom was like, 'You know it would be a lot healthier if you eat three meals a day, then you wouldn't snack so much.' Because it used to be that, if I didn't eat breakfast, I would snack literally like all day long, and now that I eat breakfast, I get filled up so I don't want to snack all day long."

Joe, age 12, stated, "It helped when my parents went on *Weight Watchers*. All the junk left the house."

While most received help from parents, one child needed advice and encouragement from her physician to get started. The doctor informed the child as to why making healthier food choices may help prevent disease. Susie, almost age 12, recalled,

I had a lot of time to change my eating habits. I used to eat because, you know, kids pretty much eat unless the parents have strict eating rules. They pretty much eat whatever you want to, whenever they want to, cause you know. One thing is, when my mom found out she was diabetic, I had to change my eating habits a lot. And the doctor told me that if I don't, I could have a chance to be in the same situation that my mom is in. So I had to start eating healthier. Stop drinking pop. I don't drink pop at all anymore. Maybe every now and then, MelloYellow or Mountain Dew, but mainly I have bottled water or a cup of water.

Ann described how her visits with the dietitian and the instruction she received at classes were helpful, but did not provide the motivation she needed. Ann's reactions to a more recent formal and structured weight loss program were twofold: First, she may have been more ready developmentally to accept taking the initiative to make the changes that were suggested; and second, she may have needed weekly monitoring and structured meal patterns as opposed to making small changes one step at a time, which is what is advised and used more often with children and families.

Changes in Activity: "I did something good for myself."

Changes in eating habits were not the only lifestyle change accomplished. More often children reflected upon changes in activity and how they had developed a specific exercise routine and dedicated a specific amount of time spent to exercise or sports. In fact, sports and enjoying outside play were described throughout each interview. Karen expressed how she learned to incorporate walking into her daily routine and her philosophy of exercise:

Like, um, I go to the Y. I walk to the Y, and I get on the treadmill or do regular exercises, exercising like sit-ups, push-ups and then I walk back home. Like a long walk, to the Y and my house, it's like over a mile, a long walk, but it's a good walk. Because I got the habit of walking at school. Like I had gym, class and I didn't want to run, and my gym teacher taught me how to walk faster, and ever since then I started walking, walking like everyday. I walk like anywhere I want to go, walking to my friend's house, or walking up and down the end of the block or something. So that's what I've been basically doing, like almost everyday. Or if I want to walk to the park, then I go just walk to the park and then get on the swings and then go home. I go outside and play more often. And like I didn't want to, but

now I go outside and play with my friends. My friends, we'll walk down to the park and play, and then we'll walk back home, or then we'll go work out. Like yesterday, I was working out with my friends, and we worked out for about an hour. And the day before, me and my other friend, we worked out for 2 hours total. We worked out playing a little bit of basketball and I just like playing outside.

Debbie and Susie shared how they also like to play outside with friends and find activities that are convenient. Debbie stated,

Well, during the summer, I swim. And like during the winter, I live like by really close friends in the neighborhood, and I always have friends over like my really best friend, and we all play like hide-n-go seek. It sounds really kiddish but and, cause we have a really big neighborhood.

Susie also found how it was easier to get outside and play; Susie described her previous routine and how it changed.

I used to always come home from school, get out my homework, get on the couch, and watch TV all day and eat. I had to start going out with my friends and running around and playing and getting more active with sports and stuff. We love to travel, and I'm pretty much you know [pause]. I love to go to the Smoky Mountains and just walk around and stuff. I really, yeah, I really have a different, like I care about myself a lot more.

Some children evidently needed more structure to their activity program. Sharon described her workout regime as

Like for me I didn't consider something like softball fun, but I didn't play enough of it to be exercise. . . . After I made the food changes, then I started my exercise, and I would do

that, back then, probably 20-25 minutes a day. But then as the years progressed and everything, it's up to an hour now, and I have a lot of muscle toning exercises and then cardio-stuff like that. And on the weekends that I don't workout because I workout Monday through Friday, and I can eat. Like, I can eat my meals, and it doesn't affect me. Because I was afraid that if I didn't work out that I might gain weight and everything. But it doesn't happen, and I guess your body gets accustomed to the changes, and I guess it does boost your metabolism after a while when you've done it for so long, and it's a good thing.

Katie also needed that structure. She stated,

Well, whenever I go to the gym (and this is going to sound super lame) but whatever. Whenever I go the gym, I'll run and I'll do some weight training, but I don't, really don't like doing weight training that much, but I'll do some weight training. And I'll go back into the cardio room. And when I get out, I just feel so good about myself because I know that I did something good for myself and usually I am at the gym for about an hour and that, and whenever I get out I am like "yes." You know I did something good for myself, and it really does makes you feel good.

All of the children interviewed mentioned how exercise became a part of their daily routine. Katie, Sharon, Mary, and Becky described in detail the structure of the exercise programs that they followed, stating that they were exercising 4-5 times per week with a combined cardiovascular and strength training regime. This would compare with similar exercise routines prescribed in a structured program. Four of the children (Joe, Karen, Debbie, and Susie) shared that exercise was built into their daily routine. The children described less structure but

also stated how they focused on going outside and playing as opposed to previous habits of coming home, sitting on the couch, and watching TV.

Another important concept that emerged was the ability to know signs of relapse and overcome problems or problem solve. Becky shared how she realized that she had played around and did not follow the suggested plan. As a result, her symptoms of PCOS and insulin resistance became worse. She became more consistent and added intense exercise to her daily routine. Ann created her own motivation as she became more curious about the diabetes and wanted to understand the disease. She spoke about her curiosity as she woke up and decided to learn about disease on the Internet. She was astounded by some of the blogs she read. Other individuals' insights and details of day-to-day experiences encouraged Ann to become more focused on making behavioral changes.

Sharon described how she re-evaluated her menu and exercise routine so she no longer needed to work out every day to maintain or lose weight. Sharon's experience was very powerful as it was her own determination that precipitated her parents becoming involved. Sharon also described that her grandmother was instrumental in helping her become and stay motivated. Her workouts were done at her grandmother's house, and from Sharon's description and accounts of what progressed through the years, she often stayed with her grandmother for a month or longer. Sharon did not share the reasons she stayed with her grandmother, although she did mention that her father, a firefighter, traveled to different regions in that position. Also, from the picture Sharon described, her family shared property with her grandmother, aunt, and uncle. She lived up the hill from her parents, which provided the opportunity to stay with her grandmother often. Sharon was able to identify the pitfalls in her environment that led to unhealthy habits, and as she

said, she “had to get everyone on board.” As the children told their stories about how they were able to make lifestyle changes, they expressed what it meant to be able to prevent disease and improve how they felt physically. Katie stated she continues to remind herself and keep with activity as well as allow “treats” on occasion, and Ann shared how she feels now that she has the knowledge about how to balance her intake and will continue to use monitoring as a lifetime evaluation tool.

Social Support of Family: “Mom is my rock, and I shoot hoops with Dad.”

Attempting to stay on track with lifestyle changes, especially eating foods that most friends may not eat or finding ways to stay active, can be difficult during the “tween” and “teen” years. The children’s understanding of the environment around them and who was supportive during the day-to-day trials and events was of importance. Each child spoke of who was most supportive, frequently mentioning mother’s support followed by their father’s support. Many children spoke also of friends who became involved. More often they spoke about how friendships motivated and encouraged them. Physicians and other community resource groups were acknowledged, and several children stressed how feedback from their doctor increased compliance.

When speaking about making changes in eating and activity, most often, children described how their relationship with their mother grounded them into staying on track. Zack, age 16, described how his mother is always there for him.

The one who supported me through this was my mom, and I love her to death, and I thank her for that. But that she is pretty much the only one who has supported me the whole way through that. My parents are divorced, and it was pretty much after they got divorced that

they figured all this out. I went through some hard times, and you know they figured out this so it got even harder. I trust [pause] always asking help from my mother. There are always times when she couldn't, but she tried her hardest and that helped.

Katie, age 13, and Ann, age 16, both described their mothers as great role models. Ann stated her mother is "the one who is her rock." Both girls emphasized how each mother reminded them not to give up and that they could overcome the obstacles they faced as they were young and had more to do in life. Becky described her mother in a jovial way and imitated her mother as she would constantly tell her and tease her about her clothes getting too big. Stating that her mother said, "You are getting on my nerves cause you're losing weight."

Along with the support of mothers, children also stated how fathers became involved. Joe, age 12, shared how he and his dad keep active. Joe stated, "And I'm not doing karate anymore. I'm playing basketball outside, [pause] me and my dad shoot hoops." Mary emphasized how her dad was a key figure in the initial days of beginning to exercise.

That's when we started the whole exercise program. We actually did one through the YMCA called "Strong Kids" where it was twice a week, and then my Dad would take us three to four times a week. So we were working out about four to five times a week for about an hour or an hour and a half for the whole 11 months until then-so we could start heading it off so it wouldn't get worse.

Although most families were described as being very supportive, on occasion, there were times when families were not be as supportive as the child needed. Several children became frustrated and angry because there appeared to be little support or cooperation with helping them achieve goals. Sharon described her experience with her parents and other family members:

Then I had to get my family along with it too because it was really hard for me to have to say, “Yeah, I can’t really eat this,” but then, if they had it made me really want it. So especially if it was something I like. So you can’t go get pizza every time you want it because I can’t have it, and I know that’s a bad thing, but I felt that everybody should have to help me out especially at the age I was. Especially because I was 12 years old when I started and food was just my enemy [grins] because it’s hard, I mean I don’t know. I don’t think I am a comfort eater, I am just an eater. When I was little, my family they would eat at a different time, and whenever they would eat, then I would eat too, and then they would say, “Do you want a cookie?” I would say, “Sure I’ll take a cookie.” And like now, I mean I can have those things, but just not all the time. And if I could have not given in and given in to the temptation of all the good stuff. I really wish I had because it would have been so much better for me and probably a lot better for everybody else too. I mean, but I just wish, I would have because it’s kind of hard when you’re around a lot kids who eat. And it’s OK, and then they don’t. They always ate pretty much whatever they wanted, and they, my mamma, she was a very small person and she didn’t gain much weight, and she was always constantly doing something. My mom and dad, they, it didn’t affect them as much because they weren’t the ones having to be on the diet. They weren’t the ones having to lose all the weight and everything. But eventually, I think that they started to see that it really was going to be best for me if they tried to cut down on some of the sweet stuff and got more healthier foods.

Karen expressed how she felt she experienced a double standard in the context of her family.

But at my house, my mom will tell me to look up what diabetes means and then I just get mad and frustrated. . . .But I just can't help it because, like my brother, he eats a lot of sweets. So I think that my mom, she tries to tell everybody that we should eat healthy in the house, but nobody eats healthy but me. And my dad--my stepdad, he's diabetic also, and he was diagnosed with it last year, and my mom was like "Everybody's going on a diet" so everybody went on a diet for like 2 days.

Supportive Friendships: "We help each other out."

Parents were mentioned as the most supportive throughout the years the children had been changing lifestyle habits. However, friends and other significant people in their environments also were mentioned as instrumental people as they helped each child achieve his or her goals. All of the children interviewed shared experiences that they had with friends and friendships over the past 3 years. Zack, Becky, Sharon, and Mary all spoke about how the friendship with one person that was made prior to diagnosis continued during their transition from middle school to high school. They stressed that these same friends provided emotional support as they made changes in their lifestyle. Mary shared how her friend used to come over and get her to exercise, and now those roles have reversed. Mary talked about how her friend encouraged her to exercise.

And my friend then, too, at the time. She was kind of chubby. Not as bad as me but we would or she would call me up and, "OK, we're going to work out. We're coming to get you." And then I'd be, "Oh, don't." But then she was there and I'd be "no, sorry" but she would kind of force me into it to be honest with you. But I really appreciate it now, but then, but now, I really appreciate the fact that she kind of pushed me into and kept me going.

Becky and Sharon shared how their friends were extremely supportive, always there for them. Becky's friend, Brenda, was the person who pointed out her weight loss and complimented her success often. Sharon had a similar friendship with Nancy, who also needed to lose some weight. More importantly, Sharon mentioned how Nancy was always there for her; she could tell her anything, and she helped her through several periods of transition and stress. Sharon described her friendship with Nancy,

Well, her and me have been friends since 6th grade. She has got this attitude that, whenever you are around her, you can't help but smile. She is just so funny. She's got--she's a really great friend. And she has always been there for me, and recently though, oh, about 7, well actually 8 months ago, my mamma was killed in a car accident. And she came, and whenever she comes to my house or I'm upset or something, like that she is always right there for me. She is the only person I have known that I can talk to for two to three hours at a time, and I hate talking to the phone. Whenever my mom will call someone, or me, I am usually on there a minute and a half, and then I am done. You know, I mean, I hate talking on the phone, but I can talk to her forever. She just understands, and we were supposed to lose weight together, but she wasn't as big as I was, but she was big enough. For her to lose some weight and get into better shape, but that never did happen.

As Sharon recalled how she had a strong friendship that has helped her during the last 4 years, Becky also shared how her friend Brenda was so supportive,

Umm [long pause], well, one of my friend's, Brenda. Um, I've known her since, well, like we've been friends since like 5th grade, and she noticed the weight loss. Like at Band Camp we rode together and we see each other almost like everyday. So she noticed it. And besides

seeing me out of my loose clothes towards school--like she saw a difference. Well, she said, "Like are you losing weight?" Well because, like for me, like, I guess, I wanted to have a confident answer and say "Yes" I am, but, umm she's like, "Are you losing weight"? And, I said, "Yes" and she said, "Well, like, you look really good." I go, "Thanks!" (Both laugh).

How friends were supportive varied to some extent. The children who were in middle school spoke of their friends, not in the same emotional context but in terms of how important it was to feel they belonged. When Mary, Joe, Debbie, and Susie spoke of friends and how they hang out, the essence they portrayed was that the relationships were an important part of who they were becoming and played a key role in feeling like they belonged to a group. Sometimes individuals became friends because of a common issue or problem; Susie has friends who have Type I diabetes. Her friendship and ties with them are slightly different. Susie spoke of how they help each other by explaining the complications of diabetes to each other and observing each other's habits so they can help each other. Susie explained how friends help each other.

She needs to follow me. I need to follow her. We need to help each other. I give her some advice, what I do. Exercise and eat right, have good self-esteem about yourself, don't stop taking your medicine like I did, don't try to get sick like I did. I'm lucky that I didn't get sick, but now that's she's diabetic and if she doesn't take her insulin and doesn't take her medicine, she can get very sick and ill. Just take your medicine and take care of yourself before you start taking care of everybody else. Don't worry about anything else, be what you need to be, and stuff. We help each other out.

Susie also described her friendship with a boy who is a friend of the family, and they see the same endocrinologist. As she recalled the conversation she shared with her friend, she spoke of

how he helped her gain trust and respect for her doctor. Her friend's advice and understanding of how the physician helps them helped Susie understand and respect the advice given at office visits. They support each other and share what they hear and learn when they see their endocrinologist. "My friend, William, I didn't know it, but he has Type I diabetes, the same type as my other friend who has the nutrition book and stuff. He talked to me too! He said 'Susie, our doctor, he's a good doctor, he's worked with a lot of people'."

Social support also comes from the community and doctor offices. Two children emphasized how their physician was a source of support. Susie shared that she feels support from her doctor, even if she has not done as well as she would like. She described her last doctor visit as

My weight-I don't like my weight. Half the time I gain ½ a pound and that really gets to me. But my doctor he really helped me out. He really, he's really nice. He understands what I'm going through so then he doesn't like, "Susie. you shouldn't did this." He helps me out, he talks to me about it, you know. Good doctor, good parents, good family, good friends.

The physician also can be an instrumental influence on how children experience motivation and support. Becky explained how her physician reacted to her weight loss.

Well, my doctor maybe, she was just so shocked with that much weight that I lost in 6 months. I mean, well, it shocked her. Because like she had not seen the difference because she had shown me a scale from, well, I don't know, how far back, but a scale. And how it had brung back up to how it had been brung back down. I mean so she was probably one of the persons or one of the people that had, umm, like made it like known to me and stuck in my head.

Many organizations offer classes or programs that are meant to help educate and motivate individuals to lose weight or prevent disease. Mary spoke of her experience at the YMCA.

That's when we started the whole exercise program, we actually did one through the YMCA. We actually did a program called "Strong Kids" where it was twice a week, and then my Dad would take us 3-4 times a week. And the trainer that I had at the YMCA was like insanely awesome. Because everything was fun with her but it was definitely a hard-core work. And if I was having problems, like in school or with friends, I could call her. And we could talk about it, and we could just hang out, and she was pretty razz.

Mary also spoke about her focus on how she was motivated to continue to improve herself and implement other lifestyle changes after attending camp. Mary described how camp helped her focus.

Actually, yeah, because, the summer, the summer before last, which was I was still on the Metformin and had some weight issues, and I went to the Girl Scout camp-Camp Tanasi. And I was a riding instructor for 3 or 4 weeks, I don't remember. And that was, I don't know, and there is so much work involved with having a horse and taking care of a horse and riding and all that. And you can't really be out of shape and you really dedicate yourself to that. And this was 15 horses, and that really kick-started me into, when I came back getting really involved with my horse.

Support does not always come directly from people one knows very well. Two of the children shared how people in the community and individuals they see on a regular basis have made comments that are motivating and encouraging. Sharon described people at church.

I go to church, and every time I go it's just like they make me feel amazing. I mean they are always complimenting me on my weight loss and how good I look and all these elderly people. I am the only youth in my church, and we used to have a large youth group . . . When I go into my pharmacy, there is this one pharmacist in there, and she compliments me all the time, and I don't even know her or barely know her. I never had a conversation with her, I have only said hello or good-bye or something like that, and she'll tell me every time I come in how good I look and how much weight I've lost, and she is so nice. Especially when there are a lot of people around, it kind of makes me embarrassed that they are hearing that I lost so much weight. Because it makes me feel good that people do recognize the things that you do.

Becky also described how she received compliments from previous teachers when she visited her sister at school and how that had been encouraging.

Many of the young girls described how relationships with boys had been a major turning point for them. Some alluded to the fact that they have a better self-image and, in turn, now have boyfriends or vice-versa. Katie described how her friendships have led to feeling better about herself.

So I didn't have any friends and I didn't like going out, but I have gotten a little older and I go out with my friends all the time and I do stuff with them. And I finally have a boyfriend now. And you know, and it's getting a lot better and--But no, people are not mean to me anymore. I'm glad that I have a lot more friends now. And I'm a lot more social, and my friends tell me all the time how pretty they think I am, and that really helps me. And my boyfriend, I've been with him for about a month and a couple of weeks now, and he's

helped me a lot too. Because every, like almost everyday, I'll be like "Oh, my gosh, I am so ugly" because I just love when people telling me I'm pretty. [*Laughs*]. But I'll say, "Oh, my gosh, I am so ugly", but he's like "No, you are so gorgeous." You really don't understand. And people tell me that a lot, and I don't say that to brag about it, but it just makes me happy 'cause used to people would never say that to me.

Becky has feelings that are similar to Katie's feelings, but she also shared how she has informed her boyfriend about her past.

I'm happier, I have a boyfriend now. I feel really good--it just makes me feel so much better It makes me feel better about myself. He's very nice, he, I told him about everything because it was kind of hard not to bring that part back out. Because it was like a part when I was not as happy as much. Um, he tells me I'm beautiful all the time and makes me feel better than I already feel. Um, and he's just really nice.

Becky continued to tell how she has confided in her boyfriend about her past weight problem and current insulin resistance.

I mean it was easy, just we've been together for about 5 months, and so I mean like we had a friendship type thing. So, because like, I really didn't tell anybody except for one of my best friends. I was embarrassed. Um, now I can a little bit more, it was easiest to bring it out more now that I have changed, and it's changed me as a person. Because I am a lot happier and I feel more like confident when I do stuff and like people at school, like they compliment me more, and that feels good!

Each participant described how he or she understood the support system around them. They shared how family, primarily mothers, provided the most encouragement and support.

They also provided examples of how families have become involved in helping them to make healthier choices and purchases and participate in activities with them to help them stay active. Some children reflected on how certain friends, teachers, and community resources had aided them and provided support (both emotionally and in regard to offering more concrete resources). Several children identified their physician as a source of support. How children perceived the support system around them and how this helped them achieve goals towards better health was of importance.

Psychosocial Environment: “You have to live with it.”

The day-to-day emotional and psychological issues that overweight children and children with health problems face often differ from those of children of normal weight and without health complications. The children shared their feelings about some of the problems they faced during the time they began trying to make changes and learning about their health problems. Three children spoke of how they researched diabetes either in books that parents had or on the Internet. Ann created her own motivation as she became more curious about diabetes and wanted to understand the disease. She spoke about her curiosity as she woke up one night and decided to learn about disease on the Internet. Other individuals’ insights and details of day-to-day experiences encouraged Ann to become more focused on making behavioral changes. Ann recalled waking up in the middle of the night as she worried.

I don’t know, it was really weird. I was just lying in bed, and it was like the first night I had like thought about everything. And we had had a long meeting with the doctor and about everything. And I don’t know, I’m the type of person that you’ll tell something to, but I want to know more about it. Like I don’t feel like I’ve known enough about a subject. And

so I was just laying there, and I got up in the middle of the night and just went to the computer . . . But I want to know more about this and see what other people have said about it. Which is kind of funny because you wouldn't expect a 4th grader to want to do something like that.

There was a bunch of stuff. I remember there were . . . in particular there was a message board, and I remember, I don't remember the exact thing, but there was this girl that said that she just . . . she was just always in pain. And said that she just had to take so many shots, and so many pills, and per day . . . because I take three pills a day. And I think that's a lot. I don't think any kid my age should have to take that many pills, or take three pills a day. But I mean, obviously, I have to, and I don't mind anymore because I've done it for so long. But just . . . the stuff she's gone through and the stuff she has to do. Because she could only eat a certain amount of sugar and because of her blood sugar compared to what I was eating at the time. And so I was like, I don't know how I could do that. And she couldn't go out to eat without her nutrition facts and without having her shots or else she could die. And I was just, I was amazed by that entire story. It really opened a lot. It really opened my eyes to a lot of things.

Susie's and Karen's parents encouraged them to understand more about the disease. As many of the children revealed how they made lifestyle changes and dealt with some of the barriers, their scenarios and thoughts demonstrated how they moved through the stages of change. Susie, Ann, Karen, and Becky all provided examples of how they would move from the contemplation stage, of wanting to make changes, but also were ambivalent in deciding what to do next. Susie spoke of the cries and the talks she would have and how she would have difficult times. Susie gave

details of how her mother reminded her to review the materials in the folder from the classes and read about diabetes. Susie's mother also reminded Susie about the consequences of diabetes (obtaining the knowledge) that provided the motivation needed at the time. Susie, in turn, responded by wanting to continue to make better choices. Karen shared how she felt after her mom encouraged her to understand what was going on in her body and how she reacted.

Like, she would tell me to read it, but I won't read it. And I just go into my room, and I'll think about what everybody has told me. And told me to watch out, look out for sugars and because you could go into a coma and you will die and then I'll get scared and I'll start crying. And then I'll think about what they have said, and then when I think about it, I'll be like I am going to turn my life around.

Susie explained how she has realized that it is up to her to take care of herself. She spoke about how she reacts to her friend who has Type I diabetes or has some low blood sugar reactions. She is also spoke about how she self-coaches.

Face it maybe--face the truth--get over it. You have to live with it. As long as you have it take care of it, make sure it doesn't happen again. 'Cause me and my friend, we don't really talk about like, "*My mom did this, my mom did that. She won't let me eat this, she won't let me have that, umm.*" They get really upset. "*Why do I have this? Why does it have to be me, you know?*" I'm like, well, maybe-I don't want to say it's your fault, but maybe you should have thought about it longer because I remember she'd always yells at her mom like "*It's not my fault I have this.*" I'm like, well maybe it isn't, but maybe it is...face the fact that maybe it is your fault and stop blaming it on your parents, you know. Because your parents can only do so much and you have to take responsibility for yourself. They can only tell you

and help you so very much to the point they get tired of telling you to do something that you have to get over and grow up and do it yourself. Because when you get older and you have nobody there, you have to take care of yourself. Face it . . . face reality . . . you have to take care of your body.

Susie continued,

I have a different perspective on my body because you have to take care of it because it takes care of you. You know, I really have to respect it as much as it respects me.--

It didn't seem fair at first but now I know why- it didn't seem fair, But I know it's fair because my doctors aren't going to hurt me and they want to help me. They want me to live longer. They don't want me to be sticking myself with a needle for the rest of my life. They want me to be happy, be a normal little girl and have fun, like that. (*big sigh*)

Teasing and Bullying:

"That's not the way you should be talked to or the way you should be treated."

Several children experienced forms of teasing and being bullied about their weight and health problems. They recalled scenarios in the lunchroom, supermarket, and school classrooms.

Katie stated how it was "inevitable."

Well--um you know, whenever I felt bad and, you know, and--um--depressed about it because at school kids were just, people are mean. You know, and it just made me feel really bad, and whenever I would want to just sit there on the couch.

Ann has had several confrontations about her weight. She described in detail an experience she had with friends, who backstabbed and bullied her.

Oh gosh no, oh, [pause], I've been through so many, like, I've been teased. I've been like, I was always a really chunky kid since I was little. I was always like the bigger person in my class and so, but I've always been an outspoken person. I may have had low self-esteem, but I was the kind of person that would always let you know what I'm thinking, and I know there's people who don't like that and there's always the mean girl wherever you go. So, umm, I'm trying to think, though, there was this one incident I remember that, umm, these girls that, I've actually talked to them since then but, and it's really funny, they just, they were horrible to me. [Interviewer: and what grade was this?] This was 5th grade.

[Interviewer: Ok] And I remember because I used my aoi and my instant messenger (IM), and it was before "My Space" and everything like that, and there's profiles. There is like Your Profile and I don't even know what happened, like I barely talked. Like I used to be good friends with these girls. They were in my grade; they came to my birthday parties, like we were friends. And I remember one day, I got home and I got on IM, and they had changed everything. Like they hacked on and they just, they changed my screen name and they put like "Ann's A FAT A" and they changed my profile and they said I'll never get a guy, and they did just horrible stuff and stuff like you should never say to anybody. So, I found out it was them. and then my mom was just so tore up about it and she just, like I was crushed and I would not leave my room."

Ann described further how she dealt with this incident and how she became a stronger individual.

And I remember my mom called her parents, and it was just like this big, like butting heads thing, and I remember that she came up to me. I think it was like 2 weeks after that and she

was like “ANN [*sing-song-like voice*], she was like “I have to say I’m sorry blah blah blah blah blah, . . .” and I was just, remember it was so funny, and I remember I was like, well I’m not going to say her name, but I’ll call her Rebecca--Ok, so Rebecca came up to me and she was like “Ann, my mom said I had to say I was sorry da da da da da.” And I was like, “You know what, I thought you were my friend, you’re obviously not, and I don’t need your apologies. I may not be the skinniest person and may not be the most best looking person, but I know that I have a better heart than you do.” At this moment right now, I was like I can’t believe I said that, I told this to my mom and she was just, she was real surprised this came out of my mouth--she was like that sounded so mature. And I was like I was like um; “I would never say that to a person. Do you know how much that hurt me?” I was like, “ I thought you were my friend. I would never do anything like this to you.” She wouldn’t say anything; she just looked at me like she refused to say anything. And I remember I was like, I was like, “I hope . . . I hope this never happens to you so you don’t have to go through the same pain that I went through” and stuff like that, and she just walked away. And you know, I was just like, “I don’t care,” and I talked to my mom and my mom said, “You know there’s always going to be people out there like.” I was like, “So I guess like, stuff happens like that.”

Ann recalled this event as if it was yesterday, and she continued to describe her feelings and how she feels about herself now as a result of this incident.

I would never take any of it back because obviously it’s given me a thick skin and it’s helped me be the person I am today, you know. I think teasing is just a part of life, there’s no

fighting it. It just makes you a stronger person, I think. So, because I've been teased a lot, like, throughout the years I've been called names when I've walked by people.

Ann also shared another experience with teasing and bullying.

I remember another time like I was in the cafeteria and my mom doesn't know this. I got milk thrown at me. Yeah, and people they would call me "Cow," and they would throw a milk thing at me. And it was horrible, and that was, and that was mainly the years when the teasing was really bad, 5th through 7th grade. That was just when it was really bad. I remember in 6th grade I never really wanted to go to school. Seventh grade. Seventh grade I lost all my friends. I did. I lost all my friends. It was probably the most depressing year. The people I thought were my friends obviously weren't so, but I don't know.

Ann was not alone, although Ann's experiences do seem more problematic than others. Becky and Karen also experienced forms of teasing. Becky described her experiences of how teasing continues to happen in high school.

I mean, even in high school, people are very mean. They don't really care about other people themselves. I have had experiences where other people tear you down, and they say you're ugly or you're overweight, and when you hear that, it sticks in your head. Because you know you get compliments one day and then you have another person who doesn't like you that much tell you, you are ugly and overweight. I mean it tears you down even if it's just that one person.

Becky continued with an example of how teasing happened in a supermarket.

Like if I am at school or in the grocery store and you hear somebody whisper behind your back. Like whenever you are overweight and in the food aisle and they make a comment like

“Why are you in the food aisle? Haven’t you eaten enough?” Like they make smart comments like that.

Karen also had similar experiences. Karen discussed how she would give out her Halloween candy to classmates: “I’ll pass out to everybody and I guess’ cause I was so overweight and they are pointing at me, like maybe she has diabetes.” Karen also described how classmates responded to overweight peers.

And I’ll start feeling bad inside. And they saw this big girl on TV, and they thought, they were like, “We are going to pick on Karen because she is big as her”. And I guess because I was overweight they just laugh and point at me and they are always pick on big people.

Susie also described how kids can be mean, and she stated her philosophy about others making fun.

But I know’ cause kids can be kids, and they will make fun of people, especially because with certain issues. Don’t worry about them, that’s not the way you should be talked to or the way you should be treated. Don’t worry about it. Just take your medicine, and take care of yourself before you, start taking care of everybody else. Don’t worry about anything else; be what you need to be, and stuff.

Ann’s story of teasing and bullying was the most dramatic example. How Ann dealt with the situation (i.e., withdrawal) and how she described her emotions (i.e., depressed and alone) would be expected. Ann described how she was able to find within herself the courage to speak to those who hurt her. Her accounts of how she managed to maintain her self-esteem are examples of her own resilience and ability to adjust psychologically. Mary, Becky, Karen, and Susie also mentioned teasing, but Becky and Karen were the only other individuals who provided examples

of teasing about weight and disease. When Becky and Karen reiterated these events, they shared how these individuals made them feel and how they kept those hurt feelings to themselves.

Becky's earlier descriptions of ways that people could tear others down were followed by her belief that many children already are very conscious and concerned about what others think and say about them. She thought that negative comments from peers impacted how one looks at self and created feelings of poor self-esteem and body image. Several girls discussed how they felt about themselves before losing weight and after they were diagnosed with insulin resistance. They referred mainly to how they disliked their bodies and, as a result, did not feel good about themselves. Katie, now 13, described how she felt initially, at about the age of 10 years.

Yeah, in like 4th, 5th, 6th grade [*somewhat laughing*] I really didn't have any friends, and you know I wasn't very social because that was the way I was- I mean I thought I was ugly and fat and so [*giggling and somewhat embarrassed*] and so I didn't have any friends. . . .

Yeah, I was really hard on myself' cause I would tell myself all the time, why can't I be like everybody else? You know, 'cause like they're pretty and skinny and stuff, and I wasn't.

Mary, now in high school, had similar feelings about herself, and she described her feelings when she was in middle school.

I had a lot of issues with that, and it made me mean and I didn't have a whole lot of friends. I don't know. I assumed that they were always talking about me and saying mean things about me. And I have a lot more self-esteem, and it's really helped like at school. Because it's no fun in high school when you're the outcast. I mean, when everybody had social things going on and you weren't invited or you didn't want to go because you were afraid to see people. Or like in the summer, my friend had a pool, and I wouldn't want to put a

swimsuit on to go to the pool. Stuff like that, . . . And then there's like gym--which was like a huge thing all through middle school. You had to dress out and it was like recreation shorts and a white shirt, and it was really uncomfortable because the locker room had no stalls or anything that you could isolate yourself to change. Because the vast majority of girls were very small, because I'm like a lot taller than most of my peers. It was slightly irritating, and I had a lot of issues with that, and I was very uncomfortable with it. And then this year, when I took gym, it was like a completely different thing. I could go and participate in all the things, and I didn't have to go "Oh gosh--I hope I don't look fat."

Becky, also in high school, reflected on her appearance and her changed self-perceptions, "Well, since 7th grade until now--I feel a lot better. Like I mean, I didn't feel like the prettiest girl in school. Umm, I mean like you couldn't pay me enough to wear a dress and like now I just love to wear dresses and you can't get me out of them [laughs]." Sharon described also how she is still trying to develop her own self-image and confidence. Sharon shared her experience of looking back at pictures of herself 4 years ago and how she felt then compared to now.

OK, this is actually interesting because when I was younger in elementary school, I knew I was large, but I didn't know how large until actually about a week ago. A week ago today actually, I was watching some old home videos, and I seen myself and it embarrassed me to watch those even though it was just me and my mom and a very close friend, and it embarrassed me so much. And I think when I was young, I didn't know I was that big, and it really didn't affect me that much mentally or emotionally, probably the way you would think. Because I probably had more self-esteem then than I have now. I guess because it was elementary school, and high school changes things, and I think I

felt more confident of myself then than I feel now. It's not that I don't lack confidence, it's not that I'm not proud of my accomplishments, it's just harder when you're in a school full of people who are constantly trying to find something, threatening you, or trying to belittle what you've done or accomplished and make themselves look better. It's trying to, I guess, to reverse itself in a way with me because I was obviously a lot more outgoing then than I am now. And I don't want to lie—but, um, looking back now I wish I could take that aspect of me, outgoing, and place it with who I am now.

As the children spoke about the changes they now feel, they also emphasized how these emotions and issues could be addressed in classes or office visits. Two children stated that most professionals, when working with children who are overweight, avoid the emotional aspects of dealing with these problems. Ann stated,

Well, also you know, besides talking about health and everything, also, like how they are right now emotionally. 'Cause obviously stuff like this, it kills people; I don't want to say it kills people's confidence, but throughout the years, it just eats away at people's confidence so just telling them that people like can relate to them and relate to their stories and just like . . . So I think to help out with that, like the psychological part of it, would help out a lot too.

Understanding Self and Developing Resilience: “Just get a rope and climb over it.”

Achieving goals and taking steps so that one can improve his or her health and overall well-being appeared to happen as a result of a kind of attitude shift and/or a sense of urgency. What occurred psychologically for each individual was significant. Many of the children interviewed were able to identify what changed for them and how they understood the developmental

process. Ann described how she feels now about her weight loss and how she was able to make that happen.

Oh, yeah! I've been losing weight, and I've lost the most weight that I have ever lost in my entire life, like I have almost lost 30 pounds, and that is like amazing for me. I've not probably been at--I'm like at 186-187 pounds, and I have not been at that weight since like 7th grade. So it's huge, I'm really proud of myself. Um, I guess I am like more, just more sure of myself. I guess I have become more confident. I don't know. I am more self-aware. I should say, [*pause*] I don't know, I guess I feel I have become a better person, just a stronger person because of it. I put a lot of things in perspective now 'cause everything could be worse. I guess just a better person in general, you know. Oh, it makes me feel great.

For some of the children, there was a spiritual component to how they overcame obstacles and continued to achieve goals. Susie discussed her ideas and thoughts.

All I know is that I am really happy about who I am. I love my friends and love my family, my parents. I love the people I am around everyday, and I really am, I'm really lucky because there are a lot of kids who don't get the chance to live like I do. I'm really lucky and I have to appreciate the fact that I am here and I'm living the way I am and I'm not in Africa starving to death [*pause*], yeah.--God is wanting me to be. He didn't make me perfect cause nobody is perfect, and so I got over it when kids talked about it and stuff, and I really just let it go. And that's just who I am, and I can't change it, and I'll have to live by it everyday. I can't worry about it. Everyday, and just got over it, and middle school is going to be really hard for me because it's a whole different world completely different than elementary so I guess I'll work with that [*anxious nervous laugh*].

Ann also provided how a religious context has helped her understand what has happened while making changes and becoming healthier. Ann shared a conversation between herself and a friend.

I don't remember this, but me and my friends we were like, my friend was reading her Bible one day, and it was really funny we were talking about like hard times and stuff, and she said something like--I can't remember the actual words of this was, but it something like "you have to go through the worst possible thing or just you have to be at your lowest point before you can get a blessing or before anything can get better." So, I think that if you go to that point and if things are so bad, turn out so bad, you can see what they are going through and see like the lowest point is, and you can take a step up and see how things can get better. But that's how I would think about it.

Many of the children were able to share experiences outside of health and fitness that they felt increased feelings of self-esteem and a sense of accomplishment. Most of these experiences were related to focusing on and giving to others. They also described how they have learned about themselves as they have changed both physically and emotionally. Zack started out by explaining how he sees himself.

Usually people my age are kind of a lot different than I am. They seem to be a lot more selfish and stuff like that. I don't, I really try my hardest not to be selfish. For me, I try to bring other people before me or come across me. I usually try to think of somebody else before me.

But Zack realized that he also had to be self-focused and work for himself. He expressed his thoughts and philosophy of accomplishing what he felt he needed to.

And the first thing that came to my mind was I thought, How am I going to get around this? And because in my past there was a lot of things that happened to me and got in my way but I always figured out a way to get around it. And so I just tried to figure out a way to get around a wall. And that's pretty hard, and there aren't no doors and no easy way around. And I had to kind of think that not every thing goes by in an easy way and you have to do some things on your own. So I kind of look around and get little better and think, How are you going to overcome this? and how to get avenge. First thing that comes to your mind is a wall, . . . Just a plain wall, . . . how do you get over this? Just get a rope and climb over it. Just get a rope, and that's pretty much what happened to me is just get a rope and climb over it and keep going. But keep a positive attitude and try your hardest to not let anything bring you down.

Ann and Sharon shared their experiences with volunteering with others and how this has helped them understand themselves. Experiences with others dealing with adversity changed their perceptions on their own problems. Ann shared how working in the Cancer unit at ETCH made her feel.

Like I was actually in the cancer ward, and this just warms my heart. There was this little girl and she was just having so much fun, and she was just the cutest thing ever, and I remember she kept having to go back and like I guess go to the doctor. And every time she would go, she would just get so upset, and she came up to me and she looked and she was gorgeous and she was just like *"Ann, please don't let them put the thingy in my arm."* Which I think she meant I.V., and it was just like her eyes and she was like *I don't want to go and it just completely just killed me. and then like her doctor came and she was like "I want to*

stay with the nice lady” and it warmed my heart. It was a mixture of just happiness and then I felt bad for them because they were little, and I felt bad for them and all that. I don’t know --just helping out and stuff like that just makes me feel great. Like I love giving back--that’s just, that’s just how I am.

Sharon worked with a group of special need students at her school. She shared her experiences and her future ambitions:

Because I work with special needs children at my school and with them you have to have a lot of patience, and I love every single child in that class. Actually, I probably am in there for my first class, and I probably will be in there twice as often for my second class instead of study hall. I just love being in there, they brighten my day, and it makes you feel like everything is possible. Being in there I think makes me feel like bubblier kind of attitude.

Sharon also relayed how she has continued to strive to be a better person.

They may not always be positive, but they are not always doing bad things, so and because think everybody has a tendency to be a little negative sometimes. I catch myself doing it, and I don’t want to be like that. And I catch myself judging people, and I don’t like to judge people. But I do that, and I ask for forgiveness, and I am really a churchgoer. And I was really brought up in church with my mamma, and I just recently I felt like I needed to go back because it was really important to her and to me, you know. So, I just try not to be negative about things and not to judge others.

Each child shared some understanding or displayed feelings about how he or she increased their self-esteem and how self-confidence had increased. They shared how they felt it was important to have positive self-esteem and confidence. Susie explained.

I want to be here, I want to be a spokesperson, I want to help the people out 'cause it's hectic [hectic] and gets really hard for starting off really young to having to change your whole routine to working habits and self-esteem. You really have to build that up and stuff so, it's really bad to have low self-esteem.

Katie shared also her version of how she has changed. "I can't help it because now I really do think that I am pretty, and I just have more self-confidence and my self-esteem has gotten a lot better." Ann was more focused on how she would like to use her experience to help others.

Like I'm the kind of person who likes to find out the good perspective of every situation, but I mean I guess after that, I mean, it was really bad. But all of that collectively together has made me the person I am today and has made me stronger. And that's why I like speaking out with other people, and I have confidence and like self-esteem. And letting them know that you're not the only one going through it and it's a part of life and it gets better.

Many of the children interviewed had made many changes, and several had reached ideal weight, did not require medication, and currently had normal insulin levels. They shared how they were going to continue on the path of staying healthy. Sharon is very motivated, and she shared her usual routine and her plan to keep on track with healthy eating and exercise.

I want to be healthy, and I want to do it the healthy way. Well, like when I'm working out, well, like this past week or this past month, I've been trying not weigh as much. I weigh every two weeks or once a month, and that way if I lose four pounds a month that will be fine, and if I lose 8 pounds, that will be OK too because I've been told that one to two pounds a week is healthy, So, either way, that will be healthy, and actually I did lose that

this past month and was very pleased even if it is something like that and, even if it's just 4 pounds, that is 4 more pounds.

And I noticed when I was taking my medicine it would kind of make me really, really, regular with my bowel movements [*laughs*]. And so it was a good thing that, even though I was working out, I couldn't keep food and doubling my weight loss. Needless to say, I am very proud of my weight loss, and usually I am very modest about things, but when you do something and you feel so great and, I don't know, it makes me feel so good that I did it, and I did it without you know any kind of surgery or diet pills or any of that stuff so [*laughs and smiles*] . . . Yeah, I have the strength to kind of, but I don't want to kind of, you know, limit me to go out and eat with friends every once in a while. So I think it is good to be able to do things like that. I also think it's healthy not to feel bad if you do something like that, and once in a while, it's not going to hurt. If you're not doing that all the time and you are regular with your workouts or you're doing that daily or you're doing that every three to four days, then you know. Every couple of days and I think it will help your overall feelings--psychologically' cause being overweight can take a psychological toll. Well,' cause people poke fun at you, and you don't feel like you want to feel so I think a lot of your psychological and mental and emotional feelings all kind of affect your health too when you're going through something like being overweight or underweight. Whatever it may be that a person is going through--that is what I think of healthy.

While Sharon had an overall plan, several children wanted to pursue sports and have found motivation to make a team or participate in sport activities. Becky lost weight by playing tennis,

and said she has been working hard to get better. Zack had a similar goal since he wanted to get back on the football team. He stated how he would like to get in shape.

Actually there is something down the street like this Kung Fu and that my mom and I saw, and I thought I might want to start that because it makes you exercise and stay in shape and learn something else. Because if anything happens in the future, it is good to have something behind you, and you know how to use that and if something bad happens, you got something behind you. Like martial arts, they try to teach something so that you can control you, like the personal you, kind of like the military does, and physically overcome yourself too, so I figured that would be good before I play football again.

While some focused on sports, others had a general focus on diet and exercise. Ann shared the process of how she hopes to move forward.

Well, I always have little goals for myself. But as of right now, like as with my whole health and everything, I just keep it to where it's at or get better. I mean right now I'm at probably at the best health that I've ever been at in my life. So whatever I can do to just keep myself healthy and keep me staying where I'm at, I'm fine. I, especially since my LA Weight loss is over, but I've learned so much from it that I can use it from this point to the rest of my life. Which I'm glad that I started it now because, since I'm 16 and I've learned all this stuff that I need now, like it's going to help me through my entire life. Like I'm always going to have that knowledge in the back of my head.

Susie's ideas were somewhat broader, but as she described her next steps in staying healthy, she also described what some of the motivations were behind her ideas and thoughts.

Like I said--you know the nutrition book, I don't want to overwork myself, I want to make sure I'm doing what I'm supposed to do- but I want to take more advantage than a lot of people will do that. I want to take that advantage of being healthy and staying healthy, healthy. [*Laughs and discusses her accent, "I have a horrible accent" . . .*]

She continued by saying.

Keep working, keep working on it, make it better. Do what I'm doing but maybe improve a little and make it better because I don't want to be in a wheelchair and get pushed around by a nurse all day, everyday, have to take insulin pretty much so stop being able to eat what I want. And just keep doing what I'm doing, and every now and then, I can eat something, like seven days pick one day out of that week and eat it--every other week. But I'm really glad because if I hadn't listened to my mom, my family. Him upstairs. My doctor, I wouldn't, you know. I wouldn't have the advantage I have and I wouldn't be able to eat what I eat now. If I wouldn't have listened to him, I wouldn't be where I am now.

Susie continued to describe her motivation to not to take pills.

Yes, they are so disgusting, and they have all these flavors, and it still tastes awful. Like kids' Tylenol and Motrin. I can take that, but because it's meant to taste like that. That other stuff not meant to be taken [*laughs*].

Karen mentioned how she is still really struggling with finding balance and getting weight off.

She described what her emphasis was now in relation to feeling better about her progress.

'Cause I'm having trouble losing this area right here [*grabs at stomach*] and it's just hard for me to lose a whole lot of weight. And the school year's coming up, and I'm not trying to get laughed at so I'm just trying to eat right, play right, you know, do anything I can

before my time is up because I don't want my time to be up. So, I'm trying to eat the right things and not lose nobody. 'Cause my cousin's dad, she lost him, no she lost her mom because she was a diabetic also, and she had to go to dialysis and she lost both her kidneys, she couldn't see. They took her off the machine, and then they brung her back to life, and then she died. That made me realize that she was looking out for me too in her death. So, I have a lot of people watching over me, they're like "Watch your weight." And I'm like OK--I'm going to watch my weight, and I am thinking in my mind, *I can do this, I can lose it.* I can. --So, I'm trying to lose it, trying my best.

As the children described how they wish to stay in shape, Becky emphasized the mental determination it takes and provided examples of how she has maintained her determination.

Becky stated.

I mean the biggest thing that I've learned while going through this whole thing is, you know, to never give up and to never say you quit. Because, like I said, I went in 7th grade, and she told me to lose weight and I was "Yeah, like whatever." And then I stopped taking my medicine, and she told me when I went back that I have PCOS and "You did not have this before and I'm thinking you played with it." And now I might be having some kind of *[pause]* I don't know what you call that disorder type, because I was playing and didn't take it seriously. I mean I could have quit there and been like, you know, it's not ever going to change, and I could have just stopped and been like, you know, "Oh well, if I have it" but just like never give up because even in school I strive to get perfect grades. I try to get perfect grades and never give up, even if the class is beating me. Keep going and at least get a B. Umm, I'm like the biggest for me was not to give up because I'd take my pills one day

and wait 3-4 days to take it. I mean, that's not healthy at all. I mean, so not to give up and to have some kind of motivator there, even if it's you. If it's your mom--just somebody to motivate you. And somebody that you know who will always be there. I mean, just have a constant person you can always talk to or the type of person who will lift you up even if you're not feeling so good or anything [*pause*]. Because now for me, before, when I went shopping, "No, ohh great, we're going shopping" and have to get the big clothes. But now I'm like, "OK, we're going shopping! [*Laughs*]. I get to get the cute clothes." At least now it is different, I mean, it used to I would not want to go shopping at all.

Summary

All the 10 children interviewed achieved physiological outcomes that represented decreasing risk of developing Type II diabetes. Several themes emerged as children were interviewed about how they progressed through stages of making changes in diet and activity. All children indicated that changes in diet and exercise were important. Many discussed how they had needed medications, and several of these children now no longer required these medications. Of importance was the understanding of disease. Children reported how they were motivated to pursue changes in lifestyle and maintain those habits they have created over the past years.

The behavioral changes that were made also were attributed to having support of family and friends. As the children spoke about how these changes occurred, they described how they progressed through the various stages of change. The individual behaviors were influenced by both internal and external contextual factors within the family and environment. The contextual factors of the social environment support behavioral change and social learning theories. How

the families adapted and how families and children found resources, and motivators within their environment were crucial to making the necessary steps for change.

In this group of children, the changes they described about how they felt about their self-esteem, confidence, and body image were very positive and important. Each child not only shared personal examples and experiences, but also many were able to identify how the changes in lifestyle had affected how they felt about themselves, both physically and emotionally.

CHAPTER FIVE

CONCLUSION, DISCUSSION AND IMPLICATIONS

In 2007, an Expert Committee convened to revise the 1998 recommendations for the assessment, treatment, and prevention for child overweight and obesity (Barlow & Expert Committee, 2007). Recommendations were revised after a decade of scientific evidence became available. The recommendations recognized the social and environmental aspects related to child overweight. The expert committee identified ways that healthcare providers and health care systems can be part of the efforts addressing child overweight and disease prevention at all levels (Barlow and the Expert Committee, 2007). The recommendations for treatment emphasize theoretical models that are based on behavioral change, social learning theory, and cognitive behavioral therapy. Barlow and the Expert Committee (2007) stressed that research be continued on how obesity can be addressed in the office settings. However, they emphasized that lifestyle behaviors are the targets for change.

In this study 10 children who were overweight and diagnosed with insulin resistance were interviewed using phenomenological inquiry. For this study, I wanted to find how children would describe the experiences they incurred as they made lifestyle changes that reduced risk for disease. The children's stories depicted the progress made over a period of 3 to 4 years and how their physical and psychological development evolved over that period of time. By using the phenomenological approach, I gained insight into how the children interpreted disease and how they used multiple avenues to become healthier and reduce risk factors for disease despite many barriers. In the interviews, children focused on how they made changes in diet and activity; described social support networks; described experiences of teasing and bullying; discussed

changes in self-esteem and body image; and provided advice and words of motivation that they would give to others their age with pre-diabetes. Children were empowered to be able to share their stories to help others. I found that by looking through the lenses the children interviewed provided, I saw the meanings of their actions and steps they had taken to become healthier. They shared feelings about who they have become and how they understand themselves.

Discussion

The themes that emerged from the ten interviews included (a) positive lifestyle changes, (b) social support and family, (c) supportive friendships, (d) psychosocial environment, and (e) understanding self and developing resilience. In the first section of this discussion, the association of the outcome data and what is known in the current literature are addressed. The following sections of the discussion are structured to discuss how the themes of the children's narratives and other results complement behavioral change theories, social learning theories, and cognitive and psychosocial developmental changes as related to disease prevention.

Interviewing children at different ages and with varying cognitive abilities provided the "new and different meanings" (Dahl & Boss, 2005, p. 75) that each experienced and how these experiences may change as a result of being in a particular developmental stage. Comparing the results of this study to recent surveys conducted with children who are experiencing disease or overweight, I would say that the responses children provide in survey research are more often a result of a respondents feeling or having an action captured at one point in time and not what is meant or experienced as a process over time. In this study, I was able to achieve a segmented-longitudinal perspective of the interactions with family, friends, and other community resources that helped have an effect on a child's health and development.

Previous research has shown that effective parenting styles and family functioning are imperative for children to become successful at weight loss and disease prevention (Phares, Steinberg, & Thompson, 2003; Wake et al., 2004). Other studies that have examined the long-term effects of weight loss have found that family-based interventions are more successful than those programs or interventions that focus on the child alone (Epstein, Roehmich, & Raynor, 2001). In this study, the children's reports and interviews attested to what is found in other positivist studies: that parents are a major source of support, along with friendships, and both are needed (Skinner, John, & Hampson, 2000). What was found in this study that is not always as apparent in other studies is that children were self-rewarded by their own accomplishments, leading each individual to become more assertive towards making new goals and adhering to routines. The extent of teasing and bullying many of the children had experienced was heart breaking. The focus of the issue in intervention programs and previous research and scholarly work needs further exploration.

Physiological Outcomes and Understanding Disease

Many health care professionals question whether the cycle of pre-diabetes to diabetes can be reversed in youth. In this group of children, there were many remarkable changes in the physiological variables associated with both overweight and pre-diabetes. Three to 4 years prior to the interviews, all of the children interviewed at diagnosis were greater than the 95th percentile for BMI for age and gender and had insulin levels that were not in the normal range, and many had appearance of significant acanthosis nigricans. This study supports the findings by Foster (2005) and Cali, Savoye, and Caprio (2008), changes in eating habits, reduction in BMI and/or weight loss, along with increased activity showed positive effects on insulin levels and changes

in other physiological parameters in this group of children. All of the children interviewed had made changes in both diet and exercise. For children who are insulin resistant, the recommended diet by the endocrinologist is a carbohydrate-controlled diet that focuses on consuming high fiber, low-sugar, high complex carbohydrate foods (Cummings, et al., 2008). Eight of the ten children interviewed had attended the nutrition and fitness class. During the class, a sample meal pattern was provided, and each family demonstrated how to incorporate the meal plan into their daily intake. Five of the children interviewed referenced the class and the meal plan, but only one child stated how she continued to follow that plan. Of interest, that child, Sharon, had lost the most weight. Although the other children may not have mentioned following the same meal plan, many did comment on how they stay within the recommended portions and avoid the high calorie foods or limited those “special occasion” foods.

Each child emphasized how changing what he or she ate was an important first step in the process of achieving healthier outcomes. Most children recalled past diet history with little effort, sharing how it had changed dramatically from 3 to 4 years ago. Children reported that, prior to being diagnosed, they had often eaten whatever they wanted and alluded to the fact that there were few limits on what they ate or little supervision regarding how much they ate. Previous food choices were also of interest, and for many, as they spoke of the “old” choices or junk food, they realized how little they consumed the same food items currently. Many stated that they no longer crave those foods, primarily sweets, and if they did crave sweets or were tempted by others, they used the strategies they used for dealing with these tough temptations. The determination or willpower they described could be associated with their self-efficacy.

When exercise takes place, the physiological effects are increased energy output, primarily in the form of glucose utilization from the muscles and other cells in the body. When glucose is released from the muscle, the body will be able to use the glucose for energy as opposed to storing it as fat. As the body uses more energy for exercise, primarily fat stores, the rate of insulin production decreases over time, serum insulin levels are reduced. Several studies in both adults and children have shown how structured exercise programs have produced favorable outcomes for weight loss and lower insulin levels (Chang, Liu, Zhao, & Yu, 2008; Reinehr, Kiess, Kapellen, & Andler, 2004). Of interest has been the amount and intensity of exercise required for lowering insulin levels and the effects of maintaining a continuous exercise routine over time for young children and adolescents.

All of the children interviewed mentioned how exercise became a part of their daily routine. Children who participated in structured exercise programs, stating that they were exercising 4-5 times per week with a combined cardiovascular and strength training regime, had very significant changes in BMI. Prior to beginning a structured nutrition and fitness regime, each plotted at two-five standard deviations above the 95th percentile for BMI for age, while at the time of the interview plotted between the 84th and 93rd percentile for BMI for age. The children who described having less structured exercise regimes has less significant physiological changes. Children did emphasize how they focused on going outside and playing, as opposed to previous habits of coming home, sitting on the couch, and watching TV. The scenario they described as a change in activity/lifestyle complemented what often is suggested in classes and in the physician office visits, as observed by the principal investigator. This is also a focus of T.V. activity campaigns, such as the “VERB” campaign and the “Nickelodeon Fit” commercials

(Wong, Huhman, Heitzler, Ashbury, Bretthauer-Mueller, McCarthy, & Londe, 2004). These promotions on TV advocate to children to just “get up and move.”

The combined effect of changing both nutritional intake and the nutritional composition of daily intake, such as reducing fat and carbohydrates, along with portion control supports the research that underlies what is most effective in helping individuals lose weight and reduce insulin levels (Krebs & Sothorn, 2006). Exercise also is effective; it appeared, that these children who indicated that they followed an intense structured exercise routine had significant decreases in BMI as compared to children who were moderately active.

Age of the child and state of physiological maturity and puberty are also factors that cannot be ignored. Several of these children whose BMI were still above the 95th percentile and considered at risk for disease, have not had dramatic changes. These children are also in stages of pubescence. During puberty, typically occurring between the ages of 12 to 15 years, normal body fat accumulation and hormonal changes occur, the growth hormone secretion and excess body fat accumulation is a probable cause of insulin resistance during puberty (Gungor, Hannon, Libman, Bacha, & Arslanian, 2005). Children previously, who had high insulin levels prior to puberty or at onset may have difficulty with weight loss when they reach peak puberty (Travers, Jesser, & Eckel., 2002).

Understanding Physiological Outcomes

Children’s explanations about how they understood the relationship of serum laboratory outcomes, presence of acanthosis nigricans, and changes in weight loss provide confirmation that they understand the significance of physiological changes associated with decreasing their risk for Type II diabetes. If children are able to understand how growth patterns influence BMI

calculations, they also may not be so concerned about weight or weight change. Two children both spoke about how they had maintained BMI as a result of gaining a little weight and growing in height. He hoped to grow a little more in height. One child also pointed out that she was still on medicine and her insulin levels had dropped. The changes in pre-BMI and post-BMI were more significant for children who described following a structured exercise routine as compared to those children who incorporated play into their daily routine. Weight loss was also a key factor that was associated with physiological changes that occurred in this population. Those children who lost weight or decreased BMI percentiles were also the same children who no longer needed medicine, no longer had identifiable Acanthosis Nigricans, and had normalized insulin levels. Most children who had achieved these results were past the peak pubescent period. For those children under 14 years, it will be interesting to see if similar changes in physiological outcomes occur as they continue to grow and maintain weight through puberty.

Applying the Health Belief Model and Social Learning Theory

How children interpret the physicians' initial assessment and understand the concept of the diagnosis is of great importance. The backbone to disease prevention and one's self-efficacy associated with behaviors related to health often lies in how they understand the progression of a specific disease. Several children relayed their concerns about developing Type II diabetes. They described relatives who have and had Type II diabetes, the complications relatives and/or friends experienced, and how they wanted to help prevent further complications in their own body. The medical problems relatives and friends had incurred and how some children observed those experiences helped those children foresee how imperative becoming compliant with the health care providers recommendations (e.g., medications, healthier habits) would be to prevent such

complications in themselves. The three children who had been most affected by knowing other individuals also were those who seemed more traumatized and scared at the initial visit. Some children who recalled the changes they had made in food selection, several indicated how often they had difficulty staying motivated to adhere to the recommended suggestions. The “yo-yo” effect is quite common with any problem that requires behavioral change. The children who described themselves as those whose weight fluctuated from down to up or who in the past 3 to 4 years followed a meal plan for awhile and then stopped seemed to understand how those changes were reflected in the outcomes of labs that were drawn and/or with the amount of medication needed. Learning about this association of diet, exercise, weight changes, and lab results and explaining the process illustrates the stage of the child’s cognitive development.

The children’s cognitive development and their ability to process how they feel better and have achieved positive outcomes supports Bandura’s Theory on self-efficacy (Burke, Steenkiste, Music, & Styn, 2008). In this study, most of the children who had normalized insulin levels, lost weight, and reduced the amount of medication needed all were around the age of 14 years or older. It appears that during the ages of 13-16, several psychological changes along with physical maturity help adolescents’ transition and learn to overcome obstacles, become self-directed, independent, and stay motivated. These concepts involve determination, motivation, and information processing and are of interest. When the children in this study described how they established and thought about achieving certain goals and making lifestyle changes, the conceptual frameworks as described by Piaget, Bandura, and other learning theorists emerged (Crain, 2005). As described by Bibace and Walsh (1980), a child’s personal control is influenced by the child’s ability to understand the concepts related to disease and begin to manage self.

Many children voiced their concern with developing negative outcomes such as amputation and dialysis that are associated with Type II diabetes. The same children discussed in their own words methods they used to self-regulate (e.g., monitor actions, set goals, establish personal rewards) or how they chose realistic goals and managed their disease by taking medicine. In turn, as they continued to see changes based on the goals obtained and through their own self-management, they developed the confidence associated with increasing their self-efficacy of health.

Progress of Stages of Behavioral Change

Social learning theory and the Health Belief model are incorporated into the Transtheoretical Model of the Stages of Change (Theory at a Glance, 2000). According to cognitive social learning theory, the most necessary prerequisite for behavioral change is a person's self-efficacy. Burke and colleagues (2008) referenced that Bandura's theory of self-efficacy is related to the confidence an individual has to initiate change and to maintain changes. High levels of self-efficacy also are associated with knowledge, environmental support, and resources available and motivation to change (Burke et al., 2008; Butler, Rollnick, & Scott, 1996; Rosal, Ebbeling, Lofgren, Ockene, Ockene, & Hebert, 2001).

As many of the children revealed how they made lifestyle changes and dealt with some of the barriers, their scenarios and thoughts demonstrated how they moved through the stages of change. The children spoke of how family members and physicians encouraged them through the process. They identified pitfalls and were able to search for resources and to seek the support of friends or individuals in the community. They shared how they could re-evaluate their progress to stay on task or, when they struggled, learn how to seek ways to become motivated.

Some children and families moved quickly to the action phase. One child described himself as “just sliding into it,” and another child was able to make a plan on her own. Other children stated how their families got with a program right away. Those who appeared to act and change lifestyles after the first visit also continuously improved their outcomes, such as at each visit BMI or weight dropped or insulin levels and/or cholesterol levels lowered. These individuals would be described as moving to the action and to the maintenance phase quickly. As individuals moved through the stages of change, their self-efficacy of health increased, concurring with Butler (2000) who emphasized that knowledge and behavioral change often predict a person’s motivation.

Symbolic Interaction Theory: Family Functioning and Social Support

Family relationships influence the capacity for self-regulation and change (Institute of Medicine, 2001, pp. 11-12). Family functioning has been supported as a major contributor to the prevention of child overweight and in helping families dealing with disease (Golan et al., 2006; Weibe et al., 2005). Behavioral change theorists advocate that significant others are involved in helping children develop healthier habits and will help them to be able to achieve more successful outcomes. The amount and degree of social support needed for each individual varies. Some individuals’ need support to motivate them in day-to-day experiences. For children, having supportive parents is required if they are to follow recommended dietary changes. A parent or guardian typically does the grocery shopping, prepares the food, and provides the financial resources that are available for food and/or exercise programs. If parents do not understand the benefits and reasons for these changes, it may be difficult for the child to follow recommendations that are provided. Helping parents find resources that assist families with

adapting roles and responsibilities may influence how families support making changes in lifestyle choices and in turn improve overall health of the family and child.

All of the children interviewed mentioned how one or both of their parents became involved. It seemed unanimous that mothers were most instrumental in providing support. Mothers' support came in many ways. Children explained how their mother changed the family menu, stopped buying 'junk' food, and gathered low-fat recipes from physicians' offices magazines to facilitate food choices and food availability. It also was evident that mothers provided the emotional support that motivated children to continue to make changes, stay with an eating and exercise plan, endure shortcomings, and remain encouraged. The emotional needs of the child fulfilled by mother's support also helped the child learn about him- or herself and develop a better self-image and self-esteem.

The children interviewed did not portray the father as the person meeting as many emotional needs, but many shared how fathers supported them in terms of achieving goals with physical activity and finding methods to eat healthier. Fathers went with them outside to play basketball, were the leaders in exercise programs at gyms, and walked in the neighborhood or hiked with the children. Some fathers, along with mothers, participated in classes and other weight management programs allowing the father and child to help each other. The team approach is advocated in classes at ETCH and in family-focused interventions (Epstein, Roehmichh, & Raynor, 2001). As the children told their stories about how they were able to make lifestyle changes, they expressed what it meant to be able to prevent disease and improve how they felt physically. The interactions with family illustrated how symbolic interaction theory and family functioning are important for understanding what disease prevention efforts are effective with children.

Psychosocial Development

Peer Support

Friendships can be made or broken during times of stress and difficulty. Studies that have examined childrens' health-related quality of life have found that those children with supportive friendships are better at self-management of their disease and have improved physiological and emotional outcomes (Schwimmer, Burwinkle, & Varni, 2003). All of the children interviewed shared experiences that they had with friends and friendships over the past 3 years. Many spoke about how a friendship with one person that was made prior to diagnosis continued during their transition from middle school to high school. They stressed that these same friends provided emotional support as they made changes in their lifestyle. The children who were in middle school spoke of their friends, but not in the same emotional context. They spoke of how important it was to feel that they belonged. They mentioned the importance of having friends to "hang out" with and go outside and play games or sports with. When they spoke of friends and how they "hang out", the impression they portrayed was that the relationships were an important part of who they were becoming and played a key role in their feeling like they belonged to a group. These children illustrated how important groups or cliques can be in identity development. As older children explained friendships and the meanings and experiences of how friends impacted how they were dealing with changes, these children also appeared to be establishing and achieving identity. This concurs with previous studies (Madam& Swain, 1999).

The children's attitudes regarding how they had dealt with teasing and their weight problem were manifested and worked through at a very mature level for their age. How the children understood these issues showed the development of abstract and formal operations

thinking. For the children whose stories reflected a mature or later stage of identity development, it also appeared that these same children had more experiences in their lifetime with other issues or problems. This did not occur with just older children but was evident in some of the younger children and concurred with the research in adolescent psychological development have suggested that experiences of success and failures are often what provokes change and a healthy identity (Sturdevant & Spear, 2002, p. S31).

The personal models that children had developed in conjunction with peer support are consistent with the assessment of Skinner, John, and Hampson (2000) that friends provide companionship and emotional support. Having an individual who is there with you and tries to help and understand what you as a child are facing is valuable for adolescents facing disease (Lightfoot, Wright, & Sloper, 1999). Personal models of beliefs about disease and the ability to self-manage for adolescents with diabetes may mediate the relationship between peer support and dietary intake (Skinner, John and Hampson, 2000). Adolescents need a supportive peer group that supports the daily activities associated with self-management of Type I diabetes, and the more an adolescent perceives others observing or questioning their blood sugar testing or insulin injections the more likely a decreased sense of well-being in adolescents would be noted (Lightfoot, Wright, & Sloper, 1999). Peer support in the form of helping with medical issues and protecting when bullied were important factors for children with disease (Lightfoot, Wright, & Sloper, 1999).

An individual's progress and motivation often is a result of other people's positive comments and compliments are positive reinforcements. The reactions of family, friends, teachers, physicians and even acquaintances to some extent can influence how children will

adapt and maintain motivation. Physicians' reactions were very rewarding to the children and how physicians showed his or her approval was important. One child mentioned that her physician sent a note about her lab results and to keep working hard. Two of the females shared how the physician reacted to their weight loss and change in insulin level, not to mention that these changes also meant less medication. Others emphasized that the demeanor at office visits and a positive attitude on the part of the health care provider was encouraging and made the visits less stressful.

Apart from physicians, other individuals who were not seen on a daily basis had a great impact on how children saw themselves. For example, members in the community provided compliments. One child mentioned how members of her church and the pharmacist at the drugstore gave compliments on a routine basis. Others mentioned that previous teachers had noticed changes in their appearance and voiced positive approval and complimented their efforts. Other individuals in the community, such as a trainer at the YMCA and the person leading exercise at the nutrition and fitness class at ETCH, provided resources as well as literature and prizes to reinforce the children's efforts. These forms of approval and compliments received are all factors that lead to developing a better self-image and self-esteem.

Psychological Development and Self-Esteem

Along with a strong family support system, Glasgow and Anderson (1995) suggested that for adolescents, peer support may have a great impact on metabolic control and adjustment to illness and disease management. Skinner, John, and Hampson (2000) examined if whether social support and personal models are predictors of self-care and well-being in a group of adolescents with Type I Diabetes. Determining which factors (self-esteem, social support, life event changes,

or health beliefs) within the HRQOL assessment are affected is important when developing treatment plans.

Teasing about weight is one of the most common issues affecting a child's emotional development that is associated with child overweight. Teasing may occur at school and in the home and may lead to beliefs and attitudes about appearance, self-worth, relationships with boys, and poor satisfaction with one's body (Borra, Kelly, Shirreffs, Neville, & Geiger, 2003; Phares, Steinberg & Thompson, 2003). Low self-esteem and depression have been found to be associated with overweight status for children (Brown, McMahon, Biro, Crawford, Schreiber, Similio, Waclawiw, & Striegel-Moore, 1997). Physical appearance and peer acceptance additionally impact self-esteem and depression (Brown et al., 1997).

The psychological effects of being overweight and how this affects a child's self-image and self-esteem are of great interest and are a recurring issue. Prepubescent years, middle school, and puberty are times when these issues become more profound. Teasing, bullying, and other forms of peer rejection and verbal abuse were reported to have been experienced by the children in this study. To be a child with a problem can only provide more ammunition for those who are good at being the bully. The overweight child or child with disease is an easy victim. The children who are able to deal with these issues and not become isolated or depressed often means they have the ability to look inside the self and feel a greater sense of self-worth, be more mature, and develop resilience from other life events. Many of the children interviewed discussed how they have been teased or bullied because of their weight. Because most children who are insulin resistant are also overweight, it would not be known that they are pre-diabetic, so

it would be less likely that a child would be teased because of a result of having a disease but more likely because of being overweight.

Stories of teasing and bullying and how children dealt with the situation (e.g., withdrawal) and how they described emotions (e.g., depressed and alone) were remarkable and depict resiliency and an ability to adjust psychologically. As the children shared their stories, the hurt was expressed in their eyes, but as they spoke about how they have dealt with those memories, it appeared that they had grown emotionally from the event. They allowed themselves to move on and see themselves; they had greater self-esteem and had developed more self-confidence over time.

When children were asked how they felt they had changed in the past 3 to 4 years, most of the children commented first on how they felt about themselves as a person followed by how they felt they had changed in relation to their physical abilities. They described themselves as more confident and more mature than their peers. Many stated they had a greater awareness of who they were as a person and that they had greater self-esteem. They were happy with who they were as compared to previous years when they did not feel good about how they looked. They can look in the mirror and like what they see; they are not as self-conscious as before when dressing for gym, will wear a bathing suit in front of friends, and will now wear dresses because they are willing to show their legs. Along with the emotional and mental growth that occurred, several children also shared how they felt they had changed physically. Many were much more active and could accomplish mile runs without stopping or going up and down stairs without huffing and puffing. How they changed in terms of physical shape also put several in the mindset to attempt to compete athletically. The changes in physical ability were motivators to

continue to improve in activities that were healthy, developed self-confidence, and helped them become socially active.

When children were asked what goals they had for future health or how were they going to continue to manage their weight or insulin levels, each child reiterated descriptions similar to what they had been doing already. Many shared that they would continue to eat the foods they had been eating and limit high calorie, high carbohydrate foods. Several children also clarified that they would allow themselves to have certain foods on occasion. Many focused on staying active and pursuing other physical activities. Five of the 10 children stated that it was important to never give up and always have someone you know who can support you in your goals. Another motivator for several children was to continue to be able to stay off medications and prevent disease.

Implications and Future Research and Clinical Interventions

What children experienced and how they expressed their understanding of disease and the process of making changes to improve their health has many implications for future research, hospital and community based programs, and individual clinical encounters. The group of children interviewed provided ideas and perspectives needed to help individuals involved in intervention and prevention of child overweight efforts.

Implications for Health Care Professionals

One of the main trajectories to be taken from this research was the understanding that children and parents learn about the association of insulin resistance and Type II diabetes. Physicians and other health care providers who can find methods on how to educate, teach, and help individuals understand what is happening in their body are of great importance. Two of the

children mentioned that the information they had received on diet was confusing and that they still had questions about the information. Both of these children were 10 to 12 years of age when they attended the class. What the children may have not understood when they attended classes on nutrition is of interest. Several factors are possible reasons: (a) The content may have been above the children's reading or cognitive level at the time; (b) the instructor may have not provided enough examples or time for the activities used to make meal plans; or (c) the parents may have taken the active role and not included the child in developing meal plans and label reading, leaving the child confused and not understanding information presented. Having children evaluate class materials and other information presented would be valuable in improving the classes offered. There are several methods that can be put in place to achieve this goal. Designing an easy to read, pictorial handout or brochure may help physicians convey age appropriate information as well as provide parents with medical information that can be passed on to other caregivers and family members. Additionally, incorporating the same information as a cartoon-like commercial may improve the understanding of the physiological effects of insulin resistance for classroom lectures and office videos. By changing how we teach and using technology, these methods may improve how families understand the disease as well as provide the motivators for why lifestyle changes are important.

Children who were interviewed also provided suggestions on what was important to them and gave advice for improving intervention programs and interventions in office-based settings. Two of the children stressed that (a) they needed a better understanding of why taking medication on a daily basis was important and (b) methods to enhance taking medication prescribed. Because taking medicine for a pre-diabetic child is not as crucial as is taking insulin

for a Type I diabetic child, children with pre-diabetes may not see the importance or become motivated to comply. When some of the children did not comply with taking the prescribed medications, the physicians emphasized to them that physical symptoms had worsened or lab values had increased. It seemed that the importance of taking medication was realized at that point. Some of the children felt that, if it had been explained earlier how important it was to take the medication, it might have changed overall compliance initially. One child explained how she spoke to her physician about this issue, and they devised a treatment plan so she could take all her medications at one time.

Many individuals stressed that returning to see the doctor was a key factor in their progress. Therefore, finding methods that would improve the follow-up rate for physician visits also may improve the number of successful outcomes. Investigating the procedures used for follow-up and using different methods, such as e-mail reminders or telephone interviews, would be possibilities to increase the number of interactions between the child and health care provider.

Another important suggestion that some children made was that, physicians and other health care professionals emphasize the time frame it takes to make changes and reach realistic goals. We all want things to change overnight, but hearing that weight loss of four pounds per month is an average amount lost or knowing to expect pitfalls is of value as reported by the children. Suggestions support the study by Burke and colleagues (2008), which found that individuals who had participated in weight loss programs also wanted advice on how to deal with issues related to changing eating and activity patterns and assistance with how to not become overwhelmed or discouraged.

Several children were enthusiastic about being a spokesperson for future groups. Future clinical encounters and classes could possibly implement discussions of the emotional issues children face. One of the limitations in this study was that human subject approval for video recordings and sharing audio recordings at a later time was not requested. Future studies would benefit to include video and audio sharing as part of the protocol, so that the voices and images of the children who have lived the experience can be shared with children dealing with similar issues and professionals working with children. Another option is to ask children who did participate to come and share what they have accomplished at classes. Including an audio or video recording of a child discussing changes and feelings in classes, or having an individual (child) attend a class may help other children and parents have the child's perspective and become motivated.

Incorporating a psychological screening tool and parenting survey may help physicians and other health care providers more successfully to address these issues with the child and family members. Future studies might include interviewing parents and focusing on children who have not had as many favorable outcomes. Comparing the two groups of children, those with and without favorable outcomes, will only provide more insight into how we can further develop frameworks for future programs.

Implications for Child Overweight Programs and Clinics

Many child overweight programs use a multidisciplinary team approach that include a behavioral therapist, a psychologist, and/or a social worker as part of the counseling team; a dietitian; a physical therapist; a nurse; and a physician. A similar care team is the protocol for most outpatient clinical diabetic programs. For a child with Type I or Type II diabetes who

comes to the ETCH clinic, every 3 months the child and/or parent meets with a dietitian, social worker, physician, and nurse to assess physiological outcomes and to determine what is needed in regard to helping the family/child manage the disease successfully and address any emotional or social issues. Incorporating the same team approach would be a benefit for children with pre-diabetes. Mentioned by several children, but specifically by Ann, it's important to incorporate discussions about bullying and teasing into either individual physician visits or classes. She stated that, the emotional topics often are avoided. Creating dialogues of the emotional issues overweight children may face will make future classes and programs more effective and will provide a better comprehensive approach to both educative and interventive programs.

Similar to narrative therapy and motivational interviewing, phenomenological research has been incorporated into family therapeutic sessions with success (Dahl & Boss, 2005). It would be interesting to incorporate a session using phenomenology with the child and/or parent at the visit where outcomes have not changed or worsened. Using phenomenology at a particular point in the care process may assist the provider, child, and his or her parents/family to determine what is understood and might capture what may be perceived as barriers to motivated engagement. Incorporating the parent and/or a family member may help clarify what other environmental issues may be creating barriers and could help in the development of educational goals for children.

What was said in the office visit had great impact for some of the children in this study. Continuing to make efforts to determine what models or methods of communication and what forms of interaction motivate children who are at risk for disease is needed in the scientific

literature. Physicians are the front line of action when it comes to addressing and helping change the problem of child overweight.

Future Implications for Community and Schools

Several children who were interviewed emphasized how they utilized community resources. Children also discussed the role of physical education as part of their activity and how some aspects of the physical education program helped them see differences in their levels of physical fitness. Sharing information from the children's interviews with organizations and other community programs may help facilitate and motivate those institutions to provide a variety of programs for children and adolescents and offer scholarships and other means of low-cost health care services. If hospitals and physician offices are aware of what is offered in the community, they might also be more likely refer to those institutions and provide their clientele with better resources. As we learn more about what works in the community and at different ecological levels, the community is more likely to work together in helping with efforts in child disease prevention.

Future Implications for Current Policies

In the past 3 years, as more research has become available about the issues of child overweight and development of Type II diabetes and cardiovascular disease, efforts toward developing specific policies have been brought to fruition. In 2006, the state of Tennessee developed a Child Healthy Weight Network and coalition. Part of the coalition coordinated with major universities and leading agencies to propose and put into action policies for schools and workplaces. The school wellness policy was established for elementary and middle schools and included changes in physical education programs, food purchasing, and cafeteria sales. Changes

in food service included baking or heating foods served, with no foods being fried or having added fats. Beverages offered are low sugar and low fat and snack foods brought to school are on an approved snack list. Vending machines are turned off during the day and only available at certain times of the day. Physical education also is included in the wellness policy, stating that children should receive 90 minutes of physical activity a week, and play and movement is encouraged at recess and in class activities (Knox County Wellness Policy, 2006).

In addition to the school wellness policy, several other community programs have been developed. Children in this study described some of these changes and shared how these efforts have helped. Boys and Girls Clubs offer after-school programs that emphasize health and are currently managed by the local health department (Knox County Wellness Policy, 2006). Parks and Recreation departments have created additional greenways and tennis courts in local parks to add space and opportunity for safe walking and activities. More fitness centers have also added kid/child friendly programs to the fitness programs. Phil Bredesen, Tennessee's Governor, initiated a statewide program titled "GET FIT TN" to address the overwhelming issue of the epidemic of Type II diabetes and overweight (Colton, 2006). Efforts to assess how these changes have impacted the health of children are continuing to emerge.

One of the major issues challenging health care professionals is the lack of reimbursement for pre-diabetes services because the child does not yet have diabetes. Other successful long-term programs that are incorporating a multidisciplinary approach with groups of children who are overweight and with complications are most likely funded by grants. To provide the combined services of what may be considered optimal treatment is costly and not all is reimbursed in most outpatient clinics. Insurance coverage for preventative services was

recently passed by Congress on July 6, 2008 and will become effective in January 2009.

Although most of this legislative work supports medical nutritional therapy and mental health reimbursement for the elderly under Medicare, this gives hope that soon other preventive services may be reimbursed (American Dietetic Association, 2008).

Halfon and Hochstein (2002) developed the Life Course Health Development Framework to advocate for policy and research. The premise behind the framework is that there are differences in developmental health throughout the life span that will explain the nature of how disease develops over time (p. 458). The framework challenges policymakers to rethink how to improve the nation's health by finding the positive outcomes and relationships that exist with them across the life span. Halfon and Hochstein suggested assessing individuals who are free of disease as compared to constantly focusing on the prevalence of disease and mortality. There may be differences found between groups that are related to developmental stages that could help support health policies for both individuals and community health assets (p. 457).

Differences in the health development trajectories of individuals and populations reflect the cumulative and programmed effects of risk and protective factors on health development. The Life Course Health Development framework offers a developmentally unified way of interpreting new research findings and identifies research issues that deserve immediate attention (Halfon & Hochstein, 2002). Tracking children and adults over time using time series data, could guide policies and interventions and promote positive health development. Children in this study were followed at different stages of development and we captured their stories about the process of how they become healthier over time. This study supports the perspective of the Life Course

Health Development framework and can add information to the overwhelming prevention and treatment of the global issue of child overweight.

Limitations of the Study

Several limitations characterize this study. The first limitation was in obtaining enough information to be able to identify a large enough group of children from which to select a sample that met the established inclusion criteria. There are several reasons why this became a limitation. Data that are available through access to hospital computerized medical records can be confounded because not all children return to see the physician at the same time or even every 3 to 6 months. Approximately 50% of the children referred in 2004 had not returned for a follow-up visit with the endocrinologist by the end of 2004. Several factors may be reasons. First, many of these families live 30 minutes to an hour away from the hospital and availability of transportation during office hours or the need to take time away from work for an office visit maybe difficult. Second, parents may not perceive that the child has a true problem. Third, in this population, the age of the child may have prevented the child from returning to the physician. Many children over 16 years will begin seeing an adult family practice physician who also may be able to oversee the complications of pre-diabetes. Thus, these children could be lost to follow-up but still be receiving care elsewhere. Finally, children may not return to classes because the time between visits is too long; they cancel, reschedule, or forget to make the second appointment. Other reasons could be that health insurance did not reimburse sufficiently for the first visit and, therefore the children did not return because of financial constraints.

Two other limitations to the study are time-related issues. During the initial phase of the study (June 2006), children seen in 2004 were identified as the sample of children meeting the

criteria established. Once the study was approved and interviews were to begin, some of the initial children who met the criteria were too old to participate. In future studies with this population, planning for participants up to 20 years of age is recommended to avoid limiting participation because of age restrictions.

A second limitation that occurred was several children returned to the physician for a follow-up visit after the initial group of children identified as a potential participant was determined by data gathered during the months of June 2007 through January 2008. The principal investigator sent out recruitment letters in May 2008. Several children visited the physician after the initial recruitment phase and experienced either weight gain or their insulin level increased. When contacted children felt that they did not have positive outcomes and, therefore, did not want to participate. After this occurred, the principal investigator re-analyzed several data files before sending out additional waves of letters to parents and children to avoid confusion. Possibly knowing when children have a follow-up visit would assist with avoiding this issue. Finally, several children may have made progress in achieving healthier lifestyles but were not identified because most inclusion criteria were based on lab results. Because physicians do not always require labs, this may have limited the number of children who had positive outcomes.

Sampling was another limitation. More females than males participated. We were not able to have comparable numbers of females and males, because we had fewer males who had achieved positive outcomes in the group of children who matched inclusion criteria, and several who did have better outcomes were not interested in participating. Finding methods to make interviewing more appealing to adolescent boys would add to future studies.

Access to additional information about the child's family living arrangements and documented medical history would have answered some of the questions that arose after children were interviewed. Many children spoke of brothers and sisters, and several did not. Although discussion of the family occurred during the interview, what members of the family lived in the child's house and information about step-brothers or step-sisters, adopted members, or older siblings did not always emerge and this information is not available in the child's medical chart. In relation to medical history, two children had discussed getting sick, but it was unclear how they were sick or if the diagnosis was related to pre-diabetes, for example, did a child experience a high or low blood sugar reaction? Was the child's understanding of getting sick in reference to going to the doctor or the Emergency Room? The descriptions about the child's sickness and documentation from the physician were not available to be verified; therefore, it is difficult to know if the child understood the meaning of the "sick" event.

Additional mixed methods of qualitative inquiry and quantitative methods would have added to this study. Including a parent survey or parent focus group would have added a component of what parents understood were the important factors contributing to changes in lifestyle. Parents would have been able to describe motivators they felt encouraged the child as well as what encouraged them as parents to become involved and how they worked through the process of making changes themselves in how the family functioned. Previous studies that have examined children's HRQOL also have had parents complete a questionnaire at the same time or as part of the study to compare reports and outcomes. Including information from parents would have clarified certain questions that arose after interviews, such as family history, understanding of disease, and children's issues with self-image and first visit experience.

Several children who had met criteria may have participated in the study if data had been collected by telephone interview or on a web-based chat page. Although not the focus of the present study, adding different types of methods to reach this audience would have increased participation and the differences in stories and experiences shared would be of further interest.

Strengths of the Study

To date, no other study has been conducted using phenomenology with children with insulin resistance. Few studies have incorporated interviewing overweight children. This study was able to capture the words and experiences of 10 children who had decreased risk factors associated with developing Type II diabetes. The children who participated in this study also represented a true outpatient population in an endocrine clinic where outcomes were followed over a 3 to 4 year time frame. Aside from the child and family possibly receiving a formalized education session on nutrition and activity, unless the family sought other outside resources, no other intervention or education was provided. Therefore, the success stories are truly attributed to those families and children who were able to act on advice and suggestions of the physicians and education on nutrition and activity as well as other resources in their environment they may have accessed.

Although unintended biases are in every study, for this study every approach to avoid biases was employed. To prepare and immerse the principal investigator conducted two pilot studies and participated in a bracketing interview. Additionally, the principal investigator did not review any recent medical record chart notes or records prior to the interviews. Notes from medical records were gathered after interviews had taken place and included in separate files of information in order for the principal investigator to verify outcome and understand some of the

physiological and emotional changes that were either addressed or not addressed in the interviews.

Along with the interviews, there were several other sources of data available to bring the whole picture of each child. The physiological data as well as the number of times the child returned to the physician and the physicians' notes all contributed to making each child's narrative a larger and more in depth story. By using the other sources of information, I was able to gain a better understanding of how positive outcomes had been achieved in the lives of these children.

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APPENDICES

APPENDIX A
Sample Letter to Parents

LETTERHEAD

Date

Parent or Guardian Name
Address

To the parents/guardian of _____,

During the last year you and your child met with an Endocrinologist at East Tennessee Children's Hospital and your child was referred to the Department of Food and Nutrition for education on nutrition and fitness. According to your physician, your child's weight and insulin values have decreased. We are very interested in learning about how your child has accomplished these important lifestyle changes that are related to preventing disease.

We are selecting children who made changes and reduced their risk of Type 2 diabetes. We are asking you to allow your child to participate in a 45-minute to one-hour interview. During the interview your child will be asked to tell us about being healthy and what he/she has done to become healthier.

In the next week, we will be contacting you to see if you will agree for your child to participate in this study. If you have specific questions related to the study, please contact Juliann Chavez or Kathy Mount, Director of Food and Nutrition at 541-8442.

Thank You,

Juliann M Chavez
MS RD LDN
Doctoral Student, University of Tennessee
Department of Nutrition, ETCH
PO Box 15010
Knoxville, TN 37916
(865) 541-8442

APPENDIX B
Permission for My Child to Participate in a Research Study
PARENTAL PERMISSION FORM

I. Purpose of the Study:

This study is designed to learn how children with insulin resistance make lifestyle changes that improve overall health and well-being.

II. Procedures to be Followed:

Juliann Chavez, a Doctoral Student at The University of Tennessee and Clinical Dietitian at Children's Hospital, will interview your child for 45 minutes to an hour. The interview is part of a dissertation research project that will help researchers and health care professionals understand how a child thinks and feels about health and what a healthy lifestyle means. During the interview your child will be asked to tell his or her story about what changes he/she has made to become healthier. Some of the questions that may be asked include:

1. What does it mean to you to be healthy?
2. What changes in eating and activity did you make?
3. How do you feel about yourself?
4. What were the hardest changes you made?
5. What advice would you give to others your age trying to work at being healthier?

What your child says will be recorded on a tape using a tape recorder. Ms. Chavez will listen to the tapes several times to understand what your child thinks and feels. When the interview is complete what your child has said will be typed and reviewed by another researcher to make sure the tapes and written notes have the same information.

The interview is confidential. Nothing from your child's interview will be included in your child's medical record. The tape recordings will be stored safely in an office at The University of Tennessee. To protect your child and his/her identity the recordings and all other documents that list children who told their stories will be stored separately and only what a child says may be reported but not the child's name. The recordings will be erased and typed notes will be destroyed after three years. Ms. Chavez and Dr. Priscilla Blanton are the only individuals who have access to the tapes and typed notes. Your decision and your child's decision about being in the study will not influence his or her medical care at East Tennessee Children's Hospital. What we learn will be used for presentations and articles for professionals by reporting general statistics on the percentage lab values decreased, ages of children who participated in the study, and specific information that children said about the changes they made and the motivation needed to make those changes. Medical information followed since the referral to Food and Nutrition from the Endocrine clinic contributes to the study and an additional form is included allowing access to your child's Personal Health Information collected for this study.

III. Potential Risks of Participation in the Study:

The interview is very similar to a having a talk with a friend or teacher. No lab tests or other tests will be done. Your child will just tell how he/she made changes. Some children may not

want to answer questions, may become nervous, or may decide that they do not feel like talking. To help your child feel at ease, Ms. Chavez will show him or her where they will talk and start the interview with an activity such as playing a game. Your child will also know that you are in a room nearby. Your child will also be told that he/she does not have to answer all questions and may stop the interview at any time. If for any reason your child becomes upset, we will stop talking and destroy the tape if wanted. A social worker on call at ETCH will be contacted if you or your child would like to talk with someone else. At the end of the interview, your child will be able to select a prize, such as a gift card to the mall, Laserquest pass, or admission to Dollywood.

IV. Potential Benefits:

Being in a study and talking about an accomplishment may increase your child's feeling of success. Knowing he/she has helped other children and that his/her ideas are important may help your child continue to make healthy choices.

V. Other Options:

The other option to your child being in this study is your decision not to allow the child to participate.

VI. Liability:

There will be no payment to you for being in this study, and no payment for treatments or injury resulting from being in this study. However, by signing this form, you are not giving up any legal rights to obtain compensation for injury.

VII. Research Related Inquiries:

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of being in this study,) please contact, Juliann Chavez, East Tennessee Children's Hospital- Food and Nutrition Department, PO Box 15010, Knoxville, TN. 37916 or 541-8442.

VIII. Patient Rights Information:

General questions concerning your rights as a participant in research protocols or questions about research related issues may be addressed to the Institutional Review Board Chairman, East Tennessee Children's Hospital through his secretary at (865) 541-8477 or The University of Tennessee Office of Research Compliance Officer at 865-974-3466.

IX. Voluntary Participation Statement:

Being in this study is voluntary. There will be no penalty or loss of benefits for refusal to participate. You may stop being in the study at any time without penalty or loss of benefits to which you are otherwise entitled.

X. Parent Contract:

I have received a copy of this permission form. I confirm that I have read the above permission form. The potential risks and benefits have been explained to me and I understand. I willingly volunteer and give my permission for my child to be in this study.

Child's Name

Date

Signature of Parent

Date

Signature of Witness

Date

Signature of Person Obtaining Permission

Date

APPENDIX C
Consent to Participate in a Research Study
CHILDREN 14-16 YEARS FORM

I. Purpose of the Study:

This study is to learn how children with insulin resistance make lifestyle changes that improve overall health and well being.

II. Procedures to be Followed:

Juliann Chavez, a Doctoral Student at The University of Tennessee and a Clinical Dietitian at Children's Hospital, will interview you for 45 minutes to an hour. The interview is part of a large research project that will help researchers and health care professionals who work with children understand how children think and feel about health and what a healthy lifestyle means. During the interview you will be asked to tell your story about the changes you have made to become healthier. Some of the questions that may be asked include:

- What does it mean to you to be healthy?
- What changes in eating and activity did you make?
- How do you feel about yourself?
- What were the hardest changes you made?
- What advice would you give to others your age trying to work at being healthier?

What you say will be recorded on a tape using a tape recorder. When the interview is complete what you have said will be typed and reviewed by another researcher to make sure the tapes and written notes have the same information.

This interview is private. Nothing from your interview will be included in your medical record. The tape recordings will be stored safely in an office at The University of Tennessee. To protect your identity all other documents that list your name will be stored in different offices. The recordings will be erased and the typed notes will be shredded after three years and access to these tapes and files will only available to the Ms. Chavez and Dr. Priscilla Blanton. Your decision about being in the study will not affect your medical care at East Tennessee Children's Hospital. What we learn will be used for presentations and articles for professionals by reporting general statistics on how lab values decreased, ages of children who participated in the study, and what children said about the changes they made and motivation needed to make those changes. Your name will not be used when we report what you may say.

III. Potential Risks of Participation in the Study:

The interview is very similar to talking to a friend, teacher, or like being on a talk show. No lab tests or other tests will be done. You will just tell Ms. Chavez about changes you have made in the last year. To help you feel calm Ms. Chavez will show you the room where you will talk and will start with an activity such as playing a game or drawing a picture. Your parents will be in a room nearby. Also, if you feel nervous or do not want to talk anymore, you may ask to stop the interview at any time. If for any reason you become upset, we will stop talking and erase the tape if wanted. A social worker on call at ETCH will be contacted if you would like to talk with someone else.

At the end of the interview, you will be able to select a prize such as a gift card, passes to Laserquest, or admission pass to Dollywood.

IV. Potential Benefits:

Being in a study and talking about yourself should give you a feeling of success. Knowing that you have helped other children and that your ideas are important may help you to continue to make healthy choices.

V. Other Options:

The alternative to you being in this study is your decision not to participate.

VI. Liability:

There will be no payment to you for being in this study, and no payment for treatments or injury resulting from being in this study. However, by signing this form, you are not giving up any legal rights to obtain compensation for injury.

VII. Research Related Inquiries:

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of being in this study,) please contact, Juliann Chavez, East Tennessee Children's Hospital- Food and Nutrition Department, PO Box 15010, Knoxville, TN. 37916 or 541-8442.

VIII. Patient Rights Information:

General questions concerning your rights as a participant in research protocols or questions about research related issues may be addressed to the Institutional Review Board Chairman, East Tennessee Children's Hospital through his secretary at (865) 541-8477 or the University of Tennessee Office of Research Compliance Officer at 865-974-3466.

IX. Voluntary Participation Statement:

Being in this study is voluntary. There will be no penalty or loss of benefits for refusal to participate. You may stop being in the study at any time without penalty or loss of benefits to which you are otherwise entitled.

X. Contract:

I have received a copy of this permission form. I have read the above permission form. I understand the potential risks and benefits. I want to volunteer to be in this study.

Child's Name

Date

Signature of Parent

Date

Signature of Witness

Date

Signature of Person Obtaining Permission

Date

APPENDIX D
Permission to Participate in a Research Study
Assent of the Child Ages 9 – 13 Years:

Your parent/guardian told me that you are willing to help me. The doctor you saw here at the hospital told me that you are working at being healthier. Today I would like to talk with you about how you have made some changes to become healthier. I am going to ask you about what you have been doing in the past year. I think what you tell me will help many doctors and other people who want to help children stay healthy. What you say will be recorded on a tape recorder, but we will not use your name. This will keep what you say private. We will also look at some other information from the doctor about your blood tests and last visit to the doctor. The information about the changes in your blood work will show how the changes that you made have helped you become healthier.

Being in a study and talking about yourself should give you a feeling of success. Knowing that your ideas are important may help you to continue to make healthy choices. You do not have to be in this study, it is your decision to participate. You may stop talking or ask questions at any time. If you decide that you don't want to talk to me anymore, just tell me. You can just say, "I don't want to talk anymore."

I have explained this research to this patient in age appropriate terms and the child has given verbal assent to participate in this research.

 Child's Name

Date

 Signature of Witness

Date

 Signature of Person Obtaining Assent

Date

A copy of this form will be given to the parent and guardian.

Potential Risks and Benefits: There will be no payment to you for being in this study, and no payment for treatments or injury resulting from being in this study. However, by signing this form, you are not giving up any legal rights to obtain compensation for injury. If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of being in this study,) please contact, Juliann Chavez, East Tennessee Children's Hospital- Food and Nutrition Department, PO Box 15010, Knoxville, TN. 37916 or 541-8442. General questions concerning your rights as a participant in research protocols or questions about research related issues may be addressed to the Institutional Review Board Chairman, East Tennessee Children's Hospital through his secretary at (865) 541-8477 or the University of Tennessee Office of Research Compliance Officer at 865-974-3466.

APPENDIX E

Sample Assent and Procedures Script

I. Examiner: Hello, my name is Juliann Chavez. Your parent/guardian told me that you are willing to help me. The doctor you saw here at the hospital told me that you are working at being healthier. Today I would like to talk with you about how you have done this. I know you will do a good job because it is like telling me your story. How does this sound to you so far? (Child's response). OK-are we ready to start?

First, I am going to ask you to say some silly phrases to test the tape recorder that I will be using. Then we will talk about what you have been doing in the past year or two. I think that what you tell me will help many doctors and other people who want to help children stay healthy. Are you willing to help with this project? (Child's response). Great! I think you will find talking to me easy and fun. *Is there a special character you like that we can talk about? (Child's response-which may also be the child's code name during the interview).*

If you decide that you don't want to talk to me anymore, just tell me. You can just say, "I don't want to talk anymore." Okay? (Child's response).

Thank you! We are going into the next room to talk. I have a beanbag chair, a fuzzy chair, and the chair across the table from me. You can sit where you want and I will sit across from you. There is also some water and other drinks if you want any. Help yourself at anytime.

Are you ready? Great then ...Let's begin.

II. The researcher will use the following procedures during the interview:

- Maintain a pleasant facial expression.
- Give general reinforcement or probes by means of these example comments:

"You must have really worked hard to do that."

"Wow! How did you think to do that?"

"Did anyone help you think about doing that?"

"You must have been are really listening when you went to the doctor. Is that what he/she told you to do? "

"Can you think of anyone else you know who you think is healthy or made healthy changes?"

III. The examiner will use the following procedures at the end of test administration:

- If the child asks to stop talking, the interviewer will maintain a neutral expression, stop the recording, and say, "All right, thank you for helping me again. Let's go outside the room to your parents."
- When the interview is completed, the examiner will say, "Thank you for helping me again. You have really worked hard today. Here are some "prizes" to choose from for all your work. You may choose one. Let's go outside the room to your parents."

IV. These behavioral management guidelines will be followed during the interview:

- Prompts will include phrases such as:
 - "Would you like to draw a picture of something you think is healthy?"
 - "Did you want to play a short game of cards?"
 - "Please don't touch the (tape recorder)."
- If the child appears nervous or refuses to talk about being healthy or does not want to participate in any other activities that are intended to make he/she feel more comfortable, the interview will be discontinued.
- If the child appears or makes remarks that lend to becoming embarrassed or singled out, the researcher will address these remarks so they are not disregarded and refocus the child to address the positive aspects of the changes he/she has made. A discussion about goal setting for another outside activity or interest will follow (ex. musical instrument, acting, church group or school club) to encourage positive changes the child has made.

APPENDIX F
Health Insurance Protection Privacy Agreement for Research

Confidentiality of Study/HIPAA Authorization:

The information obtained by this study will be held strictly confidential and will be available to only to the researchers listed on this form. Giving the information to any other person or institution is prohibited. Under federal privacy regulations, you have the right to determine who has access to your child's personal health information (called "protected health information" or PHI). Your child's PHI used for this study may include your child's medical history, results of physical exams, lab tests, x-ray exams, and other diagnostic and treatment procedures, as well as basic personal information, such as address and phone number. By signing this permission form, you are giving the researchers at East Tennessee Children's Hospital access to your child's PHI collected for this study. Those involved in the oversight of this research may have access to your child's PHI collected in this study. This may include the Department of Health and Human Services, the Food and Drug Administration, the Institutional Review Board at ETCH or others as required by law.

Your child's PHI will be used only for the research purposes described in this form. You may choose not to provide access; however, your child will not be able to participate in this study. Your child's PHI will be used until the end of the study unless you cancel this authorization. If you choose to provide this access, you may stop this authorization in writing at any time by contacting the principal investigator listed on this form. If you cancel the authorization, continued use of your child's PHI is permitted if it was obtained before the cancellation and its use is necessary in completing the research.

 Child's Name

 Signature of Parent

 Date

 Signature of Parent

 Date

 Signature of Witness

 Date

 Signature of Person Obtaining Authorization

 Date

APPENDIX G

Results and Discussion of Pilot Studies

Two forty-five minute to one hour interviews were conducted. These consisted of an interview with a 17 year-old male and a 12 year-old female who had been referred to the researcher as a result of increased weight gain within the last 18 months. In addition to the interviews, field notes from each child's client file, conversations with parents, and open-ended surveys completed by parents were gathered.

Seven themes evolved from the interviews. The themes that pursued during the interviews were; idea of healthy, dealing with issues, self-esteem, support systems and resources, knowledge, ideas for others, and stressors/emotions.

Idea of Healthy

The first theme evolves from the question why did you want to lose weight or make changes regarding health, diet, and exercise. What is a child's idea of healthy? Understanding healthy and being healthy was referred to as being thinner and related to body size and body image. In the interview with the twelve year old female she responds to the question by stating:

" Um..mm, because I wanted to be healthy"

INTERVIEWER: Were you unhealthy? FEMALE: I don't really know but I wanted to get thinner.

INTERVIEWER: So what made you think you needed to get thinner?

FEMALE: Because the scale was going up.

INTERVIEWER: The scale was going up and that was not good. FEMALE: Right

INTERVIEWER: Um so what did you do? Tell me a little bit about your

FEMALE : umm I tried to eat healthier

INTERVIEWER: Did anything change? FEMALE: I felt healthier

The interview with the 17 year-old male provided meanings of healthy with a broader view, his response included the following description of himself and viewpoint of body image.

MALE:" Well I was overweight since I was about 8 years old and we lived in Maine. and it became really hard then but then when we moved here it was harder. I did not have many friends and I remember being like only one of the big kids in my class. – I remember that there I just felt like I did not belong-I mean it was nice that some kids would pick you because you were bigger because you may be stronger, but I am not stronger. Big does not mean strong.

In relationship to body image the female added her idea of her own growth pattern and idea of strength.

INTERVIEWER: So are you still growing?

FEMALE: Well I guess, I think so, I hope I want to get taller----I am short

INTERVIEWER: How much taller do you want to get? FEMALE: I don't know

INETRVEIWER: Why do you want to be taller?

FEMALE: Because I'm short---I am shorter than everyone else.

INTERVIEWER: Do you think you being short affects anything- like playing sports?

FEMALE: NO.. Not those that I play.

INTERVEIWER: On a scale of 1-10 where do thing you fall in regard to strength---

FEMALE: I guess an 8.

Parents were asked, what they felt promotes making changes in one's lifestyle regarding food and exercise habits and they replied; "*age, variety, HEALTH*" and – "*for my daughter the way she looks*". The parent's answers were related to their child's responses. Conversational notes from telephone conversations with parents prior to appointments and followed after initial contacts closely matched the child's ideas and attitudes.

Results from a qualitative study of children, parents and teachers found children aged 8 to 12 years general concerns were about their physical appearance and performance. Attitudes toward healthy lifestyles or having good health were not a concept. More often healthy eating had negative connotations such as parents making them eat fruits and vegetables. They stated that "fitting in" and not being seen as "different" were major concerns (Borra et al., 2003).

Both of the children interviewed reported on strength and size. Each reflected on body image. The perceptions of being healthy and environmental influences supports several theories (see Figure G1).

The social learning theory model and socio-ecological model are the premise behind the Health Belief Model and the Transtheoretical Model for the stages of change. One of the stages of change includes taking action, a second theme that evolved (Theory at a Glance, 2000).

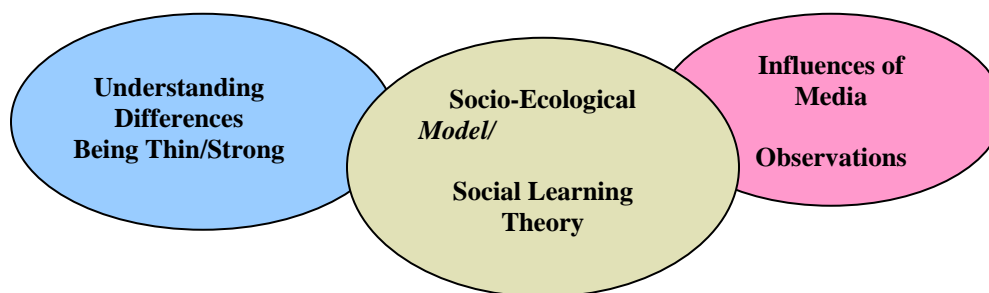


Figure G1: Diagram of Relationships

Motivation: Taking Action

Motivating factors encourages the continuation of making decisions and also looking for the knowledge needed to make change. During the interviews the children were asked what made them decide to make changes in their daily diet and activity. The individual accounts of what inspired these decisions vary for each child. For the older child, the motivation is based on emotion and assessment of his health and family. He states:

“and then I just got really depressed and one day I thought I am really feeling bad and anxious and I told my mom I thought I was going to have a breakdown about this and then we came to see you, and then my mom because of her health –you know she is middle aged and there are lots of problems that can happen so I wanted to do this and she said she needed to lose weight and she started the Atkins diet, so she started following a diet and I wanted to do this too”

A person’s self-efficacy or the conviction that one can be successful to execute a behavior is required to produce the desired outcome. More often for those 8-12 years of age concerns are a result of failed athletic ability. For the 12 year-old female, the motivation is based on desire to be accepted within a group. She states:

INTERVIEWER: OK, so what about exercise-did that change?

FEMALE: I got more of it. Well, At school you can’t be on a team until you are in seventh or eight grade and I had to get more exercise so I could make the team, so that kind of helped.

INTERVEIWER: Which team was that? FEMALE: Volleyball and softball

INTERVEIWER: And now you can play volleyball and softball

FEMALE: Yeah, I’m not playing now but I help teach swim lessons and am on track, our volleyball team meets twice a month-it’s a training league.

Motivating factors include the continuous feedback and support from someone or something. Cognitive Social Learning Theory proposes that reinforcements are not the sole determinants of behavior but that behavior changes with the observations of others.

Support/Self-Esteem

Two themes emerged based on the concept of reinforcement, these themes include support and self-esteem. Support from either parents', peers, coaches and teachers are often found the most influential. Support may also be drawn from resources or feedback. Support and feedback increases the self-esteem for an individual as well. The motivation for the young female was to make a team, this decision was supported by her parents. From field notes her mother was very involved in setting up appointments and setting goals. The interview transcriptions demonstrate the recall from the child of how she was supported by parents.

“ INTERVIEWER: so how did you, did you go to a volleyball camp to get the exercise to make the volleyball team or what did you do on your own?”

FEMALE: I got a ball and started practicing, and my dad played volleyball and he helped me

FEMALE: I jogged and rode my bike, stuff like that

INTERVIEWER: so you had a good reason and your Dad was good coach or resource?

FEMALE: yeah

INTERVIEWER: What about knowing what foods to eat? How did you know what would be a better choice?

FEMALE: umm my mom

The interview with the male child also revealed support from his mother, but also included those outside the home such as friends and doctors.

THE MALE CHILD STATES: well my mom was starting with the Atkins and she asked the doctors if they thought that was OK for me and then we started following that and doing palates and you know our whole family is overweight so we all needed to do this”

“ well, I was at 250 and I am now at 216 so 34 pounds since really September.

My friends noticed –that’s about all”

Additionally, later in the interview the male expresses his own feelings about the changes in his body and appearance and reflects by stating:

“ Well, most have seen it in my face – I mean they are like—WOW-- you look so different you look really good they can’t get over my face I mean that has been the most difference-- I mean my neck was so fat (he pulls at his neck) and then the acne was really bad I mean you really don’t know it is hard to describe but this is the most difference.

The other thing is that it is really weird where the weight comes off, like I lost weight in my feet and my hands and my neck, and my back-I did not realize how much fat was on my back that’s really nice because when I go shopping for clothes I say “I need a large” not an extra Large. This really feels good. pants and now I am a 36 in a pant—for a 15-year-old 38 pants is just too big.”

INTERVEIWER: that must make you feel really good that they notice has anyone else noticed like teachers.

MALE: “no (long pause) not really that would be really nice if they had (seemed disappointed). Maybe, I don’t know.... but really it is just my friends and the doctors –the doctors have been really supportive Dr. B and Dr. A, they say you are doing great and just tell me to keep trying, well the doctors here Dr. B and Dr. A were very encouraging they would be so good at saying how well I was doing and just tell me keep it up and I was in a couple of weeks ago and I had weighed 220 and then I had a sinus infection and weighed 216 and that was really good to see”

These impressions and observations of others assist in helping the male child feel much better about his own accomplishments. The visits to the physician and the feedback have been motivators to continue with the efforts in maintaining a healthier dietary intake and exercise routine. The female child recalled her own accomplishments of being able to make a school team and previously noted that she assists with teaching swimming. The support of others within the child’s environment, even though these events are infrequent, they remain salient toward achieving feedback and encouraging further changes. Others observations and comments may be the critical component needed to move to the next stage of change.

Dealing with Difficult Situations/Making Choices

The third theme was making choices and dealing with difficult situations. In terms of handling situations that may encourage poor eating choices, one must be motivated and have adequate knowledge to address these issues. Thus understanding the motivating factors encourages the continuation of making decisions and achieving the knowledge needed. The food choices made or changed were discussed in each interview. Each child indicated how he/she dealt with making choices.

MALE CHILD STATED:

“We eat lots of broccoli, lots of broccoli. I think I have had too much broccoli with cheese. My mom will cook it and mash it because this is something that she likes to do—I don’t know why its

kind of weird --no white breads, rice, pasta, none of that –lots of meat- steaks and chicken –you can eat as much butter as you want and cheese-I eat a lot of cheddar cheese.

INTERVIEWER: Do you think you will ever eat bread or pasta again?

MALE:” we tried the low carb bread .. it really was not that good., I used to eat a lot of candy and sweets but I know how much this has made a difference. and what I eat .. I mean I did not realize how much I was eating and how bad some foods are- all those white foods and carbs and I would just eat sweets. Oh yeah and fruit – you can’t have a lot of fruit.”

FEMALE CHILD STATED:

“Umm instead of chips for snacks, I would eat apples.

Umm instead of Taco Bell, which is where we used to go a lot, we got Subway.”

Both children discussed how they coped with choices regarding hunger/satiety and how they resolved these feelings.

MALE: I do get hungry but I also get used to it. We eat a lot of vegetables especially broccoli, I get hungry –like now, I’m getting hungry now :I try to do something else, like go study or do something, just not think about it, and palates have really helped. But I haven’t been doing those as much lately.

FEMALE: “Umm I ride my bike more, and then my bike broke (laughs)...

Umm, I would rather have chocolate but I went with it”

Feelings of hunger occur everyday and in many cases depending on the environment, foods may be available that are tempting and make it difficult to abstain. In the parents’ survey, the parents commented on how they managed the home environment. The parents remarked on influences that assist with promoting changes in lifestyle. These statements were provided on their surveys:

“Parents should focus on one habit at a time, i.e... eat breakfast, drink water, decrease carbonated beverages. When you get one under control go to the next. Parents control what food comes into the house, when meals are served and that the child is at the table. This starts at birth.”

Knowledge

Knowledge is an important part of learning and making the choices. For instance, in one interview we discussed making a game for children. The idea the child thought would be fun was a game called FOODOPOLY (re-make of MONOPOLY), a fun way to learn about making healthy decisions or food choices. She describes the game as follows:

“OK, there would have to be this one character that goes around and chocolate would have to be the bad person

INTERVIEWER: So let's think about that and that you are the good person, playing the game foodopoly in the past 2 years what were the bad things –

“: Too much candy “

INTERVIEWER: And how many times did you have too much candy?

“: I don't know—a lot”

INTERVIEWER: A lot why was that bad?

“: Because it was not healthy”

Labels were often placed on foods-as good and bad. This perspective of good and bad foods continued in the interview with the male child.

INTERVIEWER: Do you think you ever will eat any of those foods?

MALE: “ maybe but I am so focused right now and I know how much a difference it makes, I do miss pasta, I loved spaghetti I think I might eat bread and pasta again but it will be awhile .I just don't want to blow it I have worked so hard. The hardest is not having spaghetti because I really like this “

During educational counseling sessions, the focus is to have a client identify the healthier foods. The concept is used so when a variety of choices are available the child will eventually select those items with greater nutrient content or less caloric value. During the interview with the female, a variety of food items were placed on a table. She was asked questions regarding selections and actual label content. Her responses were:

FEMALE: “Brownies”

INTERVIEWER: You are Right!!! –(as we compared the sugar content on the brownies, cookies and cracker packages).

INTERVIEWER: So according to the food pyramid that you know so well.. how would you rate snack choices

FEMALE: Oh.. about a seven

INTERVIEWER: So what are your top five snack choice?

FEMALE: um – soup and ummm apples

Having the knowledge does not always indicate that the behaviors will change. Younger children often repeat what they have been told, but they act by following what someone does or provides as an example. In the two pilot interviews, the children both had some knowledge of food items and were able to select healthier, more nutrient dense options. The understanding of making the choices and why foods were selected was not portrayed. The most common influence for the food choices made for these two children were often food availability in the home.

Ideas for Others

During both interviews, the children were asked what ideas they may have for a class that provides information to families on how to make changes in everyday life regarding weight. This was presented in the form of asking the child to consider making up a skit or TV commercial that would promote this theme. The male child had many ideas on this theme. His responses and ideas included:

MALE: “ well the best thing is to do this for yourself and not for someone else – you have to want to feel good about you—not the girls or trying to look like someone else – like having a six pack abs – I’m not like that and I won’t I mean that is not the type of work that I want or want to do to get that –although I do like the palates and that has helped a lot and I would like to join maybe a gym because I want to firm up some but you have to do this for you and your health.”

INTERVIEWER: What do you want to do in the future? If you were going to put one a play or something how would you do this what type of script would you write?

MALE: “ well I would have someone who is fat or not real skinny because that is more realistic and they should tell him or her that they did...if someone is skinny they do not know how others may make them feel. I would talk about the different diets and what is right and not right and what may be best for one person but not another, I would tell the what I did and how this worked for me and but they may help find something for them “

He added:

MALE: “I would really like to do something for this country. I think we are in really bad shape and I would like to do something. I like acting and writing, I think this would be a good way I can express how I feel and get a message out. I think I could write a book or something like that.... That would be a goal.”

In the survey the parents completed they commented to the following questions:

What advice would you give to others your age trying to work toward losing weight?

Stick to what works, give support, do as a family.

What advice would you give to others your age trying to work toward making healthy choices or trying to achieve a healthy weight?

Make it fun, get support, stay focused. Hard to stay on track until you see results, then it’s easier. I think she feels better and is more active than before.

Stressors/Emotions

The last theme emerging from interviews were the effects of stressors and emotions that may influence changes. During each interview and in other sections these were also combined with the themes discussed as motivators. The effects of life transitions and stressors on weight interact with quality of life. For children these may be deaths or illnesses of pets, close friends and family members, divorce or separation, changes in schools, or transitions such as leaving home. The male expressed his emotions of how he was anxious about his appearance. He also indicated that previously the following events occurred.

*“Hum my dog got sick and that was hard so we gave him away
because we had a hard time with this and let’s see....
My grandfather passed away –that was really hard because we were really close”*

The female indicated that she moved into middle school and this created a desire to be on a school team, possibly the desire to belong. For many children, the desire to belong can be an added stressor or add emotions that they have difficult adjusting. Often, food can be a security item, or used as a means of control, resulting in two types of disorders, anorexia nervosa and binge eating.

Discussion

The purpose of this pilot study was to describe the motivating factors and influences toward making changes in diet and exercise for children who were working at achieving a healthy weight. Interviews with a 12 year- old female and 17 year- old male were conducted. Each interview provided a glimpse of their own perceptions and meanings of how they approached changes in their lifestyle regarding diet and exercise. Themes that emerged support many of the theories surrounding the social learning theory, stages of change model, health belief model, and the Socio-Ecological model (Theory at a Glance, 2000).

One of the interests was to investigate how the children perceive a healthy weight and why is a certain weight desired. Differences were noted amongst the male and female interviewed on their desires or goals toward weight and impressions of others. Both reflected on strength and body composition as important factors related to health. For both children, achieving a specific weight, was not the motivator, more importantly was “feeling better” about themselves. The perceptions the children shared about being healthy related to strength and physical well-being (less tired,

more energy). Healthy was not defined as a certain BMI or weight because of height. The children's perceptions and definitions are important as they addressed one of the issues presented, if there are different meanings regarding what is healthy. These meanings are important for clinicians to recognize. Often secondary complications such as high cholesterol or prevention of diabetes are used to promote change. Addressing issues such as; how often are you tired, how do you feel after participating in gym, when you look in the mirror what do you see; are questions worth pursuing. The children's meaning reiterate what other qualitative studies have found that general concerns were about their physical appearance and performance (Borra, 2003). Attitudes toward healthy lifestyles or having good health were not a concept.

Suggestions for working with teens are to reinforce that they are normal, build trust through sharing personal experiences, be genuine, not the "expert" adult, be nonjudgmental and respectfully curious about their experience, and support self-awareness rather than expecting compliance (Ominshinski & Harrison, 2004).

Who or what were influences? What motivated the child to take initial steps toward making changes? The influence of parents and physicians appeared to be the most common influence that evolved from the interviews. The emphasis of support systems, resources available, parents, friends, and physicians cannot be over-emphasized. In the interviews of both children, the mother and the child's physician had an impact on the progression of making changes but also supporting the change and providing positive feedback. Quantitative studies reviewed found that questions and constructs were based on responses of adolescents and their own perceptions, beliefs and habits. Parental concern was addressed, but only from the perspective of the adolescent (French & Story, 2001). In these interviews there seems to be a reciprocal effect for parental involvement, what may be critical is the amount and extent of involvement and support versus parental control. Schluterman, Fox, & Benson (2003) analyzed the relationship of parenting style and BMI using data from Wave 2 of the National Survey of Families and Households demonstrating interactions between parenting style and BMI on outcome measures of self-esteem, self-efficacy and life satisfaction.

Parents, friends, teachers, coaches and physicians may have a critical impact on a child's progress. Qualitative studies that have been conducted with children and adults are few. Borra et al. (2003) inquired with teachers and parents what their attitudes, perceptions and behaviors were

in regard to preventing overweight in childhood and explored potential avenues for communicating messages. Themes that evolved from this study were needing attainable goals, self-esteem issues, communication challenges such as “where do I start” and parenting skills and priorities.

Each child reflected on the changes they made in relation to diet and activity. Each child increased the amount of activity and decreased foods that were in high in sugar. Controlling the amount they consumed and monitoring portions were other methods of modifying dietary intake. In the interviews, these specifics were not noted by the children, but they were able to provide explanations of what food items and activities made differences in achieving overall changes in both weight and body composition.

Family messages are also important. The experiences the parents conveyed as the child approaches weight loss methods and achieves goals were valuable. Parents’ advice for others included to make it fun, get support, and stay focused. They mentioned that it is often hard to stay on track until you see results, then it’s easier, and to keep trying to find healthy choices that the child likes. Along with the children, the parents mentioned their perception on how the child felt “ I think she/he feels better and is more active than before “.

These interviews were pilot interviews, additional in-depth interviews for this phenomenological studies with children achieving a healthy weight are required to saturate the data. Children of both genders are needed and ideally a child representing each life stage in the pre-post teen years would elaborate on the influences and cognitive learning skills. Those children experiencing stressors and/or life changes such as parental divorce, joint-custody, parental health problems, poverty, or changing schools are also needed. The impact of stressors on diet quality and food availability, transportation and food selection is an issue requiring more knowledge. These impact on the role of social support, appetite, food regulation, eating habits, and multiple caregivers can complicate the situation.

Future Implications

These pilot interviews support many frameworks but also suggest ways in which a five-minute conversation from a health practitioner may have great impact. Health practitioners have reflected on the barriers they experience when addressing overweight children (Story, 2002). In addition to not feeling adequately skilled, they felt that they might offend mothers when talking

about weight, counseling was driven by protocols, and their nutritional advice often conflicted with the advice from the mothers' relatives, friends, or primary care physicians (Chamberlain et al., 2000). Motivational interviewing has begun to replace traditional interviewing in nutritional counseling as well as general pediatric counseling and is an area worth exploring. What a doctor says in the office setting has been noted as effective in the adult settings, but the influence in pediatric settings is of further interest (Glasgoe, 1998).

How influential parents can be, especially during the teen years is of great interest. Exploring parenting style and establishing parental guidance classes at schools and churches for those parenting different life stages may be excellent ways to enhance parenting styles and provide support networks.

Another concept that pursued from this study was how the voice of the child becomes imperative when discussing intervention programs for children and families. Children provided great insight and have excellent ideas, using their words, skits, and role- playing scenarios may enhance current programs, community classes on wellness, school based curriculums, community service projects and vocational programs.

APPENDIX H

Interviewer's Experience with Phenomenology

The purpose of using phenomenological inquiry was to gain insight about the experiences and perceptions children have related to disease prevention and changing lifestyles. Using the phenomenological approach allowed each child to provide his or her own story as well as guide the interview. Several questions were constructed throughout the interview. Questions were often reworded to guide and help the child elaborate on their own thoughts and experiences over the past years. All children were very open and shared their understandings, habits, and challenges of dealing with lifestyle changes and confronting the problem of possible disease. As an interviewer the process of identifying those who had achieved successful outcomes had its rewards and challenges. Conducting the interviews was very rewarding. Children and parents were excited to be able to share their stories and often went beyond what was expected to participate; this was without the knowledge of obtaining an incentive. Before the interview many parents relayed to the interviewer either on the phone or after the interview was conducted their perspective of the physiological changes the child had accomplished, short stories of their feelings, and pride in the child's accomplishments. This made conducting interviews very easy and often led to few introductions, as children were quite enthusiastic to reveal their experience.

After each interview, themes were constructed. Themes from one interview to the next were very similar but each individual offered a new perspective that related to a theme already developed or new theme. As all stories evolved, each story or experience differed and became unique to what I considered the child's personality.

Of the children interviewed the boys (2/10) spent less time talking about their emotional experiences. Often during these interviews several questions or the child's responses were repeated as a means to clarify what was meant and help lead the child into another part of the story. One of the boys adapted very well during the interview once the subject was changed from health and behavior to the child's current or future ambitions. The interviewer/researcher specifically asked details about an activity, assuming this would help the child feel that he was "the expert" and create another opportunity so that he could feel rewarded about his accomplishments. Having the ability to incorporate the child's interests is very helpful when establishing rapport with the child as well as finding means to decrease anxiety and communication barriers.

The females interviewed were very open about the relationships they had with friends and boyfriends. Although this was not the main focus of interviews, it became a very important leading conversation during the interview process. Girls eagerly expressed their emotions and past experiences that led to how they developed a greater appreciation of their character and increased self-esteem. These young women also were very open with their stories and were eager to share how the process of becoming healthier led to improved self-image, self-confidence. Throughout the interview a sense of maturity and pride appeared to develop.

VITA

Juliann Chavez was born in Dallas, Texas in 1964 . She attended St. Monica Catholic school and Ursuline Academy in Dallas. She has nine sisters and three brothers. Her parents are William E. Walker and Doris M. Walker.

Juliann Chavez received her Bachelor of Science in Scientific Nutrition and a Master's degree in Nutrition with a minor in Sociology at Texas A&M University. She completed her dietetic internship in the U.S. Army and continued on active duty as a dietitian for 12 years. During her years in service, Juliann Chavez specialized in pediatric nutrition and provided nutritional therapy to all ages. During her military career, she also managed a hospital cafeteria and taught at the Army Medical Department Center and School in San Antonio, TX. She assisted with several research studies, developed program objectives for nutrition and physician assistant programs, and spear-headed community health education for families at local schools and child care centers.

In 2000, Juliann Chavez and her family moved to Knoxville, TN. Her interest in education and research continues. Currently she is pursuing research in the community and clinical settings as a doctoral candidate in Child and Family Studies. Juliann Chavez, works with Knoxville Pediatric Associates as a consultant, and continues seeing families and children today at each office location. In 2003, the opportunity to work with a grant through Children's Hospital emerged, allowing her the opportunity to provide and construct nutrition classes at the hospital and throughout the community.

Juliann M. Chavez is a clinical dietitian and provides individual counseling, group classes, and community education throughout Knoxville and East Tennessee. Her primary focus is on child and family nutrition, with an emphasis on disease prevention.