Anxiety in Children/Youth with Bowel and Bladder Dysfunction and Their Parents: Impact of Medical, Educational, and Psychosocial Factors

Leslie Cristen LaVergne

University of Southern Mississippi

Follow this and additional works at: https://aquila.usm.edu/dissertations

Recommended Citation

LaVergne, Leslie Cristen, "Anxiety in Children/Youth with Bowel and Bladder Dysfunction and Their Parents: Impact of Medical, Educational, and Psychosocial Factors" (2012). Dissertations. 803. https://aquila.usm.edu/dissertations/803

This Dissertation is brought to you for free and open access by The Aquila Digital Community. It has been accepted for inclusion in Dissertations by an authorized administrator of The Aquila Digital Community. For more information, please contact Joshua.Cromwell@usm.edu.
ANXIETY IN CHILDREN/YOUTH WITH BOWEL AND BLADDER DYSFUNCTION AND THEIR PARENTS: IMPACT OF MEDICAL, EDUCATIONAL, AND PSYCHOSOCIAL FACTORS

by

Leslie Cristen LaVergne

Abstract of a Dissertation Submitted to the Graduate School of the University of Southern Mississippi in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy

May 2012
ABSTRACT

ANXIETY IN CHILDREN/YOUTH WITH BOWEL AND BLADDER DYSFUNCTION AND THEIR PARENTS: IMPACT OF MEDICAL, EDUCATIONAL, AND PSYCHOSOCIAL FACTORS

by Leslie Cristen LaVergne

May 2012

Children and youth with special health care needs are impacted both physically and psychologically by their medical condition. Furthermore, parents of children with special health care needs experience increased symptoms of anxiety related to their child’s condition. Literature suggests the negative impact may be lessened by providing psychosocial family-centered supports. This study investigated the anxiety levels of children with bowel and/or bladder dysfunction and their parents, finding the relationships of anxiety among mothers and child/youth, as well as mothers and fathers. No significant relationship was found among fathers and child/youth. Further, it explored the impact of medical, educational, and psychosocial factors of proximity to specialized medical care, presence of a medical home, income, school absences, formal educational planning, professional support, and non-professional support as potential predictors of child/youth and parental anxiety. Results indicated income, school absences, and gender of parents had a significant impact on the anxiety scores of the parents, but not significant to the child’s anxiety scores. Non-professional support was found to be potential factor in relation to parent anxiety.
ANXIETY IN CHILDREN/YOUTH WITH BOWEL AND BLADDER DYSFUNCTION AND THEIR PARENTS: IMPACT OF MEDICAL, EDUCATIONAL, AND PSYCHOSOCIAL FACTORS

by

Leslie Cristen LaVergne

A Dissertation
Submitted to the Graduate School of the University of Southern Mississippi in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy

Approved:

Dr. Hollie Filce
Director
Dr. Richard Mohn

Dr. Marge Crowe

Dr. Dana Thames

Dr. John Bishop

Dr. Susan A. Siltanen

Dean of the Graduate School

May 2012
ACKNOWLEDGMENTS

I would like to thank the dissertation chair, Dr. Hollie Filce, and the other committee members, Dr. Richard Mohn, Dr. Dana Thames, Dr. Marge Crowe, and Dr. John Bishop for their support throughout the duration of this project. I would especially like to thank Dr. Hollie Filce for her guidance and patience even when I know it was not easy. Furthermore, special thanks go to the Department of Curriculum, Instruction, and Special Education at the University of Southern Mississippi (USM) for providing a challenging and supportive academic community.
TABLE OF CONTENTS

ABSTRACT ....................................................................................................................... ii

ACKNOWLEDGMENTS ................................................................................................. iii

LIST OF TABLES ............................................................................................................. iv

CHAPTER

I. INTRODUCTION ............................................................................................ 1
   Children with Bowel and/or Bladder Dysfunction
   Parents of Children with Bowel and/or Bladder Dysfunction
   Theoretical Framework
   Statement of Problem
   Purpose of Study
   Research Questions and Hypotheses
   Limitations and Delimitations
   Definition of Terms
   Conclusion

II. REVIEW OF RELATED LITERATURE ................................................. 18
   Children with Bowel and/or Bladder Dysfunction
   Educational Needs and Supports
   Medical Needs and Supports
   Psychosocial Needs and Supports

III. METHODOLOGY .................................................................................... 54
   Research Questions and Hypotheses
   Population and Sample
   Data Collection Procedures
   Instrumentation
   Dependent Variables
   Independent Variables
   Data Analysis Procedures
   Summary

IV. ANALYSIS OF DATA .............................................................................. 66
   Research Questions and Hypotheses
   Analysis of Data
Frequencies and Descriptives of Demographics
Frequencies and Descriptives of Instrument Outcomes
Correlation Analysis Outcome
Multiple Regression Analysis
Summary

V. SUMMARY ........................................................................................................87

Summary of Findings
Discussion
Anxiety in Study Participants
Factors Related to Anxiety in Parents
Implications for Practice
Recommendations for Further Research
Summary

APPENDIXES .......................................................................................................109

REFERENCES .......................................................................................................120
# LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Common Causes of Anxiety According to Age</td>
<td>43</td>
</tr>
<tr>
<td>2.</td>
<td>Summary of Population Diagnoses</td>
<td>69</td>
</tr>
<tr>
<td>3.</td>
<td>Summary of Population Age</td>
<td>70</td>
</tr>
<tr>
<td>4.</td>
<td>Summary of Educational Plans and School Absences</td>
<td>71</td>
</tr>
<tr>
<td>5.</td>
<td>Summary of Family Income</td>
<td>72</td>
</tr>
<tr>
<td>6.</td>
<td>Summary of Proximity to Care</td>
<td>73</td>
</tr>
<tr>
<td>7.</td>
<td>Summary of Professional and Non-Professional Care</td>
<td>74</td>
</tr>
<tr>
<td>8.</td>
<td>Suggested Score Range for RCMAS-2 and AMAS-A Scales</td>
<td>75</td>
</tr>
<tr>
<td>9.</td>
<td>Overall Frequencies and Means for RCMAS-2 Total Anxiety</td>
<td>76</td>
</tr>
<tr>
<td>10.</td>
<td>Overall Frequencies for Fathers AMAS-A Total Anxiety</td>
<td>77</td>
</tr>
<tr>
<td>11.</td>
<td>Overall Frequencies for Mothers AMAS-A Total Anxiety</td>
<td>78</td>
</tr>
<tr>
<td>12.</td>
<td>Correlations</td>
<td>80</td>
</tr>
<tr>
<td>13.</td>
<td>Model Summary for RCMAS-2</td>
<td>81</td>
</tr>
<tr>
<td>14.</td>
<td>ANOVA Summary for RCMAS-2</td>
<td>81</td>
</tr>
<tr>
<td>15.</td>
<td>Model Summary for AMAS-A Fathers and Mothers</td>
<td>82</td>
</tr>
<tr>
<td>16.</td>
<td>ANOVA Summary for AMAS-A Fathers and Mothers</td>
<td>82</td>
</tr>
<tr>
<td>17.</td>
<td>Coefficient Summary for Fathers and Mothers</td>
<td>83</td>
</tr>
<tr>
<td>18.</td>
<td>Model Summary for Fathers AMAS-A</td>
<td>84</td>
</tr>
<tr>
<td>19.</td>
<td>ANOVA Summary for Fathers AMAS-A</td>
<td>84</td>
</tr>
<tr>
<td>20.</td>
<td>Model Summary for Mothers AMAS-A</td>
<td>85</td>
</tr>
<tr>
<td>21.</td>
<td>ANOVA Summary for Mothers AMAS-A</td>
<td>85</td>
</tr>
</tbody>
</table>
CHAPTER I

INTRODUCTION

The National Center for Education Statistics reported the number of children and youth between the ages of three and twenty-one receiving special education services has increased each year since the development of Individuals with Disabilities Education Act (1997). In 1976 through 1977 an estimated five percent of all children and youth in public schools were served by services provided by mandates under IDEA. By 2006 that estimate increased to approximately nine percent. Specifically, students who qualified under Other Health Impairment (OHI) accounted for nine percent of students with multiple disabilities such as hearing impairment, orthopedic impairment, visual impairment, traumatic brain injury, or deaf-blindness (Aud et al., 2010). Furthermore, the most recent National Survey of Children with Special Health Care Needs (CSHCN) reported an estimated fourteen percent of children in the United States (U.S.) under the age of 18 had a special health care need. Additionally, the survey reported an estimated twenty-two percent of households in the U.S. had one child with a special health care need (U.S. Department of Health and Human Services, 2000).

While both IDEA and Section 504 of the Rehabilitation Act of 1973 identify CSHCN as eligible for services in an educational setting, identification of these children may be difficult. Difficulty in identification may be due to the complexity of their conditions and the impact the special health care need has on the child’s ability to adapt to the school environment. According to Palfrey, Singer, Walker, and Butler (1986) 47.8% of children who received special education were affected by chronic health conditions and 17.8% had multiple health conditions. In order to fully benefit from
school, CSHCN frequently require additional services and/or accommodations related to their health needs through the course of the school day. Both the physical and psychological effects of the chronic condition are an important aspect to be taken into consideration when providing services and accommodations related to the child’s health and learning experience in school (Lowe, 2005). In order for the school to provide appropriate services some suggest, parents, educators, and medical personnel work together to develop educational and health plans which benefit the child in the school setting (Lowe, 2005).

Parents of children with chronic illness are at higher risk of psychological distress, including depression and anxiety (Berge & Holm, 2007; Lopez, Mullins, Wolfe-Christensen, & Bourdeau, 2008). Berge and Holm (2007) indicated the increase in psychological distress may be due to uncertainty regarding the progression and/or prognosis of illness. Furthermore, Boss & Greenburg (1984), reported parental anxiety related to the child’s health can lead to boundary ambiguity. Boundary ambiguity includes two concepts: 1) expectations about who is in charge of what tasks in the family system and 2) perceptions of who is included and excluded in the family system. Specifically, boundary ambiguity can occur when a lack of clarification occurs concerning what behaviors or roles are expected of family members regarding the care of the child with the chronic illness. This lack of clarification can lead to role confusion and dysfunction within the family system.

Parents of children with chronic health conditions often overcompensate for the child’s illness (Ludman, Spitz, & Kiely, 1994). This overcompensation may be a result in an attempt to decrease anxiety and other psychological symptoms associated with the
stress of daily care of a child with chronic illness. As a result, the child may not learn the
needed self-care and independence in order to be successful across environments and
may have difficulty adapting to the illness. Thompson, Gustafson, Hamlett, and Spock
(1992), described adaptation to illness as a complex set of interactions which included
medical, developmental, behavioral, familial, and psychosocial factors.

Children with Bowel and/or Bladder Dysfunction

Within the broader category of children with special healthcare needs are those
whose conditions impact their continence. Bowel and bladder dysfunction are associated
with abnormalities in either storage or elimination of urine or feces (Berry, 2005). These
children often require strict diet commitments and experience fatigue, pain, decreased
physical condition, hospital admission, surgery, use of medication, and/or incontinence.
Common diagnoses impacting continence include, but are not limited to, neurogenic
bladder, enuresis, imperforate anus, Hirschprungs’s Disease, Crohn’s disease, and Irritable
Bowel Syndrome. These children not only have physical effects, but psychological as
well (Caldwell et al., 1997; Needham, Crosnoe, & Muller, 2004).

Parents of Children with Bowel and/or Bladder Dysfunction

Like their children, parents have been shown to be impacted psychologically by
chronic illness in their children. A pilot study was conducted which investigated the
psychological status of children with bowel dysfunction and their mothers (Funakosi et
al., 2005). The results of the study indicated, in most cases, anxiety and depression were
present in both the mother and child which required some form of psychiatric
intervention. Furthermore, mothers of children with anorectal malformation aged six
years or younger had higher levels of anxiety and depression than mothers of affected
children ages 7 to 11 years. While there is a limited amount of research related to psychological status of children with bowel and/or bladder dysfunction and their mothers, to date there is no report on the status of both mothers and fathers of these children.

Theoretical Framework

An individual’s first experiences of interpersonal relationships are with and through the family. Families are compromised of people who have a shared history and can have a strong influence on each other’s beliefs, behaviors, and/or relationships (Carter & McGoldrick, 1999). Until recently, professionals in the field of psychology focused on the individual and not the family as a system. From the family life cycle perspective, functioning, development and symptoms are examined within the context of the family culture, as well as, the roles and responsibilities of each family member. The following family models provide theories regarding family functioning during times of transition and change. The Transactional Stress and Coping Model offer a theoretical basis for successful transition, specifically for mother and child, during a time of social change within the family, including the diagnosis of a chronic illness. To broaden the theoretical frame work the Family Systems-Illness Model was included to encompass the family as a whole, not just mother and child.

Transactional Stress and Coping Models

According to El-Matary (2009) children with chronic illness face many obstacles in daily life, including illness adjustment. Children with special health care needs often require multiple therapies such as physical, speech, and occupational therapies to aid in managing symptoms of illness (Gasalberti, 2006). These obstacles and therapies can often be very involved and time consuming for both the child and caregiver and require a
positive adjustment to illness in order to be effective. Positive transitions to illness are reported to be the result of successful planning, implementing, evaluating and balancing the lives of the parents with the details of the child’s life in order to achieve family cohesion and increased quality of life (Ankeny, Wilkins, & Spain, 2009).

As a result of increased complication of daily life, children and families are at risk of developing psychological distress (Hocking & Lochman, 2005). Variability in adjustment can be the result of disease severity, family dynamics, and psychosocial adjustment, all of which mediate the relationship between illness and psychological adjustment. Research regarding child and parental adjustment to illness has shifted from studying specific illness characteristics to family-systems based research. The Transactional Stress and Coping (TSC) model is a theoretical model based on Bronfenbrenner’s ecological systems theory (Hocking & Lochman, 2005). The model depicted chronic illness as a stressor to which the family and child attempt to adapt. The TSC suggests adjustment to illness is not a direct function of the illness, but mediated by transactions between the illness (type and severity) and demographic (age, gender, and socio-economic status) characteristics, and child and maternal adaptation processes. The primary focus of the model is the child and maternal adaptation processes which is theorized to be correlated with adjustment to illness of children and their mothers over factors such as illness severity and demographic characteristics.

Pinquart and Silberseisen (2004) conducted an analysis of theoretical considerations on prominent psychological theories regarding human development in times of social change, including the TSC. The authors defined social change as changes that took place within family, school, work life, or a broader social system. As a change
occurs, such as diagnosis of chronic illness in the family, the individual is confronted with immediate developmental decisions that set up possible constraints to further possible developmental change. According to Valsiner (2006), these constraints can result in limiting development of the individual and the family, which can increase uncertainty among family relationships and change the course of development. The diagnosis of a chronic illness can be a constraint on families and requires social change within the family dynamics. Often roles are shifted and decisions made at the time of diagnosis and directly after can affect the developmental change of the family and child.

*Family Systems-Illness Model*

While the TSC provides a helpful structure in which to explore family adjustment to illness, it is specific to the mother and child interaction, and does not include the family as a whole. In order to broaden the scope and depth of insight into families of children with chronic illness, the Family Systems-Illness Model (FSI) may provide further insight. The FSI is useful in the discussion of psychosocial factors affecting children with chronic illness and further describes the need for treatment of the family as a whole.

The FSI is based on the systematic interaction between an illness and the family over time. It provides a psychosocial guide for psycho-education, assessment, and interventions for families with chronic illness and/or disability (Rolland, 1999). The FSI identifies psychosocial implications of the illness, family functioning, and resources as the primary determinants of successful versus dysfunctional coping and adaptation to chronic illness. The model includes three dimensions: 1) psychosocial types of disorders; 2) major developmental phases; and 3) key family variables. The model was
developed to attend to expected demands of phases of the illness and/or disability; family system dynamics regarding developmental challenges; multigenerational coping patterns related to illness and loss; and belief systems including culture, ethnicity, spirituality, and gender. The model seeks to identify the psychosocial demands of illness over time as well as the strengths and weaknesses of the family, thus allowing clinicians to identify potential challenges for a particular family and develop an appropriate intervention for coping and adaptation (Rolland & Walsh, 2006).

*Psychosocial typology of illness.* Typically, medical professionals classify illness based on biological criteria to establish a diagnosis and course of treatment for individuals with chronic illness. The psychosocial implications of the diagnosis are rarely included in this practice, which often leaves families without psychological supports and services. The FSI psychosocial typology was designed to close the gap between the biological and psychosocial implications of chronic illness for patients and families. It can also provide treatment teams with a plan to conceptualize chronic illness in terms of those biological and psychosocial needs specific to an illness. Rolland and Walsh (2006) suggested grouping chronic conditions according to critical biological similarities and differences that may have distinct psychosocial challenges. The practice of illness patterning can vary in terms of onset, course, outcome, incapacitation, and the level of uncertainty regarding prognosis and path of illness.

*Onset.* Rolland and Walsh (2006) defined onset of illness as acute or gradual. Acute-onset illnesses often require affective and practical treatment plans that are compressed into a short time. This requires professionals to mobilize rapidly and have appropriate crisis management skills. Families of individuals with an acute-onset illness
often have increased stress with heightened emotional responses. In such situations, families may need guidance to tolerate the high stress environment in order to make sound decisions and problem-solve effectively regarding important decisions related to the health of their family member. The onset of bowel and/or bladder dysfunction may occur at birth due to a congenital issue or later as a result of an illness or injury.

Course. According to Rolland and Walsh (2006), chronic illness can follow three broad trajectories: progressive, constant, or relapsing/episodic. Progressive illnesses were defined as chronically symptomatic and worsen gradually over time. The family often experiences the constant presence of symptoms and the possibility of continual role changes as the illness progresses. Family members may experience increased strain and exhaustion with minimal relief from the demands of the illness including constant care giving and financial burden over a lengthened period of time (Rolland & Walsh, 2006).

Constant illnesses were defined as those that have an initial event followed by a stable biological course (Rolland, 1999). The course of illness can be predicted over a long period of time including potential disabilities that occur with a particular illness. The potential for exhaustion of psychosocial and financial resources can increase in families of individuals with constant illness, although minimal strain is placed on new family roles over time (Rolland & Walsh, 2006).

Relapsing or episodic illnesses were defined as those with periods of low-symptoms and stable that alternate with periods of increased symptoms and exacerbation (Rolland, 1999). Families of individuals with illnesses that relapse or are episodic can experience frequent transitions and a wide variation between crisis and non-critical periods, which can create uncertainty. In order for families to effectively function;
flexibility and increased organization need to be present. Worry or concern regarding reoccurrence can lead parents to be hyper vigilant in an attempt to control their child, which can create conflict between parents and child (Rolland & Walsh, 2006). When a child experiences bowel and/or bladder dysfunction, they may fall into any of these categories relating to course.

**Outcome.** The psychosocial health of an individual with chronic illness and his/her family can be reliant on the expected outcome of an illness. The outcome of an illness can vary regarding length of life span to death depending on the severity and type of illness. A family’s initial expectation and reaction to the outcome of illness is greatly affected by their ability to cope with death or dying, as well as, the experience of long-term care of an individual with a chronic illness. Children with bowel and bladder dysfunction often have a positive prognosis. However, surgeries and other invasive treatments are required for the children to remain healthy. During these procedures, it is possible for parents to experience a loss of control due to their child being at greater risk. In order for parents to cope with this anxiety, information and better understanding of complicated medical procedures and outcomes is reported to provide a sense of control and a decrease in anxiety.

**Incapacitation.** According to Rolland and Walsh (2006), disability can involve impairment of cognition, sensation, movement, stamina, physical disfiguration, and those associated with social stigma. The degree of family stress regarding incapacitation depends on the extent, type, and timing of disability. For example, combined disabilities caused by a traumatic injury often require families to reallocate roles in less time than a disability with a gradual onset. Some illnesses can cause more stress at the beginning of
onset and ease over time. Progressive illnesses and cause stress to build over time as the illness worsens, but also allow the family to adjust gradually. Again, children with bowel and/or bladder dysfunction experience a range of incapacitation levels.

Level of uncertainty. The degree of uncertainty regarding the path of an illness often becomes more important than all other variables regarding the illness (Rolland & Walsh, 2006). Family coping and planning can be hindered by anxiety related to anticipation and the unknown about what is to come regarding their family members health. Expectations of treatment and well-being can be upset when an illness changes course or when remission is shadowed by side-effects of treatment. According to Rolland and Walsh (2006), families who receive services to help put uncertainty in to perspective often avoid psychosocial risks related to exhaustion and dysfunction. Children and families with chronic illness often experience anxiety related to illness uncertainty due to the unpredictable nature of symptoms and prognosis. Inclusion of psychological counseling in clinics specific to children with chronic illness can greatly benefit the well-being of these children and their families by providing coping strategies and support regarding illness uncertainty (Cobham, Dadds, Spence, & McDermott, 2010; Wood, Piacentini, Southam-Gerow, Chu, & Sigman, 2006).

Developmental phases of individual and family. According to Rolland (1999), in order to place the cycles of chronic illness into a developmental perspective, professionals must understand the relationship between the illness, the individual, and the family cycles. For each variable of illness, the individual and family go through phases, each with its own developmental tasks. The presence of chronic illness can significantly alter a phase of development by its timing in the individual and/or family cycle.
According to Rolland (1999), life structure is defined as the underlying pattern of an individual or family’s life at any given stage of the life cycle. The life structure is made of various factors including job, raising a child, spirituality, and/or leisure and the importance of these factors in the overall well-being of the family. Individual development includes how individuals and the family as a whole can move between periods of transition, building, and maintaining these factors. Times of transition, including role changes due to a chronic illness, can often be the most challenging and leave a family vulnerable to increased stress and anxiety. During times of transition families and individuals must re-evaluate and take on new developmental tasks that can cause major changes in family dynamics. The main goal of the building and maintaining stage of life structures is to form a structure that enriches the life of the family as a whole in regards to important decisions the individual or family made during the previous transition stage (Rolland & Walsh, 2006).

*Family patterns related to illness.* The belief systems of a family are often developed through ongoing transactions including experiences and response to those experiences from previous generations, which can influence the perceptions and responses to current challenges. In other words, how an individual copes with stress can be learned from parents or grandparents. Shared beliefs can often help families develop a meaning of their illness experience, make decisions, and facilitate a link between the past, present, and future. Beliefs about health and medicine come from past experiences from previous generations including fears, suffering, death, and loss. Families with a high level of resilience have learned effective functioning and problem solving and approach adversity, such as chronic illness, as a shared obstacle. Clinicians can foster
resilience and decrease anxiety through helping a family make meaning of the illness experience and to normalize and contextualize challenges and distress (Rolland & Walsh, 2006).

Statement of Problem

Children with complex chronic illnesses often require a continuum of health care that includes multidisciplinary rehabilitation services and other preventive services, such as physical therapy, occupational therapy, and/or psychological therapy (Farmer, Clark, & Marien, 2003). Traditionally health care services have emphasized medical hospital and/or clinic based treatment with ancillary care provided by professionals outside of these settings. Over the past ten years a paradigm shift has occurred which focused on including community-based services which emphasized family-centered care (Farmer et al., 2003; Geist, Grdisa, & Otley, 2003). This shift was conceptualized to meet the medical, educational, and psychosocial needs of the child. Although this conceptualization is ideal for the future well-being of children with chronic illness and their families, the current health system falls short in providing these services (Berwick, 2002).

Family-centered treatment is often comprehensive and includes a multidisciplinary team consisting of educational, psychological, and medical professionals in order to meet the psychosocial needs of the child and his or her parents or caregiver. While it is generally accepted that well-being of the child and family are inter-related and influenced by many factors, there is little research investigating this team approach to treatment. There is even less known about the impact of various supports on children with bowel and/or bladder dysfunction and their parents.
Professionals in the field of education often lack the knowledge regarding health care and psychosocial needs of children and youth with bowel and bladder dysfunction and their families. Furthermore, professionals in the medical field often lack the knowledge regarding the psychosocial and educational needs of children and youth with bowel and bladder dysfunction and their families.

Purpose of the Study

The purpose of this study is to specifically explore anxiety in children with bowel and/or bladder dysfunction and their families. Moreover, it will explore the effect of educational, medical, and psychosocial factors on anxiety. Information on which, if any, factors impact anxiety may be helpful to service providers as they seek to provide comprehensive care to this population.

Research Questions and Hypotheses

This study will explore the following research question and corresponding hypotheses:

Research Question

How does parent and child anxiety relate to medical, psychosocial, and educational factors?

Hypotheses

H1: There is a relationship between parent and child anxiety in parents with children and youth bowel and/or bladder dysfunction.

H2: There is a difference in maternal and paternal anxiety in families with children and youth with bowel and/or bladder dysfunction.
H3: Medical services have an impact on anxiety of parents with children and youth with bowel and/or bladder dysfunction.

H4: Psychosocial factors have an impact on anxiety of parents with children and youth with bowel and/or bladder dysfunction.

H5: Educational factors have an impact on anxiety of parents with children and youth with bowel and/or bladder dysfunction.

Limitations and Delimitations

It is anticipated that the proposed study will have several limitations and delimitations. The potential limitations and delimitations are presented in the following sections, but will be revised after completion of the study as a whole.

Limitations

Potential limitations can occur in association with this research study. Participants included in this study will be asked to complete a total of two inventories regarding demographic information and anxiety. Although the anxiety inventory used for children is language appropriate, the researcher will not be able to control for parent involvement. A detailed set of instructions will be included in the packet, which will ask the parents to avoid interfering by offering suggestions to their children. Furthermore, a pilot study was conducted on children and youth ages 11-18 who participated in a summer camp for individuals with bowel and/or bladder dysfunction. The rarity of illnesses associated with bowel and/or bladder dysfunction may result in an overlap of participants in each study. As a result participants may have had prior experiences with completing anxiety inventories. Since each study is confidential there is no way to control for this overlap.
The current research study will use a different anxiety inventory than the pilot study to avoid maturation.

\textit{Delimitation.}

Participants will be limited to parents who seek care and/or support through the recruiting partners. However, there are other parents/children in the population who are not recruited. Parental participation will be delimited to those with legal custody of the child. This may include biological parents living or not living with the child or other caregivers with legal guardianship.

\textbf{Definition of Terms}

\textit{Anxiety.} Symptoms common to all types of anxiety are as follows: 1) exposure to an anxiety trigger which includes something an individual fears, separation from an attachment figure, and/or obsessional thinking; 2) an increase in the anxiety to high levels which can be accompanied by catastrophic thoughts; 3) various forms of escape behavior such as leaving school, running away from perceived danger, and/or developing ritualistic behavior (Rockhil et al., 2010). Furthermore, anxiety is the feeling that one’s safety or wellbeing is under threat and is more pervasive than simple fear and worry (Dacey & Fiore, 2000).

\textit{Bladder Dysfunction.} Bladder dysfunction is characterized by abnormalities in storage and/or emptying phase of urination and is associated with urgency, frequency, and incontinence. Often, individuals with bladder dysfunction have congenital defects which adversely affect the nerves associated with urination. This can be caused by many factors including the result of a lesion at any level in the nervous system, including the cerebral cortex, spinal cord, or peripheral nervous system (Verpoorten & Buyse, 2008).
**Bowel Dysfunction.** Bowel dysfunction is characterized by abnormalities in the storage and/or elimination of fecal matter. Often, individuals with bowel dysfunction have congenital defects which adversely affect the nervous systems associated with digestion and elimination (Funkakosi et al., 2005). Children with bowel dysfunction often have severe constipation or diarrhea which can cause fecal incontinence and/or abdominal pain (Nisell, Ojmyr-Joelsson, Frenckner, Rydelius, & Christensson, 2003).

**Children with Special Health Care Needs.** Children and youth who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional conditions and who also require health and/or related services beyond that required by children generally (Child and Adolescent Health Measurement Initiative, CAHMI, 2002).

**Chronic Illness.** Chronic illnesses are medical conditions that last for more than 3 to 6 months in duration. The degree of functional limitations imposed by the illness can vary depending on the severity of the illness (CAHMI, 2002).

**Parents.** Parents will include mothers, fathers, or primary caregivers living or not living with the child with bowel and/or bladder dysfunction.

**Conclusion**

The purpose of the proposed study is to explore anxiety in children with bowel and/or bladder dysfunction and their families. Moreover, it will explore the effect of educational, medical, and psychosocial factors on anxiety. Both the physical and psychological effects of the chronic condition are important components to be taken into consideration when providing medical, educational, and psychological services and accommodations related to the child’s health. The family systems models used as the theoretical frameworks are the TSC and the FSI. The TSC offers a theoretical basis for
successful transition, specifically for mother and child, during a time of change within the family. To broaden the theoretical framework the FSI was included to encompass the family as a whole, including both parents and not solely the mother. The hypotheses were developed through use of the theoretical frameworks and research which focused on children with special health care needs, bowel and/or bladder dysfunction, and their families. The following chapter will provide extensive research regarding the need for comprehensive and collaborative medical, educational, and psychosocial planning for children with chronic illness and their families.
CHAPTER II
REVIEW OF THE LITERATURE

Children with special health care needs (CSHCN) are defined as children and youth who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and/or related services beyond that required by children generally (CAHMI, 2002). A significant number of children in the United States have special health care needs, the United States Department of Health and Human Services (USDHHS) conducted the 2005-2006 National Survey of CSHCN which reported an estimated fourteen percent of children in the United States under the age of 18 had a special health care need. Additionally, the survey reported an estimated 1 in 5 of households in the U.S. had one child with a special health care need (U.S. Department of Health and Human Services, 2008).

Children with chronic conditions may require specialized medical care and treatments, an increased number of doctor’s visits and hospitalizations, and mental health services. Additionally, many CSHCN are underinsured or have no access to medical insurance which results in inadequate health care. The increased number of medical treatments and hospitalization may result in a higher number of school absences, which can lead to social and academic difficulties in the school environment.

Children with Bowel and/or Bladder Dysfunction

Within the larger group of children with special health care needs are those with conditions that impact their ability to remain continent. The physiological and psychological effects of bowel and/or bladder dysfunction can negatively impact children and their families over time. Children with bowel dysfunction often have severe
constipation or diarrhea which can cause fecal incontinence and/or abdominal pain, which often occur after the child enters school (Diseth, Egeland, & Emblem, 1998; Nisell et al., 2003). Furthermore, children with bladder dysfunction often experience incontinence and urinary tract pain (Verpoorten & Buyse, 2008). As a result, families of children with bowel and/or bladder dysfunction continue to deal with medical problems related to illness long after treatment.

Bowel Dysfunction

Bowel dysfunction often has a varying degree of severity. Children with an intermediate or high imperforate anus generally undergo surgery to receive a colostomy immediately after birth (Nisell et al., 2003). In less severe cases of bowel dysfunction, children undergo surgery which constructs a new anus between the ages of three and six years of age. Children with bowel dysfunction who have received medical treatment often report a continuation of problems such as fecal incontinence after reaching school age (Funkakosi et al., 2005). Such is the case in children diagnosed with Hirschsprung’s disease, which causes disturbances in absorption and defecation. Children with bowel dysfunction often have severe constipation or diarrhea which can cause fecal incontinence and/or abdominal pain, which often occur after the child enters school (Diseth et al., 1998; Nisell et al., 2003). As a result, families of children with bowel dysfunction continue to deal with medical problems related to the child’s illness long after treatment.

A survey conducted on the psychology of children with imperforate anus and average intelligence, reported 17.9% had difficulties related to behavior (Tarnowski, King, Green, & Ginn-Pease, 1991). Furthermore, Diseth and Emblem (1996) reported
58% of children with imperforate anus had some form of psychiatric disorder as defined by the Diagnostic and Statistical Manual of Mental disorders, Revised Third Edition, 2000 (DSM-III-TR). Research indicated medical institutions are rarely involved in the care of children with bowel dysfunction after surgical treatment is received (Funakosi et al., 2005). According to Fasten (2000), comprehensive medical and psychological treatment of children with bowel dysfunction could improve fecal dysfunction and decrease behavior difficulties in children with bowel dysfunction. Improvement in fecal dysfunction and behavior can increase the overall well-being of the child and his or her parents.

**Bladder Dysfunction**

Bladder dysfunction often refers to an abnormality in either the storage or emptying phase of urination and is associated with urgency, frequency, and incontinence. Children with bladder dysfunction are at higher risk for contracting Urinary Tract Infections (UTI’s), as well as, developing bladder-wall damage which can further complicate the illness. Children with bladder dysfunction who are unable to empty the bladder and/or have frequent UTI’s are at higher risk of developing renal damage, which can be severe and often irreversible (Berry, 2005; Verpoorten & Buyse, 2008).

Bladder dysfunction, such as neurogenic bladder sphincter dysfunction, can be the result of a lesion at any level in the cerebral cortex, spinal cord, or peripheral nervous system. Neurologic conditions which lead to bladder dysfunction are predominantly congenital neural defects, such as tethered spinal cord, which are also associated with bowel dysfunction (Verpoorten & Buyse, 2008). Acquired causes or those occurring
after birth, of bladder dysfunction are spinal cord tumors and/or physical trauma and damage to the nervous system (Bauer, 2008).

Educational Needs and Supports

An increased number of CSHCN attend school due to advances in medical technology and the enactment of educational laws protecting the rights of children with disabilities. For many of these children, academic performance, absenteeism, and social difficulties occur due factors associated with having a chronic illness. Therefore, there is an increased need for services and accommodations available to this population. Formal educational plans provide guidance to school personnel and families when identifying and implementing appropriate accommodations for children with chronic illness. Furthermore, many medical professionals suggest developing specialized health care plans, such as the IHP, in combination with educational plans to ensure children receive appropriate medical treatment during the school.

*The Individuals with Disabilities Education Act*

Prior to the enactment of the Education for All Handicapped Children Act of 1975 (EHA), the needs of children with disabilities were not being met consistently. More specifically, Congress sited the following areas of weakness upon which the EHA was founded: 1) children with disabilities were excluded from public schools; 2) children with disabilities not attending public school often did not receive an appropriate education; 3) children with disabilities were not diagnosed which prevented them from receiving an appropriate education and; 4) states and school districts did not have adequate resources. The passage of the EHA affirmed the position of the United States Congress that a disability should in no way decrease the right of an individual to participate or contribute
to society (Yell, 2006). The most recent reauthorization of the EHA is called the Individuals with Disabilities Education Act of 2004 (IDEA) (Yell, 2006). As IDEA has been reauthorized over time, it has established a framework for the provision of a free, appropriate, public education to all children in America (Yell, 2006).

IDEA defines children with disabilities as children with mental retardation, hearing impairments including deafness, speech or language impairments, visual impairments including blindness, serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities (Yell, 2006). IDEA mandates services for children birth to twenty-one, with Part C addressing children birth – age two, and Part B addressing children ages three to twenty-one. In order to be eligible for services under IDEA, children must have a disability within the categories identified within the law and the disability must have an adverse impact on their education (Yell, 2006). The three key components which apply directly to the provision of educational services in IDEA are: 1) Individualized Education Program (IEP), 2) Least Restrictive Environment (LRE); and 3) Related Services.

Eligibility. While a child with a special healthcare need may have multiple issues that impact his/her eligibility for services under IDEA, the most obvious possibility is in the category of Other Health Impairment (OHI). The Code of Federal Regulations defines children with OHI as having limited strength, vitality or alertness, due to chronic or acute health problems that adversely affects educational performance (Yell, 2006).

Individualized Education Plans. According to IDEA, an Individualized Education Plan, or IEP, is a written statement developed by a representative of the local educational agency who is qualified to provide, or supervise the development of the
designed instruction to meet the needs of children with disabilities, the teacher, the parents or caregiver of the child with a disability (Yell, 2006). The IEP serves as a legal agreement between the school district and the child and family that identifies the child’s:

1) present levels of educational performance, 2) annual goals and objectives, 3) provided educational and related services, 4) frequency and duration of participation of general education, 5) statement of transitional services, 6) measurement of achievement (Yell, 2006). The IEP must be reviewed a minimum of once a year, and can be modified more often when necessary. The goals can be developed to promote maximum independence in self-care, as well as educational progress.

*Related Services.* In addition to educational services provided, other related services may be required in order to meet the child’s educational needs. The related services included in IDEA are transportation, developmental, corrective, and other supportive services that are required to assist a child with a disability to benefit from special education. Such services can include speech pathology and audiology, psychological services, physical and occupational therapy, and medical services (Yell, 2006). For a service to be considered a related service, the student must qualify for special education, and must have an indication that the service is necessary for the student to benefit from special education. Goals and objectives regarding the use of related services are be established by the school and documented in the IEP in order to outline how the service is necessary to enhance the student’s success in order to function in the school environment to the best of his/her ability.

Acceptable medical services are those provided by a licensed physician to determine the child’s medically related disability that results in the need for special
education services and related services (Yell, 2006). Additional health information is needed to establish implications of the child’s condition for his or her academic success and learning environment (e.g., school absences, energy level, procedures during day). The school system may be required by IDEA to provide or pay for the diagnostic medical services to obtain health information if the health condition affects the child’s learning.

School health services are provided by a qualified school nurse or other qualified person and are not limited to diagnosis or evaluation (Yell, 2006).

**Procedural safeguards.** Part E of IDEA outlines the process designed to ensure that families of children with disabilities, including students with special health care needs, are involved in decisions affecting their child’s education. As a result of these procedural safeguards, parents have the option to request an administrative due process hearing to appeal an IEP. A complaint can be filed with the state’s Department of Education to formally document of a school’s violation of IDEA. If the state does not respond appropriately to the complaint, parents have the right to file a complaint with the U.S. Department of Education Office for Civil Rights (OCR). Part E of IDEA was developed to ensure families and students have an impartial hearing on any matter related to identification, evaluation, placement, and provision of a free appropriate public education.

There have been several cases involving the provision of medically-related services for children with disabilities. In perhaps the most well-known, the *Irving Independent School District v. Tatro* (1984) case, the Supreme Court upheld that schools must provide health-related services when necessary for the student to receive an appropriate education and when the service can be provided by someone with less
training than a physician (Martin, Martin, & Terman, 1996). Schools are required to provide health services when the child is not able to participate in an educational program without the service being provided, the child requires special education services, and the health service could be performed by a school nurse or other health professional (Heller & Avant, 2011).

IDEA was established in part to ensure children with disabilities receive special education services when eligible. However, not all children with chronic illness require a fundamentally different education as described in IDEA. Rather, these children can be successful at school with accommodations including health services during the school day. These children are eligible under Section 504 of the Rehabilitation Act, a civil rights act, to receive services related to their health needs and to ensure they receive a free and appropriate education.

Section 504 of the Rehabilitation Act

Section 504 of the Rehabilitation Act of 1973 is a civil rights statute designed to end discrimination against persons with disabilities, including those with chronic illness. Although Section 504 does not supply local educational agencies with federal funding, it does mandate compliance of federal disability discrimination law in any program that receives grants, loans, contracts or other arrangements with the federal government. Furthermore, all students with disabilities who attend public schools, regardless of eligibility under IDEA, are legally covered by Section 504 (Zirkel, 2009). The Office of Civil Rights, which oversees Section 504 in schools, requires that students meet the federal definition of disability in order to receive accommodations and services. Regulations under Section 504 require that schools receiving federal aid provide the
following: 1) free appropriate public education (FAPE); 2) related services; 3) a process for implementing an individualized plan; 4) transportation; 5) pre-placement evaluation, evaluation procedures, and reevaluation; 6) appropriate placement; and 7) procedures to guarantee the rights of students (Janz, Beyer, Schwab, Anderson, Caldwell, & Harrison, 1997).

**Eligibility.** Section 504 applies to any person who has a physical or mental impairment that substantially limits one or more major life activity; has a record of impairment or is suggested to have such impairment (Yell, 2006). In E.E. Black Ltd. v. Marshall (1980), the term impairment was defined as “any condition which weakens, diminishes, restricts, or otherwise damages an individual’s health or physical or mental activity”. Children with chronic illness are eligible for accommodations and services through Section 504 under the definition of Physical Impairment, which is defined as a physiological disorder or condition, cosmetic disfigurement, or anatomical loss that affects one or more body systems including neurological, musculoskeletal, sensory organs, respiratory, speech organs, cardiovascular, reproductive, digestive, genitor-urinary, hemic and lymphatic, skin and endocrine systems (Yell, 2006).

Major life activities, as defined in the Section 504 regulations, include functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working (Yell, 2006). This list is not exhaustive. Other functions can be major life activities for purposes of Section 504. Congress provided additional examples of general activities that are major life activities, including eating, sleeping, standing, lifting, bending, reading, concentrating, thinking, and communicating. Congress also provided a non-exhaustive list of examples of major
bodily functions that are major life activities, such as the functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions.

*Accommodations Plans.* Once a child is identified as eligible for protections and services mandated by Section 504, an individualized plan may be developed. While the law does not require a written plan, most states elect to document their plans of action, both for the benefit of the school and the parent. These are commonly known as Individualized Accommodation Plans or 504 Plans. Accommodation plans typically include sections describing the background/history of the child, goals and objectives to be achieved, descriptions of accommodations, and emergency procedures and contacts. This plan is developed cooperatively among parents and school officials (including teachers, nurses, etc.), and are meant to be revisited or revised at least once a year. Members of the team should outline the child’s current level of performance and document what services and/or accommodations are necessary for the child to have an equal opportunity in the educational setting.

*Related Services.* Schools must provide related services, as necessary, to students who are identified for Section 504 (Yell, 2006). Unlike IDEA, there is no educational need component in Section 504 in order to be eligible for related services. Therefore, the only service a student identified under Section 504 may need is a related service. Under Section 504 a related service is provided by the school district in order to ensure the child receives a free and appropriate education. Related services include but are not limited to: 1) school health services; 2) psychological/behavioral services, 3) physical therapy, 4) occupational therapy; and/or, 5) transportation to and from school.
Procedural Safeguards. Public schools must employ procedural safeguards regarding identification, evaluation, and/or educational placement of a child with a disability who is in need of accommodations and/or modifications, including special instruction and/or related services, as outlined in Section 504. Procedural safeguards set forth by Section 504 require schools to obtain parental consent prior to conducting an evaluation on their child. Furthermore, schools must provide a notice to parents explaining any evaluation or placement decisions prior to implementation of these services. The notice is required to include the parent’s rights to review their child’s educational records and an explanation of the appeal process regarding any of the school’s decisions regarding evaluation and placement. If parental consent is withheld, school districts may hold a due process hearing to override the parents denial of consent to evaluation or placement, if the school district deems the child will not receive adequate services (Yell, 2006).

School Health Services

Regardless of whether the child with special health care needs is eligible for services under IDEA or Section 504, the nature of their illness often necessitates more specific planning to meet their health needs during the school day. Health care procedures have occurred more frequently in the school environment due to advances in technology and interventions (Heller & Avant, 2011). As a result teachers are encountering more students with health care needs such at catheterization and medication administration (Gursky & Ryser, 2007). In order to meet the medical needs of students with special health care needs, including those with chronic illness, teachers and school personnel
must obtain accurate information regarding health care procedures and indicate their roles and responsibilities (Heller & Avant, 2011).

**Specialized health care plans.** In order to appropriately document the child’s medical needs at school and provide services, professional associations for school nurses including the National Association for School Nurses (NASN) and the American School Health Association (ASHA) recommended the development of an Individualized Healthcare Plan (IHP) and an Emergency Care Plan (ECP) (ASHA, 2002; NASN, 2008). These plans are more accurate when developed by a school district nurse and outline school health services provided to the child, responsible personnel, and emergency procedures. The development of an Individualized Health Care Plan can aid in organizing specifics regarding these roles and responsibilities, as well as, provide basic and important information about the student’s specific health needs (Heller & Avant, 2011; Herrmann, 2005). IHPs are often very comprehensive and specific to the health needs of the child and the medical supports required during the school day. ECPs are a separate document from the IHP and include basic information about the child’s medical condition, routine and emergency procedures regarding medication, and interventions to take in emergency situations (Herrmann, 2005). The ECP is written when there is knowledge of risk of potential crisis or emergency related to a child’s health condition (Heller & Avant, 2011). Neither of these plans are designed to address the educational needs of children with special healthcare needs. However, these plans were specifically designed to document and inform appropriate school personnel of the health-related care needed during school hours. When a student is impacted educationally, and therefore eligible for services and supports under IDEA or Section 504, both the NASN and the
ASHA recommended the IHP and ECP be included in the IEP or 504 accommodations plans (ASHA, 2002; NASN, 2008). In doing so, schools would be required to provide health related services and accommodations to a child in order to increase academic success. Providing appropriate health related services to a child with a special health care need in school has the potential to decrease anxiety related to the illness and remove obstacles to learning.

According to IDEA and Section 504, caregivers, including school personnel and families, should acquire accurate and up-to-date information regarding a child’s disability including diagnosis and medical and educational progress. Furthermore, professionals in the medical field suggest school personnel and school nurse’s document information regarding health care procedures and roles and responsibilities regarding health management and condition implications. While IDEA and Section 504 require schools to provide accommodations and documentation through individualized plans, there is no official document required by law for health care. The use of the IHP could fill this gap in health care documentation, as well as, ensure a child with a special health care need receives adequate medical assistance in school.

Alternative Categorization by Condition and Implications

The regulations and guidance by IDEA, Section 504, and various professional organizations are sometimes difficult to navigate for professionals supporting children with special health care needs at school. The eligibility criteria, diagnosis categorization, and plans suggested are often not well aligned with the overarching needs of this population. Heller et al. (2009) suggested a different grouping of conditions is often needed in an educational setting that is based on medical characteristics and educational
implications. The six major categories suggested were: neuromotor impairments, orthopedic and musculoskeletal disorders, sensory disorders, degenerative and terminal diseases, major health impairments, and infectious diseases. School settings may benefit from a more specific categorization of conditions that offers a more in depth definition in order to develop affective and personalized academic and health planning for students with special health care needs.

According to Heller et al. (2009), Neuromotor Impairments refer to disorders that impact the nerves and muscles. Conditions typical to this category are cerebral palsy, spinal bifida, and spinal cord injury. Children with Neuromotor Impairments frequently have very complex conditions that affect multiple areas of functioning, including motor skills, cognitive skills, perceptual skills and/or language skills across multiple domains. The authors suggested schools consider the diverse educational implications of limited functioning of the students and plan appropriately to meet the individual’s unique academic and medical needs in order to provide a more successful and potentially less stressful environment (Heller et al., 2009).

The second category suggested by Heller et al. (2009) was Orthopedic, Musculoskeletal, and Sensory Disorders. The conditions listed in this category can occur individually or in combination with each other. Common conditions are scoliosis, cerebral palsy with hip displacement, vision impairments occurring with juvenile rheumatoid arthritis. These complex conditions often require involved assistance by a caregiver with daily living skills, such as dressing and feeding.

Degenerative and Terminal Diseases was described by Heller et al. (2009) as progressive loss of function and conditions which will lead to death. Conditions listed as
common to this category were cancer, muscular dystrophy, spinal muscular atrophy, and cystic fibrosis. Children with degenerative and terminal diseases and their families often have to face issues surrounding death and dying. Families of children must develop coping skills in regards to stressors that occur at the time of diagnosis, relate to the child’s daily medical needs, at the time of hospitalizations and exacerbations of the illness, and during developmental transitions (Melnyk, Feinstein, Moldenhower, & Small, 2001). These stressors may occur for months and include following medical processes and procedures at home, communicating with medical professionals in charge of their child’s treatment, and coping with their own fears, grief, and loss.

According to Heller et al. (2009), the category of Major Health Impairments was used to describe illnesses that do not have obvious external physical markers but severely affect a child’s functioning. Conditions in the category included, but are not limited to, asthma, diabetes, seizure disorders, and attention-deficit-hyperactivity disorder. Caregivers often have to monitor diet, exercise, changes in behavior and functioning, and medication. In addition, an emergency plan is developed for times of medical crisis such as hypoglycemia (low blood sugar and high insulin), occurrence of seizure, or an asthma attack. Often medical intervention is required, such as a glucose shot, in order to avoid serious medical complications.

Infectious Disease is the final category developed by Heller et al. (2009) and is described as an acquired infection and or a congenital infection. Common infectious diseases are hepatitis, HIV, AIDS, and Bacterial Meningitis. Caregivers are responsible to provide the child with information regarding transmission prevention and universal precautions. Children with an infectious disease are at risk for neurological complication,
developmental delays, and intellectual disabilities and should be monitored closely for changes in behavior and development. Emotional support is a critical element in treatment planning for the child and family. Often stigma is attached to individuals with an infectious disease and others may have irrational views of illness transmission. As a result, children and families often experience isolation from social settings, which can lead to depression and/or social anxiety. Other psychological implications may include the family and/or child feeling powerlessness, loss of control, loss of meaning of life, and decreased self-esteem (Barlow & Ellard, 2006; Hill, Freeman, Yucel, & Kuhlthau, 2008).

Detailed categorization such as those suggested by Heller et al. (2009) can be beneficial in identifying the medical, educational, and psychosocial needs of children with a chronic illness. Furthermore, unlike IDEA and Section 504, these categories offer information that can be specific to the development of accommodations and modifications through providing care instructions specific to an illness. Medical and school personnel and families and their children can develop a comprehensive school and health care plan that will provide adequate educational and medical accommodations and modification in the school environment.

IDEA and Section 504 mandate that children with disabilities, including those with chronic illness, be provided with formal plans to ensure their needs are met in the school environment. Furthermore, school nurses suggest developing specialized health planning for children who require medical care during the school day. In order for these professionals to fully understand the unique needs of these children, understanding of the illness can be beneficial. Furthermore, including medical professionals from a child’s
medical team outside of the school can offer valuable information and assistance when developing these plans.

Medical Needs and Supports

Children with special health care needs, including those with a chronic illness, have varied conditions which require diverse medical, financial, and psychosocial resources. Additionally, these needs can fluctuate depending on the stage and type of illness, as well as access to medical services (Kelly et al., 2008; Rolland, 1999). For instance, medical needs can escalate if the medical condition requires a prolonged hospital stay when the family can no longer provide the care needed within the home. Furthermore, children with chronic illness may require more frequent emergency room visits, hospitalizations and may need complex treatments and/or change in medications, which can increase demands and stress on the family (Kelly et al., 2008). Children with increased limitations in their daily activities due to a chronic illness spend 10 times more days in the hospital when compared to children without a chronic illness. Financial charges are particularly higher for children with chronic illness due to the number of medical procedures, supplies, equipment, and services required during a hospitalization (Fox & Newacheck, 1990).

Medical Home and Access to Care

The concept of the medical home was originally developed with children with special health care needs in mind, including those with chronic illness, due to their greater need or specialized and coordinated care (Stevens, Seid, Pickering, & Tsai, 2010). Nationally, advocates for comprehensive pediatric health care cite the establishment of medical homes for all children as a driving force for the expansion of public health
insurance coverage (USDHHS, 2008). The American Academy of Pediatrics Committee on Children with Disabilities (2005) emphasized seven features of a medical home which include: 1) accessible, 2) continuous, 3) comprehensive, 4) coordinated, 5) family-centered, 6) compassionate and 7) culturally effective. Furthermore, accessible, continuous, comprehensive, and coordinated care have been linked to high quality care which resulted in an increase in preventative care, fewer emergency room visits, decreased medical costs, and positive health outcomes (Starfield, 1992; Fulda, Lykens, Bae, & Singh, 2008).

However, there are many barriers to access to a medical home for children, especially those with a chronic illness. Children with chronic illness often have difficulty establishing a medical home due to socioeconomic status, race, and/or adequacy of health care coverage (Flores, Olson, & Tomany-Korman, 2005; Halfon, Inkelas, & Wood, 1995). Furthermore, research specific to children chronic illness indicated half received medical care that met the quality characteristics of a medical home indicated by the American Academy of Pediatrics (2002). Children with a chronic illness who were identified as a racial/ethnic minority or in lower socioeconomic brackets showed a lower likelihood of receiving quality coordinated medical care through a medical home due to restriction in access to care (Strickland et al., 2004; & Fulda et al., 2008). According to the Family Systems Illness Model, access to adequate health care has effects in terms of the incidence of illness, disease course, survival, and quality of life (Rolland, 1999).

Children with multiple, complex, and/or rare chronic conditions visit the emergency room and are hospitalized more frequently than children with typical development (Kelly et al., 2008). Coordinated care, such as an established medical
home, can be an essential part of their health care and has been proven to reduce health care costs and improve family stress (American Academy of Pediatrics Committee on Children with Disabilities, 2005). A study conducted in a community-based general pediatric clinic reported 11% of patients had complex illness involving multiple organ systems. These patients required four times more coordination or care time than patients with less complex illnesses, which included consulting with schools and dealing with psychosocial problems (Antonelli & Antonelli, 2004). In addition to time required to coordinate care by medical clinics, families of children reported one of the greatest challenges is the stress associated with coordinating the services of multiple medical and non-medical providers (Kelly et al., 2002). The establishment of a medical home that met the required characteristics of quality care could decrease these challenges for pediatric medical clinics, as well as, the stress related to service coordination for families of children with chronic illness.

Health Insurance and Socio-Economic Status

During the 1980’s and 1990’s there was an increase in health insurance coverage for children at-risk through the Children’s Health Insurance Program (CHIP) and extended Medicaid eligibility (Swigonski, Kinney, Freund, & Kniesner, 2001). This increase in the development of publically funded health insurance coverage spurred an increase in research during the late 1980’s and early 1990’s. Since then research in this area has decreased. Children with complex and chronic medical conditions often have higher health care expenditures when compared with children without a complex and chronic illness receiving health benefits through CHIP and Medicaid (Swigonski et al., 2001; Hill, et al., 2008). A study conducted on inadequate health coverage for children
with chronic illness showed that families with adequate health insurance were 67% less likely to delay care for their child with chronic illness when compared to families with inadequate health insurance (Swigonski et al., 2001). Factors associated with inadequate health insurance included: 1) exclusion of coverage of a preexisting condition, 2) no limit on annual out-of-pocket medical expenditures, 3) a deductible greater than $1,000, 4) coinsurance rates over 20% for hospitalization, physician services or prescription drugs, and/or 5) a lifetime maximum payout of less than $50,000 (Swigonski et al., 2001).

Even when families have private health insurance, that coverage may be inadequate and can result in increased medical complications for their child with a chronic illness (Swigonski et al., 2001; Weller, Minkovitz, & Anderson, 2003). Approximately 17% of children under the age 19 who are covered by a private health care plan are underinsured (Short & Banthin, 1995). Benefits and coverage available through private health care plans vary greatly due to regulations stipulated in employer-sponsored plans. The availability, adequacy, and affordability of these health care plans has decreased in recent years resulting in a decline in coverage which has impacted quality of health care of families and children of lower socio-economic status (Hill et al., 2008; Weinick, Weiger, & Cohen, 1998).

In addition to medical services, children with chronic illness may require ancillary therapies, including but not limited to physical, occupational, speech, and psychological interventions (Fox & Newacheck, 1990; Hill et al., 2008). Non-medical ancillary services are often prescribed by physicians for preventative purposes, but are limited to coverage by many health care plans if the service is identified for rehabilitation therapy.
As a result of this discrepancy, families often have to pay out-of-pocket in order for their child to receive the appropriate therapeutic care. For instance, mental health benefits are offered by private insurance plans but have more limitations and restrictions than typical medical benefits. Limitations reported regarding mental health services included restrictions in the amount of payment the insurance plan would cover, restrictions regarding the number of visits subject to reimbursement, or no mental health coverage available (Fox & Newacheck, 1990). Although rare, some medical physicians employ mental health professionals, such as a psychologist, to work within the medical clinic. If this is the case, the mental health professional can file a claim as a medical necessity under the supervision of the medical physician. Such cases include clinics offering play therapy or in-clinic counseling services to children with behavioral difficulties related to their chronic illness (Fox & Newacheck, 1990). However, health insurance does not guarantee that children with chronic illness have access to care.

Families’ experiences of illness and disability are influenced by factors such as socioeconomic status, type of illness, and access to care (Rolland, 1999; Swigonski et al., 2001). Families from diverse minority backgrounds and from lower socioeconomic status are disproportionately served among individuals with chronic illness compared to individuals with chronic illness from the dominant culture. The strain of illness can often have negative psychological effects on the individual and his or her family which may require mental health services. In recent years, most health insurance companies have limited mental health benefits available to individuals, making access to quality care financially unattainable for individuals in the lower socioeconomic bracket in the U.S. (Fox & Newacheck, 1990; Rolland, 1999; Swigonski et al. 2001).
Social and Psychological Implications of Chronic Illness

Between eight and ten percent of all children and adolescents have clinical anxiety. Anxiety is identified as the most prevalent psychiatric diagnosis in youth sixteen and younger (Rockhill et al., 2010). The development of an anxiety disorder at a young age has been linked to the development of attention deficit-hyperactivity disorder, oppositional defiant disorder, and/or conduct disorder (Kessler et al., 2005; Rockhill et al., 2010). Children and youth diagnosed with anxiety are two to four times more likely to be diagnosed with depression, which puts them at higher risk of substance abuse (Dacey & Fiore, 2002). Furthermore, youth with social phobia are at higher risk for failing to develop appropriate peer relationships, which can exacerbate social isolation (Rockhill et al., 2010). More specifically, adolescents with chronic illness are at increased risk for psychological and adjustment difficulties (Armstrong, Wirt, Nesbit, & Martinson, 1982; Cadman, Boyle, Szatmari, & Offord, 1987). A meta-analysis conducted on 87 research studies of psychosocial adjustment to illness in children ages 3-19 reported that children with physical disorders were at greater risk for developing psychological adjustment difficulties, as well as, anxiety, depression, and social withdrawal (Lavigue & Fier-Routman, 1992). Symptoms and severity of anxiety vary depending on the individual and environment. However, commonalities exist and included, but are not limited to, inappropriate fear and worry to an internal (i.e. irrational thoughts) or external stimuli (i.e. needles).

Although the terms fear, worry, and anxiety are often used interchangeably in literature, clinically they are not the same thing (Dacey & Fiore, 2002). Fear is a reaction to a threat that is focused on another individual, object, or situation. Fear is marked by
feelings of being frightened or scared (i.e. fear of needles). Worry is defined as a less intense reaction to threat than fear and is often experienced in regards to a future event, such as, anticipation of a doctor’s visit. Worry and fear can result in feelings of anxiety which is a more complex psychological experience. Anxiety is defined as the feeling of threat regarding an individual’s safety or well-being (Dacey & Fiore, 2002; White, 1999).

Anxiety can be an important tool and motivator in resolving less threatening situations (i.e. learning to swim or driving a car) and can be used to overcome obstacles. On the other hand, anxiety can be more severe and hinder an individual in engaging in activities in everyday situations, such as engaging in social events (Dacey & Fiore, 2002). Individuals with clinical anxiety often experience anxiety as a result of two types of thoughts: (1) erroneous perception of facts and reality and (2) misunderstanding the meaning of facts and reality (Dacey & Fiore, 2002). For instance, an individual who experiences a more rapid heart rate may perceive the meaning of the increased heart rate as a health problem such as a heart attack.

In recent years many studies have explored the causes of anxiety. Many have concluded that anxiety results from three factors: biological, psychological, and social (Eisen & Engler, 2006; Geist et al., 2003; Rockhill et al., 2010). Biological tendencies toward anxiety can be caused by hereditary conditions such as hormonal imbalances or abnormal brain functioning which can cause an increase adrenaline in the bloodstream. Adrenaline can cause increased heart rate, sweating, and dizziness, which are also symptoms of anxiety and associated with the alarm reaction or better known as the “fight or flight response” (Dacey & Fiore, 2002). As a result an individual may become
agitated and over-stimulated which can result in erratic sleep and eating patterns (Rockhill et al., 2010).

Psychological factors related to the cause of anxiety are described as a result of the interaction between biological factors and stress inducing life experiences (Dacey & Fiore, 2002; Mussatto, 2006; Pine, 2007). For example, when learning to ride a bike children often fall off which can result in physiological pain. The typical response is for the child to get upset, but to also forget and try again. For a child with high levels of anxiety, fear of bodily harm can be overwhelming and result in avoiding riding a bike. Overwhelming and debilitating anxiety can result in the individual becoming hypervigilant (i.e. heightened state of sensitivity) to the possibility of harm and/or threat (Dacey & Fiore, 2002; Eisen & Engler, 2006).

Anxiety is often influenced by an individual’s social experience with family and peers. Patterns of behavior are learned through interaction and observations of others in the individual’s environment (Rork & Morris, 2009). For instance, parents have a style or pattern of parenting that can have a positive or negative effect on their children’s development. Parents, mothers and/or fathers, who are anxious often share or teach their child to be fearful of the same situations or objects they are fearful of. In other words, when a child observes his/her parent in a state of anxiety, he/she may internalize the same feelings of anxiety (Eisen & Engler, 2006; Dowbiggin, 2009). The effect the child’s anxiety has on the parent is unknown. However, the Family Systems-Illness Model suggests family functioning is the result of an interaction of multiple factors, including behavior and coping styles of family members (Rolland, 1999). Taking this into
consideration, it may be hypothesized that the child’s anxiety does, in fact, have an impact on the well-being of the parents.

An individual’s experience of anxiety is affected by age and developmental stage. Infants often exhibit fear based on sensory experiences, such as loud noises or the absence of the parent (Dacey & Fiore, 2002; Eisen & Engler, 2006). Toddlers likely experience fear of strangers and have anxiety when parents leave them in the care of others, which is also known as separation anxiety. As a child becomes more mobile and develops more complex ways to interact with his/her environment, the chances of anxiety increases due to the widened range of exposure to new experiences. As a child ages, he/she may become concerned and anxious with performance, social, and interpersonal interactions (Armstrong et al., 1982; Dacey & Fiore, 2002; Rockhill et al., 2010). The possibility of an increase in anxiety is due to the development of more abstract thinking which leads to the capacity to anticipate future situations. While this can be beneficial to overcome and plan for more complex future demands, it can also lead to thinking of unpleasant events, such as a medical procedure.
Table 1

*Common Causes of Anxiety According to Age*

<table>
<thead>
<tr>
<th>Age</th>
<th>Common Causes of Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>6 to 7 years</td>
<td>loud or abrupt noises; separation from parents; being alone at night; going to school; physical harm from or rejection by specific individuals at school</td>
</tr>
<tr>
<td>7 to 8 years</td>
<td>the dark or dark places; real-life catastrophes influenced by television, movies, and/or books (i.e. floods, fire, car wrecks); being late for school or left out of events in school or with family; physical harm from or rejection by individuals at school</td>
</tr>
<tr>
<td>8 to 9 years</td>
<td>personal humiliation; school failure; parents fighting, separating or being hurt</td>
</tr>
<tr>
<td>9 to 11 years</td>
<td>failure in school or social activities, becoming sick; dangerous people</td>
</tr>
<tr>
<td>11 to 13 years</td>
<td>failure in school, sports, or social popularity; looking and acting different from others; death or life-threatening illness or disease; sex (i.e. attracting others, repelling others)</td>
</tr>
</tbody>
</table>

*Health-related anxiety.* There are many types of anxiety that can develop due to health concerns (Wheaton, Berman, Franklin, & Abramowitz, 2010). Hypochondriasis, a preoccupation with fears and beliefs about having a serious illness or an illness getting worse, is often caused by the misinterpretation of physical symptoms such as a mild stomach ache. Empirical evidence has developed over the past several years suggesting the presence of hypochondriasis, panic disorder, and obsessive compulsive disorder
frequently overlap in terms of psychological processes and development (Olatunji, Deacon, Abramowitz, & Valentiner, 2007). To make matters related to physical symptoms and anxiety even more complicated, anxiety, specifically panic disorder, is often marked by the presence of heart palpitations, chest pain, shortness of breath, dizziness, and abdominal distress, which can also be misinterpreted as physical illness. Individuals with anxiety often engage in safety behaviors, such as frequently checking body temperature or excessively going to the doctor, in order to temporarily reduce the symptoms of anxiety. Although the safety behaviors function as a temporary relief of anxious symptoms, they often reinforce the individual’s preoccupation with their physical health (Wheaton et al., 2010).

Individuals with chronic illness often face challenges related to health that can exacerbate psychological distress such as anxiety. For instance, a study was conducted on the relationship of anxiety and individuals with asthma. The researchers reported that individuals diagnosed with bronchial asthma often developed internalizing disorders, including anxiety. Also, maternal depression has been reported higher in families with children with asthma which resulted in a significant increase in problem behaviors among these children (Calam et al., 2003).

Literature on health related quality of life and well-being of families and children with chronic illness suggest many causes of psychological distress related to health. A study conducted on children with asthma, diabetes, or cystic fibrosis reported the participants perceived their quality of life to be lower than the general population. Participants in the study also reported their health interfered with participation in activities that required physical exertion, as well as, interfered with schoolwork and peer
interaction (Sawyer et al., 2004). Psychological implications of limitations on participation of activities can lead to self-consciousness, anxiety, and feelings of isolation (Higa, Phillips, Chorpita, & Daleiden, 2008).

The interest in the psychological well-being of individuals with bowel and/or bladder dysfunction has been minimal in current research, especially in the populations of children and adolescents. The scant research available has focused mainly on the relationship of psychological distress and somatic symptoms related to bowel and/or bladder dysfunction, such as diarrhea and frequent urination (Aziz & Thompson, 1998; Drossman, 1984; Gerson, 2002). A study conducted on adults with Irritable Bowel Syndrome (IBS) reported the illness was found to have an effect on both the CNS and ENS combined (Drossman, 1996). Aziz and Thompson (1998) reported that these two systems share the same hormones and neurotransmitters and therefore highly affect each other’s functioning. Drossman (1996) further contends colonic sensation and movement can be affected by psychological variables (such as trauma and stress) which are a function of the brain. These psychological variables then can result in physical symptoms such as pain, diarrhea, and bloating in patients with IBS.

**Impact of Psychosocial Factors at School**

In 2005, Brandstaetter, Leifgren, and Silkworth cited frequent absenteeism, higher levels of distractibility, and limited endurance as negative effects of chronic health conditions. Although the authors cite distractibility and limited endurance as factors related to absenteeism, there is limited research available regarding their effects. The effects result in decreased instructional opportunities and impact the child’s ability to learn content. Caldwell et al. (1997) reported factors that influenced student participation
were: lack of experience; emotional or physical effects of specific medical treatments including anxiety, pain, or fatigue; side effects of medications; class interruptions due to the time spent on health care procedures/therapies; acceptance and understanding of peers; poor self image; lack of realistic expectations by service providers; associated cognitive disabilities including specific learning disabilities, developmental delays, and short-term problems such as surgery (Wodrich & Cunningham, 2008).

Absenteeism. Students with chronic illness miss school more frequently than their peers (Caldwell et al., 1997; Sato et al., 2007; Wodrich & Cunningham, 2008). On average, youth with chronic pain associated with illness missed 21% of school days (Shapiro, Dinges, Orne, Bauer, Reilly, et al., 1995). Furthermore, increased rates of school absenteeism can be due to psychosocial factors. For instance, parents may perceive their child as in pain and vulnerable and keep them home from school for problems that would not typically disrupt learning (Shapiro et al., 1995). High levels of absenteeism have been linked to poorer academic progress (Carroll, 2010; Peterson & Colangelo, 1996). Some students with chronic illness miss a portion of each day when they leave the classroom for routine procedures (such as changing, catheterization, etc.). They may also be absent frequently for routine doctor and therapy appointments, as well as required surgeries and procedures (Caldwell et al., 1997). When frequent school absences are due to a health condition, the student has less time in which instruction and learning can occur. This can lead to inadequate levels of knowledge and a decreased understanding of critical course content (Needham et al., 2004). The effects of repeatedly missing part of a school day can be detrimental to the student’s progress in school. Sufficient school attendance is an issue that presents challenges, as some
students will require shortened class periods or school days due to fatigue and discomfort associated with chronic illness (Clay, 2004). Other potential risk factors for increased levels of school absenteeism include higher numbers of headaches, lower self-efficacy, more symptoms of anxiety or depression, lower involvement in extracurricular activities, and poor academic performance (Breuner, Smith, & Womack, 2004).

Needham et al. (2004) researched the impact of frequent absences on school performance. The researchers reported chronic illness placed a child’s academic achievement at risk and lead to decreased levels of knowledge and understanding of critical content. Furthermore, frequent absenteeism placed youth at risk for failing courses and decreased their chances of entering advanced classes with more rigorous curricula. In a study of gifted achievers and underachievers, Peterson and Colangelo (1996) reported students with frequent absenteeism performed lower than those who had fewer absences. Furthermore, students aged 7–11 who missed one-half of a school year or more were found to have a 0.7 year reduction in reading test scores and a one year reduction in mathematics test scores (Carroll, 2010).

School refusal. A common result of frequent absenteeism is the development of school refusal and avoidance behaviors. Children with chronic illness develop school refusal behavior in response to fears associated with attending school, peer reactions to their illness, or separation from their primary caregivers or parents (Eisen & Engler, 2006). Level and Leiker (2005) reported avoidance of school increased anxiety, promoted feelings of being overwhelmed, and increased the chances of depression. Children can feel overwhelmed for many reasons including questions from peers regarding their illness, being behind on assignments, and adjustment to managing their
illness in a school setting. These factors emphasize the need for comprehensive educational and psychological planning for children with chronic illness.

**Social and Psychological Implications for Parents**

Chronic illness in a child can produce stress in both the child with the illness and the family which he or she belongs to (Mussatto, 2006; Wallander & Varni, 1998). Children and their families are often required to adapt to the potential physical, psychosocial, and financial stress associated with living with a chronic illness (Mussatto, 2006). Parents of children with special health care needs are at a higher risk of psychological stress including depression and anxiety (Berge & Holm 2007; Lopez et al., 2008). According to Berge and Holm (2007) an increase in psychological stress can be due to uncertainty regarding the progression of illness and prognosis of the child. These stressors also impact family dynamics, with changes in the roles and expectations of family members (Geist et al., 2003; Mussatto, 2006).

**Impact of illness on family functioning.** The way in which a family copes with the child’s illness can be a strong predictor of the child’s psychosocial adjustment to the illness (Hamlett, Pellegrini, & Katz, 1992; Wallander & Thompson, 1996). A study conducted on family connectedness as a measure of psychological well-being of adolescents with a chronic condition reported higher scores on well-being was in direct correlation to higher levels of family connectedness. Furthermore, family connectedness was a more influential variable than the illness itself (Wolman, Resnick, Harris, & Blum, 1994). A study conducted on the impact of family functioning on chronic illness reported psychological adjustment of the child improved with higher family functioning and was
negatively impacted by the mother’s perception of decreased social support (Hamlett et al., 1992).

**Impact of Illness on family dynamics.** Increased anxiety and uncertainty related to illness in the child can lead to boundary ambiguity, which is defined as “a state in which family members are uncertain in their perception about who is in or out of the family and who is performing what roles and tasks within the family system” (Boss & Greenberg, 1984, p. 536). According to Boss and Couden (2002) ambiguous loss and boundary ambiguity are key components of the family stress theory. Both concepts were founded on the basis that meaning and perception were important in determining family responses to high-stress situations, including illness in a family member. Boundary ambiguity included two concepts: 1) expectations about who does what within the family system and 2) perceptions of who is included and excluded in the family (Boss & Greenberg, 1984). For example, ambiguity can occur to the lack of clarification concerning what behaviors or roles are expected of parent in caring for a child with a special health care need. Boundary ambiguity in parents of children with special health care needs refers to unclear expectations regarding the performance of parental roles within the family and unclear perceptions about whether the child with a special health care need is psychologically included in the family.

**Relationship of psychosocial stress among parents and children.** Parents of children with chronic illness often develop perceptions regarding their child’s well-being, such as their child being vulnerable. Regardless of whether this perception is unfounded or not, it can create an environment in which both the parent and child is more susceptible to anxiety. Lopez et al. (2008) conducted a study to examine the relationship
between perceived child vulnerability and parental psychological distress to adolescent anxiety in adolescents with special health care needs. The outcomes of the study indicated parental distress and the parents perception of the adolescent’s vulnerability related to the illness significantly predicted higher anxiety in the adolescent. Furthermore, the parent’s perception of their child’s vulnerability appeared to be the catalyst in the development of distress in the parents and anxiety in the adolescent.

Thompson et al. (1992) described adaptation to illness by children as a complex set of interactions among biomedical, developmental, behavioral, familial, and psychosocial factors. Research has increased regarding the parent-child adjustment outcome relationship in childhood chronic illness, specifically in juvenile rheumatic diseases, and cancer (Thompson & Gustafson, 1996; Thompson, Gustafson, & Bonner, 2002). According to Wallander and Varni (1998) not only was the child at risk for increased distress regarding the chronic illness, but primary caregivers were also at risk for adjustment difficulties. Such studies reported parent adjustment was directly correlated to a child’s adjustment to chronic illness. According to Lopez et al. (2008), past research focused on the relation of overall parent mental health (e.g., depression and anxiety) to child behavior (e.g., externalizing symptoms and depression), and has not addressed the relationship of specific parental perceptions to this relationship. Recent research has emphasized the adaptation of adolescent’s adaptation to the presence of chronic illness, a population that is frequently overlooked in literature (Williams, Holmbeck, & Greenley, 2002). Research indicated typical adolescent psychosocial development, such as autonomy and increased peer relationships, play increased roles in parent/child relationships.
Children and youth with chronic illness face many complex challenges regarding disease management. Family members/caregivers of children with chronic illness have increased daily demands which consist of, and are not limited to, providing a healthy environment for the child and the family, and management of the child’s daily needs associated with the illness (Carpentier, Mullins, Chaney, & Wagner, 2006). A diagnosis of a chronic illness also requires parents to educate the school system about the child’s illness regarding frequent school absences, social interaction difficulties, and educational difficulties (Harris, Greco, Wysocki, & White, 2001). Variables associated with parental adjustment to chronic illness include life stress, coping skills, compliance to treatment, external resources, and perceived control.

*Impact of illness uncertainty and attributional style on family functioning.*

Uncertainty regarding the child’s health the families attributional style of explaining the stressful events (i.e. optimistic vs. pessimistic) can lead to increased stress and anxiety in the child and the parents (Rolland, 1999). Research defined illness uncertainty as “the inability to assign meaning to illness-related events and can occur when an individual is unable to assign values to objects and events or is unable to accurately predict illness-related outcomes” (Mishel, 1988, p. 227). According to Mishel (1988) complexity of treatment, lack of information received pertaining to seriousness of illness and prognosis, and unpredictability regarding the course of illness as potential sources of uncertainty and therefore increased anxiety.

The second variable measured in this study was attributional style, which was defined as “the manner in which individuals explain the causes of events across a wide range of life domains” (Abramson, Metalsky, & Alloy, 1989, p. 361). According to the
researchers, in situations with a high degree of perceived illness uncertainty individuals searched for causes to explain and predict outcomes of the situation. The causal explanations parents developed became generalized to events not related to disease and influenced emotional adjustment. For example, if the attributions developed are negative, the perceptions of the parents caused poor psychological adjustment in multiple facets of life domains (Mullins, Chaney, Pace, & Hartman, 1997). A longitudinal study was conducted which examined the relationship of illness uncertainty and attributional style to psychological distress and illness adjustment among parents of children with chronic illness, specifically type 1 diabetes. Results of the study indicated significant relationships between illness uncertainty and psychological distress (Carpentier et al., 2006).

Summary

Children with special health care needs have unique social, emotional, and educational needs when compared to typically developing children. Social and emotional development can be enhanced by providing opportunities for social interaction with peers, learning to provide or direct personal care, reaching the same expectations as peers regarding everyday functioning and learning, and increased social interaction with adults with special health conditions (Caldwell et al., 1997). These factors can be fostered by school personnel, families, medical professionals, and mental health professionals through the development of comprehensive educational and health care planning. Furthermore, a collaborative approach to treatment and planning, both in the school and medical settings, can ensure a full understanding of the unique psychological, medical, and educational needs of the child.
Currently, there is a lack of research to guide in the development of family-centered programs in schools, community, and medical facilities for children and youth with special health care needs, specifically those with bowel and bladder dysfunction. Professionals in the field of education often do not have the experience and background knowledge regarding health care and psychosocial needs of children and youth with bowel and bladder dysfunction and their families. Furthermore, professionals in the medical field often focus on the physical treatment of the child, often leaving out the psychosocial and educational needs of children and youth with bowel and bladder dysfunction and their families. And, the overarching problem is that there is little understanding of how the issues addressed (i.e., medical, educational, and psychological) by different professionals in different agencies impact each other. The following chapter will discuss the proposed research study in detail, including the research questions and hypotheses, which were developed based on the information gathered in the review of literature summarized in this chapter, and is guided by the theoretical framework presented in Chapter I.
CHAPTER III

METHODOLOGY

Bowel and/or bladder dysfunction can impact children and their families in many ways. While there is a medical etiology primary to their conditions, they are also impacted psychologically. This requires an examination of not only medical factors, but also those related to the psychological and educational impact of the illness. It is necessary to better understand the interconnectedness of physical and psychological well-being, and explore how supports may impact the child with a chronic illness and their families. Impairment in function due to a chronic illness can result in psychosocial distress and/or psychiatric illness, including anxiety.

Psychosocial difficulties and children and adolescents with chronic illness and their families require careful identification and complex planning and treatment in both medical and psychological domains (Geist et al., 2003). There is a lack of valid, evidenced-based research to guide in the development of family-centered programs in schools, community, and medical facilities for children and youth with bowel and bladder dysfunction and their families. In regards to the educational environment, professionals in the field of education often lack the knowledge regarding health care and psychosocial needs of children and youth with bowel and bladder dysfunction and their families. Furthermore, professionals in the medical field often lack the knowledge regarding the psychosocial and educational needs of children and youth with bowel and bladder dysfunction and their families. The purpose of this study is to explore the relationship of anxiety between child/youth with chronic illness and their parents, as well as the impact of particular medical, psychosocial, and educational factors.
Research Questions and Hypotheses

This study will explore the following research question and corresponding hypotheses:

*Research Question*

How does parent and child anxiety relate to medical, psychosocial, and educational factors?

*Hypotheses*

H1: There is a relationship between parent and child anxiety in parents with children and youth bowel and bladder dysfunction.

H2: There is a difference in maternal and paternal anxiety in families with children and youth with bowel and bladder dysfunction.

H3: Medical services have an impact on anxiety of parents with children and youth with bowel and bladder dysfunction.

H4: Psychosocial factors have an impact on anxiety of parents with children and youth with bowel and bladder dysfunction.

H5: Educational factors have an impact on anxiety of parents with children and youth with bowel and bladder dysfunction.

*Population and Sample*

Children and youth with bowel and bladder dysfunction and their parents will be the included participants in this study. According to the Department of Health and Human Services, Children and Youth with Special Health Care Needs (CYSHCN), including those with bowel and bladder dysfunction, are defined as having a chronic...
physical, developmental, behavioral, and/or emotional disorders related to chronic illness and require health-related services beyond that required by children generally.

Participants will volunteer for participation through parent networks specific to parents of children with bowel and/or bladder dysfunction and medical clinics and children’s hospitals in the United States specific to children and youth with bowel and bladder dysfunction. Medical doctors and board members of the networks, clinics, and hospitals will be asked to assist in recruiting participants. After permission is established, the researcher will develop a written invitation to participate which will be disseminated by designated personnel to the parents. As it will be impossible to know how many potential participants received the request to participate through these means, the response rate will be calculated based on the number of individuals who respond to the flier and how many research packets are mailed.

Data Collection

Participants will be identified through medical clinics for children and youth with bowel and/or bladder dysfunction and parent support groups for parents with children with bowel and/or bladder dysfunction. Once the participants are identified, the parents will be asked to complete a questionnaire via an online data collection source. The questionnaire will screen participants to ensure they meet the criteria of having a chronic illness. Participants will be mailed a research packet which will include detailed directions, a return envelope, and the instruments for the children/youth and parents. Once the packet is complete the parents will be asked to return all materials to the researcher for analysis.
**Instrumentation**

Several instruments will be used to gather the data required in the proposed study. In order to verify participants meet criteria for participation in the study, *The Children with Special Health Care Needs (CSHCN) Screener*© will be used. A demographic inventory developed by the researcher will be used to collect information related to the independent variables of the study. Finally, the *Revised Children’s Manifest Anxiety Scale Second Edition* (RCMAS-2) and the *Adult Manifest Anxiety Scale* (AMAS-A) will be used to measure anxiety symptoms in participants. These instruments are described more fully in the following sections.

*Maternal and Child Health Bureau’s CSHCN Screener*. The CSHCN Screener will be used to determine if the level of bowel and/or bladder dysfunction is severe enough for the child to be considered as having a special health care need. This screener was developed to reflect the federal Maternal and Child Health Bureau's definition of children with special health care needs which is as follows: those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional conditions and who also require health and/or related services beyond that required by children generally (CAHMI, 2002).

The CSHCN Screener tool focuses on the potential consequences of chronic health conditions. The non-condition specific approach used by the CSHCN Screener is used to identify children across the range and diversity of childhood chronic conditions and special needs, which provides a more comprehensive assessment of health care system performance. In addition, the relatively low prevalence of most childhood chronic conditions and special health care needs often makes it problematic to find adequate
numbers of children with a specific diagnosis or type of special need. A non-condition specific approach makes it possible in many cases to identify enough children to allow statistically robust quality comparisons across health care systems and/or providers. As such, it is an appropriate measure by which to categorize children with varying medical diagnoses (all impacting bowel and/or bladder function) into a group for the proposed research study.

This measure is used to efficiently identify children with chronic physical, mental, behavioral and/or other conditions who also require health and related services beyond that required by children in general. The CSHCN Screener is a five item, parent-reported tool which identifies children who currently experience one or more of five common health consequences: (1) use or need of prescription medication; (2) above average use or need of medical, mental health or educational services; (3) functional limitations compared with others of same age; (4) use or need of specialized therapies (i.e. occupational therapy, physical therapy, speech therapy); (5) needs treatment or counseling for emotional, behavioral, and/or developmental difficulties. The five health consequences listed above must be due to a physical, mental, behavioral or other type of health condition which has lasted or is expected to last a minimum of 12 months. The questions are designed to be self-administered as part of a parent/caretaker survey. The screener takes approximately one minute to administer for a single child and an average of two minutes to complete when screening all children in a household. See Appendix A for a copy of this instrument.

Demographic Inventory. Demographic information will be collected using an inventory developed by the researcher. The inventory will be in the form of self-report,
which will be completed by the parent with the help of the child or youth. The categories included on the form are based on the Family Systems Illness Model, which provides potential factors that could impact the psychosocial well-being of a child or youth with a chronic illness and their families. The categories are as follows: 1) proximity to care, 2) number of hospitalizations per year, 3) socioeconomic status (income), 4) presence of a medical home, 5) type of insurance (private or public), 6) formal educational planning (IEP, 504, and/or IHP), 7) counseling services obtained and, 8) formal medical diagnosis. The information gathered from this form will be used as the independent variables in the data analysis. See Appendix B for a copy of this instrument.

**Anxiety Measures.** Children and youth participating in the study will be asked to complete the *Revised Children’s Manifest Anxiety Scale Second Edition (RCMAS-2)*, which is a published questionnaire used in children’s anxiety treatment research (Reynolds & Richmond, 2008). The RCMAS-2 standardization sample consisted of 3,086 children aged 6 to 19. The numbers of males and females included was approximately the same. The distribution across ages was fairly even, and representation of the identified demographic groups was consistent with their representation in the U.S. population (Reynolds & Richmond, 2009). The RCMAS-2 is a self-report instrument, consisting of 49 items, developed to assess the level and nature of anxiety in children from ages 6 through 19. Each item on the questionnaire requires a yes or no response. A response of yes is descriptive of the child’s feelings or actions, whereas a response of no is not descriptive of the child’s perceptions of self (Reynolds & Richmond, 2008). Furthermore, the RCMAS-2 yields scores for six scales including: 1) Inconsistent Responding index (INC), 2) Defensiveness (DEF), 3) Total Anxiety (TOT), 4)
Physiological Anxiety (PHY), 5) Worry (WOR), and 6) Social Anxiety (SOC). The score for TOT consists of the total score for the PSY, WOR, and SOC, while INC and DEF are score separately.

Parents of children with bowel and/or bladder dysfunction participating in the study will be asked to complete the Adult Manifest Anxiety Scale (AMAS-A), which is a published self-report questionnaire intended for use in evaluation anxiety levels in adults aged 19 through 59. The AMAS-A was developed as a continuation of the RCMAS-2, which will be used in this study by participants aged 6 through 18. The AMAS-A consists of 36 items and has three anxiety scales, one validity scale, and the total anxiety score. The three anxiety scales include: 1) Worry/Oversensitivity (WOS), 2) Physiological Anxiety (PHY) and, 3) Social Concern/Stress (SOC). The Lie scale was included to exemplify ideal behavior and measures the participant’s tendency in giving socially desirable responses. The Total Anxiety (TOT) scale is the sum of all scales excluding the Lie scale. Since the anxiety scales are proprietary, a copy of the instrument cannot be included in this document.

Reliability and validity of the RCMAS-2 and AMAS-A. Reliability refers to the consistency and accuracy in which scores taken from an instrument estimate the amount or numerical characteristic of a variable, such as anxiety, the test is intended to measure. Scales with high reliability will result in consistent and accurate results across item sets (questions on an instrument). A statistical analysis commonly used to measure reliability is Cronbach’s alpha and for psychological tests, such as the RCMAS-2 and the AMAS-A, estimates of .70 and higher are considered an adequate reliability score (Reynolds & Richmond, 2008; Patten, 2005; Reynolds, Richmond, & Lowe, 2003).
The authors of the RCMAS-2 ran Cronbach’s alpha on each of the subscales and the total anxiety score and were reported as follows: .92 for TOT, .75 for PSY, .86 for WOR, and .80 for SOC. The Cronbach’s alpha estimate for the RCMAS-2, represented homogeneity of the instrument items and scale scores, and were adequate in reliability (Reynolds & Richmond, 2008). The authors of the AMAS-A also ran Cronbach’s alpha on each of the subscales and the total anxiety score and were reported as follows: .91 for TOT, .82 for PHY, .85 for WOS, and .71 for SOC (Reynolds et al., 2003).

Validity refers to the degree which interpretation of test scores is accurately supported by evidence in research and theory (Reynolds & Richmond, 2008). In other words, validity refers to the accuracy and appropriateness regarding the interpretation of a test score, or in the case of the RCMAS-2, the TOT, PSY, WOR, and the SOC. One way to determine an instrument’s or an item on the instrument, validity is to compute the validity coefficient or correlation coefficient, which are measured in a range of .00 to 1.0. A 1.0 indicates an instrument has perfect validity and .0 indicates the instrument has no benefit when predicting outcomes. In order for an instrument to be considered valid the correlational coefficient must range from .60 to 1.00 (Patten, 2005). The interscale correlations for the RCMAS-2 were moderate to high ranging from: 1) .59 to .73 for the Anxiety scales and 2) .83 to .93 for the scales and TOT (Reynolds & Richmond, 2008).

Dependent Variables

The dependent variables chosen for this study will be the participant’s scores on the subscales and total anxiety for each instrument. The children and youth will complete the RCMAS-2 which will yield scores for the following categories: PSY, WOR, SOC, and TOT. The parents, including mothers and fathers or primary caregivers who live
with or do not live with the child, will complete the AMAS-A which will yield scores for the following categories: PSY, WOR, SOC, and TOT. Each score will be treated as a D.V. for a total of four for each participant in the analysis of data.

Independent Variables

The independent variables for this study are based on the categories of the hypotheses, medical educational, psychosocial, and demographic factors, and the Family Systems Illness Model (FSI) included in Chapter I (Table 2). According to the FSI, anxiety experienced by children and youth with chronic illness and their parents are related to onset, course, outcome, incapacitation, level of uncertainty related to the illness, as well as, developmental and familial factors. Furthermore, the FSI suggests adjustment to illness is not a direct function of the illness, but instead is affected by transactions between the illness (type and severity) and demographic (age, gender, and socio-economic status) characteristics, and child and familial adaptation processes (Rolland, 1999). The following interval and categorical independent variables will be used in the proposed study:

**Interval Independent Variables:**

- Proximity to Specialized Medical Care (in miles)
- Number of Hospitalizations (per year)
- Socio-Economic Status (based on federal government guidelines)

**Categorical Independent Variables:**

- Medical Diagnosis
- Presence of a Medical Home
- Type of Insurance (private or public)
• Formal Educational Plans (IEP, 504, IHP)
• Counseling Services (Individual, School, Group, Family)

Data Analysis

The following section describes the anticipated methods of data analysis for the proposed study. Descriptive statistics will be run, including frequencies, in order to get a general idea of the population in regards to demographics. Furthermore, a multiple regression will be used to analyze the data which will provide statistics in regard to the relationship between the independent variables and the dependent variables.

*Descriptive Statistics*

Descriptive statistics will be calculated and reported for all items on the Demographics Inventory as well as for the anxiety instruments (both subscales and overall scale). This will provide preliminary information about the raw data set and allow the researcher to examine which items need to be recoded or embedded in the constant before further analysis of the data using a multiple regression. The descriptive statistics of the dataset will also provide mean values in order to center and square the independent variables reported on an interval scale. Descriptive statistics, including frequency data, will also be used to identify outliers in the data (Cronk, 2008).

*Centering and Recoding Independent Variables*

Prior to running the assumptions and a regression for each subscale and total scores, all interval independent variables will need to be centered. Centering will be conducted by choosing a variable of interest and subtracting the mean, which will be identified in the descriptive statistics output. This process will be conducted for each of the interval independent variables. Centering each interval variable will reduce
multicollinearity in the regression and allow the interpretation of the coefficients to be consistent since the standard deviation is the same and the mean is zero.

The categorical independent variables will be recoded prior to running the regression and testing the assumptions. Recoding is necessary in order to assign a meaningful value to the categorical variables. In order to recode, each categorical variable will be divided into subcategories based on the results of the frequency output. For instance, educational plans will be divided into IEP, 504 plan, and IHP. A frequency will be run in order to determine which subcategory (IEP, 504 plan, and IHP) has the highest frequency. The percentages of participants with each form of educational plan will be divided into high, medium, and low and assigned a number 1 through 3.

*Multiple Regression*

A multiple regression will be used to analyze each dependent variable separately using each of the centered interval independent variables and recoded categorical independent variables. The general purpose of using a multiple regression in the analysis of this data is to learn more about the relationship between the independent variables (predictors) and the dependent variable. A multiple regression is best used with non-experimental data, when no intervention is employed, and can analyze both categorical and interval independent variables. As in the case of this research study, a multiple regression can easily incorporate multiple independent variables and allows the researcher to make statements about the effects of one variable on another. In other words, a multiple regression can be used for prediction and explanation of a hypothesis.
Summary

Children with bowel and/or bladder dysfunction and their parents will be included in this study. Participants will be identified through medical clinics and children’s hospitals specific to children with bowel and/or bowel dysfunction and parent networks specific to parents of children with bowel and/or bowel dysfunction. Each parent will complete a screener to ensure their child qualifies as having a chronic illness. Once the screener is complete, each participant will be mailed a packet, which will include detailed directions, demographic form, AMAS-A (parents), and the RCMAS-2 (child/youth). The researcher will analyze the data using a multiple regression which will analyze the effects each independent variable has on the dependent variables. Furthermore, the researcher will explore the relationship between how parental and child/youth anxiety is related to medical, psychosocial, and educational factors, which can impact the psychological well-being of the family as a whole. Demographic factors will be analyzed and investigated to see which have the greatest impact on anxiety for children and youth and their parents. In doing so, the researcher will emphasize the need for comprehensive and coordinated health and psychological care for the child and/or youth and the family.
CHAPTER IV

RESULTS

This study was designed to explore the relationship of anxiety in children with bowel and/or bladder dysfunction and their parents. First, frequencies and descriptive were obtained to describe the number of participants with above average anxiety. After documenting anxiety levels in parents and their children with bowel and/or bladder dysfunction, data were examined to identify which, if any, factors affected the presence of anxiety among the participants. These factors included educational, medical, and psychosocial factors. Reported levels of anxiety, including total, worry/oversensitivity, physiological, social were investigated using a correlation and multiple regression analysis to determine the impact of variables associated with educational, medical, and psychosocial predictors. Although research regarding anxiety of children with special health care needs has been explored, there is a lack of research specific to children and youth with bowel and/or bladder dysfunction. Furthermore, there is little research available regarding anxiety of parents of children with bowel and/or bladder dysfunction.

Research Questions and Associated Hypotheses

Research Question

How does parent and child anxiety relate to medical, psychosocial, and educational factors?

Hypotheses

H1: There is a relationship between parent and child anxiety in parents with children and youth bowel and/or bladder dysfunction.
H2: There is a relationship in maternal and paternal anxiety in families with children and youth with bowel and/or bladder dysfunction.

H3: Medical services have an impact on anxiety of parents with children and youth with bowel and/or bladder dysfunction.

H4: Psychosocial factors have an impact on anxiety of parents with children and youth with bowel and/or bladder dysfunction.

H5: Educational factors have an impact on anxiety of parents with children and youth with bowel and/or bladder dysfunction.

Analysis of Data

The following section provides in-depth information regarding analysis of data for this study. This section begins with a description of the population. Specifically, statistics are provided for participant demographics. Furthermore, statistical results provided by a multiple regression and correlation analysis are provided related to testing each hypothesis.

Demographic Description of Participants

Participants in this study were 83 families with a child affected by bowel and/or bladder dysfunction. Participants were identified through parent support groups, medical clinics, and professional organizations specific to bowel and/or bladder dysfunction. Potential participants were asked to complete an online screen in order to identify eligibility. Of the 301 individuals who completed the screener, 162 were identified as having eligible families. Research packets, including the instruments and demographic form, were mailed to the eligible participants. Of the 162 families identified as eligible,
83 returned completed packets (51.2% participation rate). The following section will provide more specific demographic information regarding the population.

**Characteristics of Participants.** Of the child/youth participants, 54.2% (n=45) were male and 45.8% (n=38) were female. When developing the demographic form, parents were identified as Parent 1 and Parent 2 in order to allow for non-traditional family units. However, of the participants, Parent 1 were all identified as males/fathers (89.2%; n=74) and Parent 2 were all identified as females/mothers (n=84). Of the total families (father, mother, and child/youth) 10.8% (n=9) were identified as single-parent households, all with females as the “parent”. Demographic information was not available for the other parent of the single-parent households. The parent role most frequently identified by fathers was biological parent (73.5%; n=61) followed by step parent (9.6% n=8). The parent role most frequently identified by mothers was biological parent (92.8%; n=77). Of the 84 children/youth included in this study, 80.7% (n=67) were identified as living in a household with both parents.

Participants were asked to identify medical diagnoses of their child. A total of 46.9% (n=39) identified their child as having more than one diagnosis. The medical diagnosis most frequently indicated by participants was Imperforate Anus (44.6%; n=37) followed by Neurogenic Bladder (30.1%; n=25). Frequency data for all diagnoses are given in Table 2.
Table 2

*Summary of Population Diagnoses*

<table>
<thead>
<tr>
<th>Medical Diagnosis</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Imperforate Anus</td>
<td>44.6%</td>
<td>37</td>
</tr>
<tr>
<td>Neurogenic Bladder</td>
<td>30.1%</td>
<td>25</td>
</tr>
<tr>
<td>Tethered Spinal Cord</td>
<td>21.7%</td>
<td>18</td>
</tr>
<tr>
<td>VATER/VACTERL</td>
<td>19.3%</td>
<td>16</td>
</tr>
<tr>
<td>Hirschsprung’s Disease</td>
<td>18.1%</td>
<td>15</td>
</tr>
<tr>
<td>Sacral Agenesis</td>
<td>13.3%</td>
<td>11</td>
</tr>
<tr>
<td>Cloaca</td>
<td>12.0%</td>
<td>10</td>
</tr>
<tr>
<td>Caudal Regression</td>
<td>9.6%</td>
<td>8</td>
</tr>
<tr>
<td>Spina Bifida</td>
<td>9.6%</td>
<td>8</td>
</tr>
<tr>
<td>Scoliosis</td>
<td>9.6%</td>
<td>8</td>
</tr>
<tr>
<td>Bladder Exstrophy</td>
<td>9.6%</td>
<td>8</td>
</tr>
<tr>
<td>Renal Defects</td>
<td>8.4%</td>
<td>7</td>
</tr>
<tr>
<td>Crohn’s Disease</td>
<td>7.2%</td>
<td>6</td>
</tr>
<tr>
<td>Cloacal Exstrophy</td>
<td>6.0%</td>
<td>5</td>
</tr>
<tr>
<td>Anal Stenosis</td>
<td>4.8%</td>
<td>4</td>
</tr>
<tr>
<td>Tracheo-Esophageal Fistula</td>
<td>3.6%</td>
<td>3</td>
</tr>
<tr>
<td>Ulcerative Colitis</td>
<td>2.4%</td>
<td>2</td>
</tr>
<tr>
<td>Bylar’s Disease</td>
<td>1.2%</td>
<td>1</td>
</tr>
<tr>
<td>Pseudo-Obstruction</td>
<td>1.2%</td>
<td>1</td>
</tr>
<tr>
<td>Down Syndrome</td>
<td>1.2%</td>
<td>1</td>
</tr>
</tbody>
</table>

*Note:* Diagnoses reported are not mutually exclusive and do not add up to 100 percent.
The mean age for child/youth participants was 12.16 (range 6-19 years). The mean age for fathers was 45.24 years (range 25-64 years) and the mean age reported for MOTHERS was 43.34 (range 29-60 years). Frequency data for all ages for children/youth, fathers, and mothers are given in Table 3.
Table 3

Summary of Population Age

<table>
<thead>
<tr>
<th>Age in years</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child/Youth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6-8</td>
<td>21.6%</td>
<td>18</td>
</tr>
<tr>
<td>9-14</td>
<td>48.0%</td>
<td>40</td>
</tr>
<tr>
<td>5-19</td>
<td>25</td>
<td></td>
</tr>
<tr>
<td>Male/Father</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25-30</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>31-39</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>40-49</td>
<td>36</td>
<td></td>
</tr>
<tr>
<td>50-59</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>60-64</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Female/Mother</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25-30</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>31-39</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>40-49</td>
<td>44</td>
<td></td>
</tr>
<tr>
<td>50-59</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>60-64</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

Note. Child/Youth ages are categorized according to the RCMAS-2. fathers does not add up to 100% (n=9 missing).

Participants were asked to identify if their child had formal educational planning (i.e. IEP, 504 Accommodations Plan, and/or IHP). The category identified the most by participants was “no educational plan” (33.7%; n=28) followed by IEP (27.2%; n=23).
Additionally, participants were asked to identify the category of absences per school year. The category identified most frequently identified was one week to two weeks (27.7%; n=23) followed by more than one month (15.7%; n=13). The frequency data for educational plans and school absences is presented in Table 4.

Table 4

Summary of Educational Plans and School Absences

<table>
<thead>
<tr>
<th>Plan/Absences</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of Plan</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No Plan</td>
<td>33.7%</td>
<td>28</td>
</tr>
<tr>
<td>IEP</td>
<td>27.7%</td>
<td>23</td>
</tr>
<tr>
<td>504</td>
<td>22.9%</td>
<td>19</td>
</tr>
<tr>
<td>504 and IHP</td>
<td>7.2%</td>
<td>6</td>
</tr>
<tr>
<td>School Absences</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No Absences</td>
<td>13.3%</td>
<td>11</td>
</tr>
<tr>
<td>1-5 days</td>
<td>24.0%</td>
<td>20</td>
</tr>
<tr>
<td>1 week-1 month</td>
<td>39.7%</td>
<td>43</td>
</tr>
<tr>
<td>More than 1 month</td>
<td>15.7%</td>
<td>13</td>
</tr>
<tr>
<td>Homebound/Homeschool</td>
<td>7.2%</td>
<td>6</td>
</tr>
</tbody>
</table>

Participants were asked to identify the type of health insurance coverage their family used including the child/youth with bowel and/or bladder dysfunction. The most frequently identified category was “Private Health Insurance” (81.9%; n=68) followed by “Public Health Insurance” (9.6%; n=8). Of the 83 families that responded, 8.4% (n=7)
indicated they had public health insurance as the primary coverage with public health insurance as the supplemental coverage. Furthermore, participants were asked to identify family income per year. Participants indicated more than $75,000 most frequently (59.0%; n=49) followed by $50,000 to $74,999 (16.9% n=14). The frequency data for income is provided in Table 5.

Table 5

Summary of Family Income

<table>
<thead>
<tr>
<th>Per year</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 25,000</td>
<td>3.6%</td>
<td>3</td>
</tr>
<tr>
<td>25,000-49,999</td>
<td>12.0%</td>
<td>10</td>
</tr>
<tr>
<td>50,000-74,999</td>
<td>16.9%</td>
<td>14</td>
</tr>
<tr>
<td>75,000 or more</td>
<td>59.0%</td>
<td>49</td>
</tr>
<tr>
<td>Do not wish to report</td>
<td>8.4%</td>
<td>7</td>
</tr>
</tbody>
</table>

Participants were asked to identify the number of hospital admissions their child/youth experienced per year. The most frequently identified amount of time spent in the hospital each year was “No Hospitalizations” (53.0%; n=44) followed by three to five days (10.8%; n=9). Additionally, one to three days and one to two weeks of hospitalizations were each identified by 9.6% (n=8) followed by two weeks to 1 month and more than 1 month each at 8.4% (n=7).

Participants were asked to identify whether or not their child/youth had a medical home which was defined as an environment through with to receive acute, chronic, and
preventative comprehensive services (American Academy of Pediatrics Committee on Children with Disabilities, 2002). Of the 83 families 51.8% (n=43) indicated “yes”, they did consider themselves as having a medical home and 48.2% (n=40) indicated “no” they did not have a medical home. Additionally, participants were asked to indicate their proximity in miles to specialized health care. Participants most frequently indicated more than 100 miles (36.1%; n=30) followed by less than 20 miles (22.9%; n=19). The frequency data for proximity to specialized medical care is provided in Table 6.

Table 6

*Summary of Proximity Care*

<table>
<thead>
<tr>
<th>Distance in Miles</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 20</td>
<td>22.9%</td>
<td>19</td>
</tr>
<tr>
<td>21-40</td>
<td>15.7%</td>
<td>13</td>
</tr>
<tr>
<td>41-60</td>
<td>13.3%</td>
<td>11</td>
</tr>
<tr>
<td>61-80</td>
<td>4.8%</td>
<td>4</td>
</tr>
<tr>
<td>81-100</td>
<td>7.2%</td>
<td>6</td>
</tr>
<tr>
<td>More than 100</td>
<td>36.1%</td>
<td>30</td>
</tr>
</tbody>
</table>

Parent participants (fathers and mothers) were asked to indicate whether or not they received professional and/or non-professional supports (i.e. mental health counseling, online support group). The category most frequently indicated by both fathers (84.3%; n=70) and mothers (83.1%; n=69) for Professional Supports was “No, I do not receive professional support”. Furthermore, both groups were asked to indicate whether or not they participated in non-professional support. The category most
frequently indicated by both fathers (74.7%; n=62) and mothers (55.4%; n=46) was, “No, I do not participate in non-professional supports”. Further frequency data is provided in Table 7.

Table 7

Summary of Professional and Non-Professional Support

<table>
<thead>
<tr>
<th>Type</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional Support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males/Fathers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>84.3%</td>
<td>70</td>
</tr>
<tr>
<td>Yes</td>
<td>4.8%</td>
<td>4.8</td>
</tr>
<tr>
<td>Females/Mothers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>83.1%</td>
<td>69</td>
</tr>
<tr>
<td>Yes</td>
<td>16.9%</td>
<td>14</td>
</tr>
<tr>
<td>Non-Professional Support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males/Fathers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>74.7%</td>
<td>62</td>
</tr>
<tr>
<td>Yes</td>
<td>14.5%</td>
<td>12</td>
</tr>
<tr>
<td>Females/Mothers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>55.4%</td>
<td>46</td>
</tr>
<tr>
<td>Yes</td>
<td>44.6%</td>
<td>37</td>
</tr>
</tbody>
</table>

Note: Fathers does not add to 100% due to missing data (n=9).
Frequencies and Descriptives for Anxiety Inventories

The following section is a description of frequency and descriptive outcomes for anxiety scores for Child/Youth, Males/Fathers, and Females/Mothers. Children/Youth completed the Revised Children’s Manifest Anxiety Scale second edition (RCMAS-2) which consisted of a total scale and four subscales which included Worry (WOR), Physiological (PHY), Social (SOC), and Defensiveness (DEF). Both fathers and mothers completed The Adult Manifest Anxiety Scale (AMAS-A). The AMAS-A consisted of a total scale and four subscales which included Worry/Oversensitivity (WOS), Physiological (PHY), Social Concerns/Stress (SOC), and Lie. The following table provides score ranges for the RCMAS-2 and the AMAS (Table 8)
Table 8

*Suggested Score Range for RCMAS-2 and AMAS-A Scales*

<table>
<thead>
<tr>
<th>Descriptor</th>
<th>Score Ranges</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>RCMAS-2</strong></td>
<td></td>
</tr>
<tr>
<td>Less Problematic</td>
<td>39 and lower</td>
</tr>
<tr>
<td>No More Problematic Than for Most</td>
<td>40-60</td>
</tr>
<tr>
<td>Moderately Problematic</td>
<td>61-70</td>
</tr>
<tr>
<td>Extremely Problematic</td>
<td>71 and higher</td>
</tr>
<tr>
<td><strong>AMAS-A</strong></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>44 or lower</td>
</tr>
<tr>
<td>Expected</td>
<td>45-54</td>
</tr>
<tr>
<td>Mild Elevation</td>
<td>55-64</td>
</tr>
<tr>
<td>Clinically Significant</td>
<td>65-74</td>
</tr>
<tr>
<td>Extreme</td>
<td>75 or higher</td>
</tr>
</tbody>
</table>

*Note: The subscale PHY on the AMAS-A ranges for Clinically Significant from 65-69 and for Extreme 70 or higher.*

RCMAS-2 Anxiety Total Scale. Children/youth (n=82) completed the RCMAS-2 which consisted of 49 items relevant to total anxiety and the subscales. The mean of the Total Anxiety score was 47.51. The descriptive category for total score ranges most frequently calculated was “No More Problematic Than For Most” (55.4%; n=46) followed by “Less Problematic” (26.5%; n=22). Further frequency data for Total Score is provided in Table 9.
Table 9

*Overall Frequencies and Means on RCMAS-2 Total Anxiety*

<table>
<thead>
<tr>
<th>Scale</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less Problematic</td>
<td>26.4%</td>
<td>22</td>
</tr>
<tr>
<td>No More Problematic</td>
<td>55.2%</td>
<td>46</td>
</tr>
<tr>
<td>Moderately Problematic</td>
<td>15.6%</td>
<td>13</td>
</tr>
<tr>
<td>Extremely Problematic</td>
<td>1.2%</td>
<td>1</td>
</tr>
</tbody>
</table>

*RCMAS-2 Subscales.* The mean score of the WOR scale was 48.23. The descriptive category for WOR score ranges most frequently calculated was “No More Problematic Than For Most” (51.8%; n=43) followed by “Less Problematic” (27.7%; n=23). Of the 82 participants 16 scored within the range for “Moderately Problematic”. The mean score of the PHY subscale was 46.72. The descriptive category for PHY score ranges most frequently calculated was “No More Problematic than for Most” (65.1%; n=54) followed by “Less Problematic” (22.9%; n=19). The mean score for the SOC subscale was 47.16. The descriptive category for SOC most frequently calculated was “No More Problematic than for Most” (62.7%; n=52). The mean score for DEF was slightly more elevated than the other subscales at 52.79. The descriptive category for DEF score ranges most frequently calculated was “No More Problematic than for Most” (63.9%; n=53) followed by “Moderately Problematic” (24.1%; n=20).

*AMAS-A Fathers Total Scale.* Fathers (n=70) completed the AMAS-A which consisted of 36 items relevant to total anxiety and the subscales. The total scores ranged from 33 to 75. The mean of the Total Anxiety score was 54.49. The descriptive category
for total score ranges most frequently calculated was “Mild Elevation” (33.7%; n=28) followed by “Expected” (26.5%; n=22). Further frequency data for Total Score is provided in Table 10.

Table 10

*Overall Frequencies for Fathers AMAS-A Total Anxiety*

<table>
<thead>
<tr>
<th>Scale</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low</td>
<td>14.5%</td>
<td>12</td>
</tr>
<tr>
<td>Expected</td>
<td>26.5%</td>
<td>22</td>
</tr>
<tr>
<td>Mild Elevation</td>
<td>33.7%</td>
<td>28</td>
</tr>
<tr>
<td>Clinically Significant</td>
<td>8.4%</td>
<td>7</td>
</tr>
<tr>
<td>Extreme</td>
<td>1.2%</td>
<td>1</td>
</tr>
</tbody>
</table>

Note: Total Anxiety does not add up to 100% (n missing=13).

*AMAS-I Fathers Subscales.* The mean score of the WOR scale was 52.81. The descriptive category for WOR score ranges most frequently calculated was “Mild Elevation” (33.7%; n=28) followed by “Expected” (32.5%; n=27). Furthermore, of the 70 participants 10 (12.0%) scored within the range for “Low” and 5 (6.0%) scored within the range for “Extreme”. The mean score of the PHY subscale was 54.60. The descriptive category for PHY score ranges most frequently calculated was “Mild Elevation” (42.2%; n=35) followed by “Low” (19.3%; n=16). The mean score for the SOC subscale was 55.03. The descriptive category for SOC most frequently calculated was “Mild Elevation” (38.6%; n=32) followed by “Expected” (31.3%; n=26). The mean
score for “Lie” was 50.57. The descriptive category for “Lie” score ranges most frequently calculated was “Low” (34.9%; n=29) followed by “Mild Elevation” (21.7%; n=18).

*AMAS-A Mothers Total Scale.* Mothers/Females (n=83) completed the AMAS-A which consisted of 36 items relevant to total anxiety and the subscales. The scores ranged from 33 to 82. Furthermore, the mean of the Total Anxiety score was 59.14. The descriptive category for total score ranges most frequently calculated was “Mild Elevation” (45.8%; n=38) followed by “Clinically Significant” (31.3%; n=26). Further frequency data for Total Score is provided in Table 11.

Table 11

*Overall Frequencies for Mothers AMAS-A Total Anxiety*

<table>
<thead>
<tr>
<th>Scale</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low</td>
<td>13.3%</td>
<td>11</td>
</tr>
<tr>
<td>Expected</td>
<td>8.4%</td>
<td>7</td>
</tr>
<tr>
<td>Mild Elevation</td>
<td>45.8%</td>
<td>38</td>
</tr>
<tr>
<td>Clinically Significant</td>
<td>31.3%</td>
<td>26</td>
</tr>
<tr>
<td>Extreme</td>
<td>1.2%</td>
<td>1</td>
</tr>
</tbody>
</table>

*AMAS-A Mothers Subscales.* The mean score of the WOR scale was 58.90. The descriptive category for WOR score ranges most frequently calculated was “Mild Elevation” (51.8%; n=43) followed by “Clinically Significant” (19.3%; n=16). The mean score of the PHY subscale was 54.60. The descriptive category for PHY score ranges most frequently calculated was “Mild Elevation” (43.4%; n=36) followed by “Clinically Significant” (27.3%; n=23).
Significant” (24.1%; n=20). Furthermore, of the 83 participants 19 (22.9%) scored within the range for “Low”. The mean score for the SOC subscale was 56.95. The descriptive category for SOC most frequently calculated was “Mild Elevation” (48.2%; n=40) followed by Expected (25.3%; n=29). Additionally, 11 participants (13.3) scored within the range for “Clinically Significant”. The mean score for “Lie” was 50.47. The descriptive category for “Lie” score ranges most frequently calculated was “Low” (38.6%; n=32) followed by “Expected” (31.3%; n=26). Furthermore, of the 82 participants 22 (26.5%) scored within the range of “Clinically Significant”.

Correlation. A Pearson correlation coefficient was calculated for the relationship between the RCMAS-2 Total Score, AMAS-A Total Score for fathers, and the AMAS-A Total Score for mothers. A moderate correlation was found between AMAS-A mothers and RCMAS-2 (r(80)= .268, p<.05). Additionally, a moderate correlation was found between AMAS-A fathers and AMAS-A mothers (r(68)= .265, p<.05). However, a correlation was not found between AMAS-A fathers Total Scores and RCMAS-2 Total Scores. The complete Pearson correlation is represented in Table 12.
Table 12

**Correlations**

<table>
<thead>
<tr>
<th></th>
<th>RCMAS Child total</th>
<th>AMAS-A fathers total</th>
<th>AMAS-A mothers total</th>
</tr>
</thead>
<tbody>
<tr>
<td>RCMAS Child total</td>
<td>Pearson Correlation 1</td>
<td>.150</td>
<td>.268</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
<td>.220</td>
<td>.015</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>82</td>
<td>69</td>
</tr>
<tr>
<td>AMAS-A Fathers total</td>
<td>Pearson Correlation .150</td>
<td>1</td>
<td>.265</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
<td>.220</td>
<td>.026</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>69</td>
<td>70</td>
</tr>
<tr>
<td>AMAS-A mothers total</td>
<td>Pearson Correlation .268</td>
<td>.265</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
<td>.015</td>
<td>.026</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>82</td>
<td>70</td>
</tr>
</tbody>
</table>

Note: Correlation is significant at the 0.05 level (2-tailed). Significant correlations in bold.

Data Analysis of Total Anxiety Scores and Predictors

A multiple linear regression was run on the dependent variable of Total Score of anxiety for the RCMAS-2 for children/youth with bowel and/or bladder dysfunction and the AMAS-A for fathers and mothers. Frequencies were run on the variables on the demographic form provided in the research packet in order to review the distribution of number of participants across each category. The predictor variables used in the model were proximity to specialized health care, family income, non-professional support (fathers and mothers), professional support, medical home, school absences, educational plans (IEP, 504, IHP and No Plan) and gender. The following sections will provide the results of the multiple linear regressions for children, parents combined, and mothers and fathers separately.
Multiple Linear Regression Analysis RCMAS-2. A multiple linear regression was calculated predicting participants total anxiety scores based on the predictor variables mentioned above. As represented in Tables 13 and 14, the regression equation was not significant (F(15, 45)=1.09, p>.05) with an $R^2$ of .266. According to the results of the analysis, the independent variables included in this model are not significant predictors of the total anxiety scores of children with bowel and/or bladder dysfunction.

Table 13

*Model Summary for RCMAS-2*

<table>
<thead>
<tr>
<th>R</th>
<th>R Square</th>
<th>Adjusted R Square</th>
<th>Std. Error of the Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>.516</td>
<td>.266</td>
<td>.022</td>
<td>10.544</td>
</tr>
</tbody>
</table>

Table 14

*ANOVA Summary for RCMAS-2*

<table>
<thead>
<tr>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regression</td>
<td>1815.282</td>
<td>15</td>
<td>121.019</td>
<td>1.089</td>
</tr>
<tr>
<td>Residual</td>
<td>5002.522</td>
<td>45</td>
<td>111.167</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>6817.803</td>
<td>60</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Multiple Linear Regression Analysis AMAS-A Combine with Mothers and Fathers. A multiple linear regression was calculated to determine the significance of the predictor variables on the total anxiety scores for parents of children with bowel and/or bladder dysfunction.
dysfunction. A significant regression equation was found (F(15,137)=2.788, p<.05), with an R^2 of .234 (Table 15 and 16).

Table 15

*Model Summary for AMAS-A Fathers and Mothers*

<table>
<thead>
<tr>
<th>R</th>
<th>R Square</th>
<th>Adjusted R Square</th>
<th>Std. Error of the Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>.484</td>
<td>.234</td>
<td>.150</td>
<td>8.938</td>
</tr>
</tbody>
</table>

Table 16

*ANOVA Summary for AMAS-A Fathers and Mothers*

<table>
<thead>
<tr>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regression</td>
<td>3340.770</td>
<td>15</td>
<td>222.718</td>
<td>2.788</td>
</tr>
<tr>
<td>Residual</td>
<td>10945.204</td>
<td>137</td>
<td>79.892</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>14285.974</td>
<td>152</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: The regression is significant at the .05 level

A significant relationship was found between parent anxiety scores and the independent variable income_2_comb ($25,000 to $49,999). Parents with an income of $25,000 to $49,999 have 7.40 percent more total anxiety when compared to parents with an income of $75,000 or more, controlling for all other variables. Furthermore, a significant relationship was found between parent anxiety scores and the independent variable abs_none (children with no absences from school). Parents with children with no absences from school have 6.46 percent less total anxiety when compared to those with one week to a month of school absences, controlling for all other variables. A significant relationship was found between sex (1= males, 0= females). Male parents
(fathers) have 3.17 percent less total anxiety when compared to female parents (mothers), controlling for all other variables. Attention should be noted for the independent variables non-professional support and income_3 as they are approaching significance. Further analysis of the independent variables can be found in Table 17.
Table 17

*Coefficient Summary for AMAS-A Fathers and Mothers*

<table>
<thead>
<tr>
<th>Model</th>
<th>Unstandardized Coefficients</th>
<th>Standardized Coefficients</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>Std. Error</td>
<td>Beta</td>
</tr>
<tr>
<td>med_home</td>
<td>1.575</td>
<td>1.545</td>
<td>.081</td>
</tr>
<tr>
<td>non_prof</td>
<td>3.004</td>
<td>1.671</td>
<td>.145</td>
</tr>
<tr>
<td>income_1</td>
<td>-.446</td>
<td>5.885</td>
<td>-.006</td>
</tr>
<tr>
<td>income_2</td>
<td>7.405</td>
<td>2.483</td>
<td>.253</td>
</tr>
<tr>
<td>income_3</td>
<td>4.006</td>
<td>2.287</td>
<td>.148</td>
</tr>
<tr>
<td>income_5</td>
<td>-1.950</td>
<td>2.754</td>
<td>-.056</td>
</tr>
<tr>
<td>abs_none</td>
<td>-6.461</td>
<td>2.474</td>
<td>-.230</td>
</tr>
<tr>
<td>abs_1_5d</td>
<td>-.700</td>
<td>2.018</td>
<td>-.31</td>
</tr>
<tr>
<td>abs_1m</td>
<td>-.384</td>
<td>2.456</td>
<td>-.014</td>
</tr>
<tr>
<td>abs_other</td>
<td>-1.985</td>
<td>3.007</td>
<td>-.055</td>
</tr>
<tr>
<td>prox_0_40</td>
<td>-.205</td>
<td>1.641</td>
<td>-.010</td>
</tr>
<tr>
<td>prox_41_81</td>
<td>2.290</td>
<td>2.206</td>
<td>.086</td>
</tr>
<tr>
<td>edu_plan</td>
<td>.955</td>
<td>1.727</td>
<td>.047</td>
</tr>
<tr>
<td>sex_comb</td>
<td>-3.172</td>
<td>1.553</td>
<td>-.164</td>
</tr>
<tr>
<td>prof_comb</td>
<td>3.047</td>
<td>2.649</td>
<td>.099</td>
</tr>
</tbody>
</table>

Note: Significance is set at p<.05. Significant predictors are indicated in bold.

*Multiple Linear Regression Analysis AMAS-A Fathers.* A multiple linear regression was calculated to determine the significance of the predictor variables on the total anxiety.
scores for fathers. The regression equation was not significant \((F(14,43)=1.16, p>.05)\) with an \(R^2\) of .27. The outcome of the analysis indicated the independent variables included in the model were not predictors of fathers total anxiety score. The model summary is provided in Table 18 and ANOVA summary is provided in Tables 19.

Table 18

*Model Summary for Fathers AMAS-A*

<table>
<thead>
<tr>
<th>R</th>
<th>R Square</th>
<th>Adjusted R Square</th>
<th>Std. Error of the Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>.523</td>
<td>.274</td>
<td>.037</td>
<td>9.115</td>
</tr>
</tbody>
</table>

Table 19

*ANOVA Summary for Fathers AMAS-A*

<table>
<thead>
<tr>
<th></th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regression</td>
<td>1345.982</td>
<td>14</td>
<td>96.142</td>
<td>1.157</td>
<td>.341</td>
</tr>
<tr>
<td>Residual</td>
<td>3572.932</td>
<td>43</td>
<td>83.091</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>4918.914</td>
<td>57</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Multiple Linear Regression Analysis AMAS-A Mothers.* A linear multiple regression was calculated to determine the significance of the predictor variables on the total anxiety scores for mothers. The results of the regression, provided in Tables 20 and 21, indicated the predictor variables did not have an effect on the dependent variable of total anxiety score. The regression equation was not significant \((F(15,46)=1.28, p>.05)\) with an \(R^2\) of .295.
Summary

After determining anxiety levels in participants, the evaluation of the relationships between fathers and mothers total anxiety scores and child/youth total anxiety scores was completed through a Pearson correlation analysis. The result of the correlation indicated that there was a relationship between total scores of fathers and mothers, as well as, mothers and child/youth which supported hypotheses one and two. The evaluation of the relationship of medical, educational, and psychosocial factors was calculated with a multiple linear regression for children, fathers, and mothers separately, and fathers and mothers combined. The results of the regression indicated there was no significance in the equations for fathers, mothers, or child/youth anxiety scores when analyzed separately. Specifically, the predictor variables related to medical, educational and psychosocial factors did not have an impact on the total anxiety scores which led to the
rejection of hypotheses three, four, and five. Although the findings of the multiple linear regression indicated no significance, the low number of participants may have had an effect on the outcome of the analysis. A regression analysis was conducted on father and mother anxiety scores combined (n=166). Significance was found for the independent variables income 2 ($25,000 to $49,999), abs none (no absences from school), and sex (male/female). Furthermore, income 3 ($50,000 to $74,999) and non-professional support (social support) were found to be approaching significance. Statistical finding for the regression analysis should be viewed with some caution due to the independent variables not being independent observations or nested. Chapter V will provide a summary of the study, offer further insight into the statistical findings, and give implications of the study and future research.
CHAPTER V
SUMMARY

Children with bowel and/or bladder dysfunction and their families can be physiologically and psychologically impacted by challenges associated with chronic illness. The role anxiety plays in the relationship of mothers and children with special health care needs (CSHCN) have been explored as a construct in professional literature (Funakosi et al, 2005; Hocking & Lochman, 2005). While findings support that maternal anxiety increases the anxiety of the child, research is limited on the relationship of maternal anxiety and how it relates to paternal anxiety. Additionally, there is an absence of research regarding medical, educational, and psychosocial supports both for children/youth with bowel and/or bladder dysfunction and their families.

Parents of children with special health care needs (CSHCN) are at risk of marital dissatisfaction and experience a lack of familial cohesion, including difficulties in parenting roles and responsibilities (Berge & Patterson, 2004; Rolland, 1999; Valsiner & Lawrence, 1997). There is increased recognition among health professionals involved in the care of individuals with chronic illness regarding the need of psychological support for the family as a unit within a clinical setting (Ross, Malthus, Berrett, & Harvey, 2009). Furthermore, research supports that psychologists can aid in the reduction of physical symptoms related to chronic illness, as well as in the enhancement of quality of life. It has also been shown that the positive effects of psychological treatment can, in turn, increase adherence to medical treatments and effectiveness of medical treatments (Ross et al., 2009; Fasten, 2000).
While there is a body of research reported on the importance of psychological support for CSHCN and their families, very little research is available regarding the importance of educational support for these children. An increased number of CSHCN attend school due to the enactment of laws protecting the rights of children with disabilities. Educational accommodations and services within the school setting are required for children with disabilities, in order to ensure academic success. However, many CSHCN are not eligible for these services because their health care needs do not have an obvious affect on cognition related to academic performance (Caldwell et al., 1997).

This study was designed to examine potential relationships among anxiety of children/youth with bowel and/or bladder dysfunction and their parents. Additionally, the study explored the differences in anxiety among mothers and fathers. Furthermore, the study explored whether or not there was a relationship between medical, educational, and psychosocial factors and anxiety in parents. The study included 83 families with children/youth with bowel and/or bladder dysfunction. As this number was lower than desired, the results and conclusions reported in this chapter should be view with some caution. The relationship of anxiety scores among parents and children/youth were compared using a correlation analysis. Further analysis of the medical, educational, and psychosocial factors and anxiety scores were compared using a multiple linear regression.

Summary of Findings

The outcome of the statistical analysis that addressed the research question and the five hypotheses were reported in detail in Chapter IV and will be summarized in this section. Descriptive data, including frequencies, were calculated for mothers, fathers,
and children/youth total anxiety scores and the subscales of worry, physiological, and social subscales. The total and subscale anxiety scores for parents were found to be above expected across each domain. However, the anxiety scores for children/youth were found to be no more problematic than other children/youth. Significance among the data were found in the relationship of maternal total anxiety scores and paternal total anxiety scores, as well as in the relationship of maternal total anxiety scores and child/youth total anxiety scores. Furthermore, these levels of significance were also found in the regression model of the parent total anxiety scores when combined, further confirming the results. When exploring medical factors hypothesized to affect anxiety, no statistically significant results were found. It may be important to note, however, the income levels of participants which were found to impact anxiety, and may have influenced the medical factor results, as parents with higher income levels have better access to care (Stevens et al., 2010). Specifically, parents with an income of $25,000 to $49,999 had greater anxiety when compared to parents whose income was $75,000 or more. While only found to be approaching statistical significance, income levels of $50,000 to $75,000 were found to impact at anxiety somewhat. The psychosocial factor of professional support was not found to impact anxiety in a statistically significant way. While not found statistically significant, the independent variables of participation in non-professional support (also a psychosocial factor) was approaching significance. When exploring educational factors, parents whose children had no absences from school had less anxiety than parents with children who had one week to a month of absences. In this area, males/fathers had less anxiety when compared to females/mothers. There was no significance found in relationship to the independent variables (medical, psychosocial
or educational factors) and the maternal, paternal, and child/youth total anxiety score or the subscales when analyzed separately.

Discussion

Data from the Adult Manifest Anxiety Scale-Adults (AMAS-A) for both mothers and fathers and the Revised Children’s Manifest Anxiety Scale Second Edition (RCMAS-2) were used to explore the relationship of maternal and paternal anxiety including both maternal versus paternal anxiety, maternal versus child/youth anxiety, and paternal versus child/youth anxiety. Furthermore, these scores were used to evaluate the relationship of medical, educational, and psychosocial factors on anxiety of participant groups. Eighty-three families (166 parents and 83 children) completed the scales and demographic forms. This chapter summarizes the study, its findings, conclusions regarding the findings, implications for services, and recommendations for further research.

Anxiety in Study Participants

It seems logical that chronic illness would cause anxiety not only in the person with the illness, but in their family members as well. While the overwhelming majority (78.3%) of mothers participating in this study were identified with anxiety (48.8% “Mild Elevation”, 31.3% “Clinically Significant”, and 1.2% “Extreme”), these levels were not seen in the affected children or fathers. The analysis of data in this study found only 16.8% of child participants had problematic levels of anxiety. While 43.3% of fathers had elevated anxiety, these outcomes were not as significant as mothers’ anxiety. Furthermore, fathers’ anxiety was not found to have an effect on children’s anxiety. A discussion of each participant group is provided in the following sections.
**Child Anxiety Outcomes.** Of the children and youth included in this study, a total of only 16.8% were found to have anxiety (15.6% “Moderately Problematic” and 1.2% “Extremely Problematic”). Furthermore, 26.4% of children and youth (n=22) were identified to be “Less Problematic” when compared to the general population and 24.1% were identified as having a “Mild Elevation” in regards to defensiveness. This is a somewhat surprising finding, as previous research has reported elevated levels of anxiety in children with chronic illness in general (Mussatto, 2006; Wallander & Varni, 1998) and in this population of youth in particular (Filce & LaVergne, 2012). This may be explained by the ages of the participants in the present study. Pre-adolescent child participants accounted for 69.6% of total child/youth included in the study (48.0% were ages nine to fourteen and 21.6% were ages six to eight). While there were not enough participants in the study to analyze the different age groups separately with any confidence, research suggests younger children may lack the cognitive capacity to make a connection of physical discomforts as symptoms of anxiety (Nelles & Barlow, 1988). This theory may explain the outcome of the research on anxiety of children/youth in this study. These outcomes suggest the participants responses were guarded or had unusually low anxiety with the aim of presenting a positive image that may not be realistic of the participant’s actual state of anxiety. This outcome of defensiveness and/or abnormally low anxiety may be due to the participant’s inability to express feelings of anxiety or the need to repress or avoid these feelings in order to cope more effectively with health or family related issues. Children who are anxious are more likely to exhibit avoidant behavior and coping strategies when faced with a challenging situation (Barrett, Rapee, Dadds, & Ryan, 1996). Research indicates the long-term use of avoidant coping
strategies can lead to negative mental health outcomes such as depressive symptoms or behavior problems (Steele, Phipps, & Srivastava, 1999). However, the use of avoidant behavior for immediate stressors can have benefits on an individual’s ability to cope with stressors. For example, avoidant coping can decrease an individual’s perceived distress at the onset of a stressful event, which can allow the individual to identify and develop plans or strategies for long-term coping of the stressful event (i.e. diagnosis of a chronic illness).

**Maternal Anxiety.** This study, like other studies of mothers of chronically ill children in general (Eisen & Engler, 2006; Dowbiggin, 2009, Calam et al., 2003), found that mother experienced increased levels of anxiety when compared to other family members. However, this study provides more specific data regarding mothers of children with bowel and/or bladder dysfunction. Of the mothers included in this study, the overwhelming majority (78.3%) were identified as having elevated levels of anxiety. The presence of anxiety is often the result of biological factors, social factors, and stressful life experiences (Dacey & Fiore, 2002; Mussatto, 2006). Specifically, research on gender and anxiety reports females are more prone to developing anxiety disorders than males (Leon, Portera, & Weissman, 1995; Barnett, Schaafsma, Guzman, & Parker, 1991). Although, the link between gender and anxiety is somewhat unclear, the outcome of this study validates the outcomes of these previous findings.

**Paternal Anxiety Outcomes.** Of the fathers included in this study 43.3% had elevated anxiety. Specifically, 33.7% had “Mild Elevation”, 8.4% had “Clinically Significant”, and 1.2% had “Extreme” anxiety, these outcomes were not as significant as mothers’ anxiety. While family theory has encouraged research on fathers, the social
The primary focus of family research is still mothers. This misrepresentation of the fathers’ roles within the family can leave the father on the periphery if included at all.

The definition of what it is to be male and a father is a social construct. The boundaries of masculine and feminine and mother and father are determined by what society deems them to be. According to gender theory, masculinity is something that needs to be proved regularly and over a life time to one’s self and to others (Helgeson, 2011). Therefore, in the case of fathers with children with chronic illness, there may be an inconsistency of how the father actually feels and how the father reacts. For instance, the father may be saddened or be overwhelmed however, he may present to his family as being unaffected psychologically in order to appear strong. This inconsistency of internal feelings and external manifestations of feeling may cause an increase in anxiety. In turn, obtaining an accurate measure of male anxiety may be difficult due to these factors.

**Relationships among Anxiety in the Families Studied.**

Beyond the mere presence of a stressor (such as chronic illness) the level of anxiety an individual experiences is often influenced by social/familial experiences. Patterns of behavior, including anxious reactions to a situation, are often learned through observations and interactions with others in the immediate environment (Rork & Morris, 2009). Therefore, this study looked for potential correlations among anxiety levels, specifically maternal vs. paternal, maternal vs. child, and paternal vs. child. A correlation analysis was conducted on the mother, father, and child/ youth total anxiety scores. A significant relationship was found between mother and child anxiety scores and mother and father anxiety scores.
Previous research indicates that children with a parent with higher anxiety are at greater risk of developing an anxiety disorder (Kessler et al., 2005). This may indicate that family dynamics have more of an impact on the child’s anxiety than the factors included in this study. It is noteworthy that, within the families studied, a correlation was found between the mother’s anxiety scores and both the father’s and child’s anxiety scores. Specifically, this finding may indicate that the mother’s relationship within the family unit is a model of how other family members cope with stressful situations, including fathers. According to prior research, children who have mothers with elevated levels of anxiety may not be exposed to appropriate coping strategies to manage difficult situations (Buckley & Woodruff-Borden, 2006). Furthermore, research reports indicate overall family anxiety is linked to differences in parenting behaviors (Greco & Morris, 2002). However, this cannot be determined within this study due to the low number of child participants which may have had an effect on the anxiety outcome scores of the children.

There are several potential explanations of the results attained in this study. The Transactional Stress and Coping (TSC) is a family systems theory which suggests a family’s ability to adjust to illness is often mediated by multiple social factors, including the mother’s ability to adapt to the illness. The influence a mother has on her family may be the result of the social construct of what is acceptable in terms of expression of feelings. According to Simon (2002) gender among the adult population is associated with characteristics of expressing emotion. Specifically, females report higher rates of anxiety and depression, while males report higher rates of substance abuse. Therefore, one can conclude that females are more likely to report and externalize anxiety and males
are more likely to not report and internalize anxiety. This theory may indicate that the mother’s anxiety level has a greater influence on the child’s and father’s anxiety than the child’s and father’s anxiety has on the mother.

While the presence of anxiety in less than half of the fathers was a surprising finding, it is noteworthy that, within the families, paternal anxiety was related to maternal anxiety. Furthermore, the finding that father’s anxiety did not have an effect on child anxiety should be noted. Gender is frequently discussed in terms of roles within a family system. Traditionally, western society expects the primary parenting to be done by mothers. Furthermore, females are more likely to have less emotional boundaries with others, to develop their identities in terms of connections with other (i.e. family), to have increased capacity for empathy, and are at greater risk for becoming enmeshed with others in the family (Nichols & Schwartz, 2001). Therefore, it can be concluded that mother’s may be more open because of less rigid emotional boundaries in regards to worries and anxiety related to their child’s illness.

A study conducted on interrelations of anxiety between mothers, fathers and children found that mothers’ perceptions of marriage and family functioning had an effect on the fathers anxiety, more so than age, educational level, or job classification, or the fathers own perception of family functioning. Furthermore, this study reported that the father’s anxiety was best predicted by the mother’s rating of poor family functioning and anxiety (Stevenson-Hinde, Curley, Chicot, & Johannsson, 2007). Specifically, men tend to emphasize personal accountability to themselves and internalize feelings. Specifically, how a man perceives his abilities to meet challenges often affects his mental well-being.
This may explain the findings of the correlation outcome that there was a relationship of mother’s anxiety scores and father’s anxiety scores.

Social scientists have developed myriad theories exploring the role of mothers within the family system, but not the fathers. For instance, according to psychodynamic theory, an individual’s mental health is typically determined by his/her relationship with the mother (Ford, Nalbone, Wetchler, & Sutton, 2008). Additionally, attachment theory, social learning theory, and cognitive development theory focus on the child’s relationship to the mother as a fundamental component to typical emotional development (Ainsworth & Marvin, 1995, Lamb, 2004).

Factors Related to Anxiety in Parents

Families are intricate systems. Research regarding families is often difficult due to the diversity and variations among families. Furthermore, the addition of a diagnosis of a chronic illness can increase this complexity. It is hypothesized that children with bowel and/or bladder dysfunction, and their families require medical, psychosocial, and educational supports in order to successfully function as a family unit specifically in regards to levels of anxiety. The following section explores the outcomes of these factors and their effect on anxiety levels of members of the families studied.

Medical Factors Related to Parental Anxiety.

Access to care, including having a medical home, has been the focus of much attention for individuals with chronic illness. Proximity to specialized health care and the presence of a medical home as independent variables were included in the analysis model. Neither variable was found to be a significant predictor of anxiety in parents or children. As discussed in the outcomes of child anxiety, the cognitive ability of the child
may have an effect of his/her ability to understand the importance of quality medical care. Although self-management of illness and independence are important factors related to the child’s mental health, these skills may not be attainable until adolescence or older. Because of this, parents often have the responsibility of management of all factors associated to their child related to health care.

The complexity and challenges of having a child with chronic illness are often overwhelming and, in turn, require the parents to prioritize the needs of their child. Furthermore, in order to manage stress and anxiety parents may view the presence of a medical home and proximity to care of lesser importance than factors related to income or school absences. Depending on the amount of specialized medical care the child requires, factors such as driving to doctor appointment may occur less frequently and therefore, is not a significant immediate stressor for the parent. Also, because the severity of illness was not explored as a predictor of anxiety in this study, it would be difficult to measure the frequency of doctor visits each child required.

While the demographic variable of family income is not specifically a medical support, income has been shown in previous research to be related to access to medical care. In this study, 100% reported having public or private insurance, and 59% reported income levels above $75,000. Furthermore, 3.6% reported an income less than $25,000, and 8.4% opted not to report their income. Income was found to have an impact on parental anxiety in this study. Participants with an income of $25,000 to $49,999 (12.0%) were found to be more likely to have anxiety than participants with a family income of $75,000 or more. The independent variable of an income of $50,000 to $74,000 (16.9%) was found to be approaching significance.
While these findings are interesting, it is difficult to explain the role income plays in this relationship. This may be due to the complexity of the individual variations of financial responsibilities of each family. For instance, the percentage of income required for health care services for the child was not measured. Research regarding health insurance and socio economic status reported children with chronic illness often have higher health care expenditures than children without complex chronic illness (Swigonski et al, 2001). Furthermore, families with health insurance coverage may be underinsured which may require more financial expenditure on health care for their child (Weller, Minkovitz, & Anderson, 2003) Depending on the severity of illness the complexity of health care costs the relationship of income and anxiety is difficult to measure within this population.

*Psychosocial Factors Related to Anxiety.*

Psychosocial factors examined in this study included non-professional support (i.e. parent support groups) and professional support (counseling services). While non-professional support (i.e., support groups) was found to be approaching significance, professional support (i.e., professional counseling) was not significant within this analysis. This finding was unexpected given the high overall percentage of parents with anxiety in this study. These findings suggest that social/community support is more likely to decrease anxiety than professional psychological services for parents of children with bowel and/or bladder dysfunction.

Anxiety is often influenced by an individual’s social environment and interactions. Furthermore, parents with children with chronic illness may seek support from others who have had similar experiences and challenges. Parent organizations may
offer a connection among members that cannot be established within the professional mental health setting. For instance, parents who are members of parent organizations often have the opportunity to ask questions and receive advice from others who have gone through similar experiences. These findings are supported by theories regarding social support.

Social science has emphasized the potential benefits of social support in general. For instance, Barrera (1986) developed three categories of types of beneficial social support: social embeddedness, perceived social support, and enacted support. Social embeddedness is related to one’s connected to others in the community, which can prevent feelings of alienation and isolation from others. Perceived social support is a belief that one has adequate supports that are available to provide information and feedback when needed. Enacted support is what others do to actually provide support (i.e. behaviors or actions of the one giving support) (Davis, Gavazzi, Scheer, & Uppal, 2011).

Despite the findings of this study, the potential benefits of professional support in regards to mental health should not be diminished. As a large number of participants had not sought professional assistance (fathers 84.3%, mothers 83.1%), the impact of such support may not be evident in this sample. Participants may not seek support since professional psychological services can often be costly and require time set aside to receive these services. These factors may have impact a parent’s decision not to seek professional treatment for anxiety.

*Educational Factors Related to Anxiety in Parents.* Children with chronic illness often experience physical and psychological challenges related to their illness. In order
to address the barriers imposed by disability (including chronic illness), educational plans are developed to address the educational needs of these children. These challenges may increase school absenteeism which can put the child at risk academically (Sato et al., 2007). Educational factors included in the research model were formal educational planning (IEP, 504 plan, and/or IHP) and school absences. Of the children included in this study 33.7% were identified as having no formal educational plan in place. Additionally 27.7% had an IEP, 22.9% had a 504 plan, and 2.7% had a combination of 504 and an IHP. In regards to school absences the majority of participants (39.7%) missed one week to one month of school per school year. Furthermore, 24.0% missed one to five days, 15.7% missed more than a month, and 13.3% had no absences from school.

As indicated in the review of literature, children and youth with chronic illness miss more school days than their peers (Sato et al., 2007). Increased school absences can lead to a decrease in knowledge and understanding of critical content necessary for academic success and progress. Parents of children who experience increased school absences may be required to spend more time at home working with their child on school activities. Furthermore, parents may experience an increase in worry regarding their child’s future success. Parents of children in this study who missed no school were found to score lower on the anxiety scale when compared to parents of children who missed one week to a month of school. Of the children included in the study 13.3% experienced no absences from school. Furthermore, 39.7% missed one week to a month and 15.7% missed more than one month of school for a total of 55.4% of children included in the study missing one week to more than a month of school.
There are several educational plans available to assist children with disabilities, including those with chronic health conditions. These plans are designed to address the educational needs of students. Formal educational plans were included in the research model as a potential predictor of anxiety. Not surprisingly, 33.7% of the families included in the model did not have a formal educational plan in place. Furthermore, the analysis indicated 27.7% of children in this study had an IEP, 22.9% had a 504 Plan, and only 7.2% had an IHP. Often, since the primary impact of bowel and/or bladder dysfunction is not necessary on cognitive functioning, these children do not present as needing academic supports. Because of this, parents may not be aware of the need of educational supports. Although, this study did not explore cognitive implications related to illness, the population included in this study may not be eligible for formal special education services, specifically an IEP. This may explain why many of the families included in the study did not have an IEP in place. However, all children with bowel and/or bladder dysfunction are eligible for supports under Section 504, and could have a 504 plan. It was beyond the scope of this study to determine if any of these plans were needed, only if they were in place.

Because of the complex nature of chronic illness many children require health services during the school day. Because of this, the finding that formal planning did not have a significant impact on anxiety was noteworthy. Research reports documentation of the medical needs of a child with chronic illness allow the school to provide quality health care can decrease barriers to academic success (Herrmann, 2005). According to the finding of this research 33.7% of children included in the study did not receive educational or health related planning. This finding may indicate that children included
in this study did not require formal planning and were not at academic risk which may explain why this factor was not a predictor of anxiety. Furthermore, health related planning, such as the IHP, has recently been highlighted in literature but is not traditional practice within an educational setting. Therefore, parents and/or children may not be aware of the benefits of having formal health-care planning within the school.

The outcome of this research indicates that medical, psychosocial, and educational factors are predictors of anxiety in parents of children with bowel and/or bladder dysfunction. Specifically, income, school absences, and gender of parents were found to be significant. Furthermore, there was a significant relationship between the anxiety scores of the mother and the fathers and children but not between the father and child. The following section offers suggested related to these outcomes in regards to practice.

Implications for Practice

The results of this study indicate there is a relationship between anxiety of the mother and the anxiety of the father and child. Furthermore, there was not a significant relationship found between anxiety of fathers and children. The analysis of the medical, psychosocial, and educational factors effect on parent anxiety revealed that income, school absences, and gender had a significant effect on the overall parent anxiety scores. Additionally, non-professional support was found to have an impact on parent anxiety. These findings suggest the need for family centered and community support for families with children with chronic illness, specifically bowel and/or bladder dysfunction.
Supporting the Medical Needs of Families

While the presence of a medical home was not found to be a significant predictor of anxiety, the need for such services should not be overlooked. Research indicates medical homes provide accessible, family-centered, and comprehensive care to individuals with chronic illness and their families (Stevens et al., 2010). This may also be a relatively new term to participants which, despite the definition given, may not have been fully understood. The importance of a medical home is a recent focus in research and therefore, may not be identified as an important aspect of quality medical care.

Furthermore, factors such as proximity to care and income may become barriers to families having access to consistent quality care (Stevens et al., 2010). Due to the extensive medical and ancillary service coordination that is needed for children with chronic illness, these factors should be taken into consideration when developing care plans for children and their families. This issue must also be explored within all socioeconomic groups to ensure appropriate needs and supports are provided.

Supporting the Psychosocial Needs of Families

A child develops his/her sense of security through connection and identification with those who care for them. Research on child development has focused on the mother-child relationship, however, when we focus solely on this relationship, we set challenging expectations of mothers that are often unrealistic and unachievable (Carter & McGoldrick, 1999). This occurrence can result in increased levels of anxiety and maladaptive coping strategies, which can make the mother a less effective member of the family system during stressful life events. For instance, mothers with increased anxiety often experience incongruent reactions to otherwise mundane situations. Furthermore,
mothers with increased levels of anxiety were found to exhibit less warmth in interactions with family members (Whaley, Pinto, & Sigman, 1999). According to the outcome of the correlation of anxiety scores, fathers and children are affected by the mother’s anxiety. If the family works as a system then one can hypothesize that this behavior from the mother can negatively affect the father and child. The outcome of this study supports the outcome of previous studies regarding the mother’s influence on family functioning. The overwhelming evidence supports the need for family-centered support for families of children with bowel and/or bladder dysfunction, if not for all families with children with chronic illness.

There are strong implications that emotional distress (i.e. diagnosis of chronic illness), including anxiety, that are not resolved can impact not only an individual, but the family as a whole (Carter & McGoldrick, 1999). In turn, the distress can act as a hindrance in the development of the family system which can negatively impact individual relationships across time. In order for a child and their family to adjust to chronic illness, there must be a reduction in defensiveness and internalization of thoughts and feelings in the father. Furthermore, families must be encouraged to share responsibly of the care of the child, as well as, promote independence within the child. In order to obtain an accurate measurement of the impact of the paternal relationship within the family, the fathers’ ability to express negative feelings, such as anxiety, should be supported by the family unit. This support can be enabled through increased communication within the family, as well as, through non-professional support groups.
Supporting Educational Needs

The finding regarding school absenteeism indicated that parents of children with no school absences scored lower on the anxiety measurement than parents with children who missed one week or more of school. Furthermore, research indicates that increased absenteeism can result in poor academic performance in school. The increase in parental anxiety and potential decrease in academic performance may indicate that supports within the school system are necessary in order to reduce absenteeism.

Although educational planning was not a significant predictor of anxiety, this should not be overlooked as an important aspect of support for a child with chronic illness. The frequency outcomes of the study indicated that 33.7% of the children included did not have a formal educational plan in place. While one cannot confirm or refute the need for such supports based on this study, health plans and 504 plans are not reported for the expected proportion of participants. The presence of these plans can guide school personnel in regards to health care for the child during the school day. Furthermore, a 504 plan and an IHP can act as safe guards in terms of safety in health care procedures and outline accommodations that may be required in order to perform these procedures.

Recommendations for Further Research

Significant findings in this study were identified regarding parent anxiety and medical, psychosocial, and educational factors. However, further research is needed to further explore these findings. Specifically, the addition of more participants can aid in the validation of the outcomes. The following section provides recommendations for
further research based on the outcomes of the analysis of data regarding the relationship of family anxiety and medical, psychosocial, and education factors.

*Further Research in the Medical Domain*

The research findings indicated families with a child/youth with bowel and/or bladder dysfunction with moderate income were more likely to have increased anxiety when compared to families with a higher income. Although, there is much research on mental health and physical health and families with low socio economic status, very little research is available in regards to the middle class. In doing so, the researcher could better judge the relationship of families with moderate income in relationship to mental health. Although severity of illness was not included as a predictor of anxiety in this study, further exploration of this can further explain the dynamics of chronic illness in regards to anxiety. Specifically, the researcher could explore the level of anxiety in parents of children with more severe symptoms and who require more complex medical treatment in both the medical and educational settings.

*Further Research in the Psychosocial Domain*

Although, the research indicated mother’s had more of an impact on fathers and children’s anxiety, further research into factors related to this dynamic would help in explaining this phenomenon. Traditionally, fathers are seen as on the peripheral when it comes to everyday tasks related to parenting. However, family theory suggests fathers may have increased levels of anxiety but are unable to express these feelings. Future research directions may examine the meditational role of both parents. Specifically, that fathers act a models for the child’s behavior with respect to observing and learning methods of coping within families with children with chronic illness. Furthermore, this
study suggests the need of social support for families with children with chronic illness. Research regarding the inclusion of family-centered support within the medical setting could be beneficial in the support of comprehensive care for these children and their families. Although, non-professional support was not explored in regards to child and youth anxiety, research regarding the benefits of this could help in the development of peer and social support for children with chronic illness.

Further Research in the Educational Environment

School absences were found to have an impact on parental anxiety. Specifically, parents of children with no absences were found to have less anxiety than parents with children with one week or more of absences. Increased numbers of absences can negatively impact the academic success of children and youth. Further research into school supports for children with chronic illness can provide support for the inclusion of comprehensive and multidisciplinary support in regards to the medical needs of children with chronic illness. While formal educational planning was found to not have an impact on anxiety, the importance of these plans for children with chronic illness should be further studies. For instance, although an IEP may not be required for this population the need for a 504 plan and/or an IHP should be present to ensure the child receives accommodations and quality health care while in the care of the school. Research indicating the effectiveness of such plans can further support the importance of health care planning and accommodations for children with chronic illness.

Summary

The purpose of this study was to determine the relationships among anxiety children and youth with bowel and/or bladder dysfunction and their mothers and fathers.
Furthermore, this study was designed to measure the effects of medical, psychosocial, and educational factors relationship on anxiety of the participants. Of the participants included in this study, mothers were found to have increased levels of anxiety when compared to fathers and children. Furthermore, the relationship of the mother’s anxiety was found to have a significant correlation to the father’s and child’s anxiety. The research model included in the data analysis included the presence of a medical home, non-professional support, income, school absences, proximity to specialized medical care, formal educational planning, gender of parents, and professional supports. The predictor variable found to have a significant impact on parental anxiety were an income of $25,000 to $49,000, no school absences, and gender. Furthermore, income of $50,000 to $74,000 and non-professional supports were identified as approaching significance. Although a significant relationship was found between parents total anxiety scores combined and the predictor variables, no significance was established when parents were analyzed divided by gender.

Although the overall findings of the study support the need for family centered services for families with children with bowel and/or bladder dysfunction, further research is needed in order to explore the impact of the predictors included. For instance, scant research is available regarding the impact of chronic illness on families identified as middle class. Therefore, it is difficult hypothesize the findings that the participants in this study who were in the category had more anxiety than families with higher income. Future research is necessary to show the importance of the explored constructs among medical, psychosocial, and educational domains. By further exploring the effect of anxiety on the family unit and within these domains, specific strategies for support can be
developed to help children with bowel and/or bladder dysfunction and their families in improving family functioning and cohesion.
APPENDIX A

THE CHILDREN WITH SPECIAL HEALTH CARE NEEDS SCREENER

THE CHILDREN WITH SPECIAL HEALTH CARE NEEDS (CSHCN) SCREENER®

Developed in Collaboration with:

AHRQ  NCQA
BACKGROUND

The Children with Special Health Care Needs (CSHCN) Screener™ was developed through the efforts of the Child and Adolescent Health Measurement Initiative (CAHMI), a national collaboration coordinated by FACCT—The Foundation for Accountability. Beginning in June 1998, the CAHMI brought together federal and state policymakers, health care providers, researchers and consumer organizations into a task force for the purpose of specifying a method to identify children with special health care needs. During the course of this project, the task force met in person six times and more than a dozen times by teleconference.

The CSHCN Screener™ is a five item, parent survey-based tool that responds to the need for an efficient and flexible standardized method for identifying CSHCN. The screener is specifically designed to reflect the federal Maternal and Child Health Bureau definition of children with special health care needs:

"Children who have special health care needs are those who have...a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."

The CSHCN Screener™ uses non-condition specific, consequences-based criteria to identify children with special health care needs for purposes of quality assessment or other population-based applications. Children are identified on the basis of experiencing one or more current functional limitations or service use needs that are the direct result of an on-going physical, emotional, behavioral, developmental or other health condition.
The non-condition specific approach used by the CSHCN Screener identifies children across the range and diversity of childhood chronic conditions and special needs, allowing a more comprehensive assessment of health care system performance than is attainable by focusing on a single diagnosis or type of special need. In addition, the relatively low prevalence of most childhood chronic conditions and special health care needs often makes it problematic to find adequate numbers of children with a specific diagnosis or type of special need. A non-condition specific approach makes it possible in many cases to identify enough children to allow statistically robust quality comparisons across health care systems and/or providers.

The CSHCN Screener is currently being used in several national surveys, including the National Survey of Children with Special Health Care Needs and as part of the CAHPS survey items in the Medical Expenditure Panel Survey (MEPS). The Agency for Healthcare Research and Quality (AHRQ) has included the screener as an integral part of the new CAHPS 2.0 Child Survey. The Screener is also formally integrated into the CAHPS 2.0H Child Survey to identify the Children with Chronic Conditions Measurement Set, a component of the National Committee for Quality Assurance’s Health Plan Employer Data and Information Set (HEDIS). English and Spanish versions of the CSHCN Screener are available.


CAHPS® is a registered trademark of the Agency for Healthcare Research and Quality (AHRQ).

HEDIS® is a registered trademark of the National Committee for Quality Assurance (NCQA).
For more information on the development, testing & application of the CSHCN Screener:


For scoring programs or other technical support for the CSHCN Screener and its applications:

**Christina Bethell, Director**

CAHMI—The Child and Adolescent Health Measurement Initiative

Telephone: 503.494.1930

email: cahmi@ohsu.edu

For technical support for the CAHPS 2.0 Child Survey, please contact:

The CAHPS Survey User Network

800.492.9261 or [www.cahps-eun.org](http://www.cahps-eun.org)

For technical support on the CAHPS 2.0H® Child Survey*, please contact:

NCQA Policy Clarification Support

[hedis@ncqa.org](mailto:hedis@ncqa.org)

User's Form:

There is no cost to use the CSHCN Screener, however, we ask that you complete the enclosed User's Form. Your input helps us to develop an understanding of our key users and to provide updates.

Please submit the User’s Form via fax (503.494.2475) or email (cahmi@ohsu.edu). We look forward to hearing from you!

*The National Committee for Quality Assurance has incorporated a version of the CAHPS 2.0 survey into the HEDIS measurement set. The version of the survey required for HEDIS is referred to as the “CAHPS 2.0H Survey.”*
Children with Special Health Care Needs (CSHCN) Screener
(mail or telephone)

1. Does your child currently need or use medicine prescribed by a doctor (other than vitamins)?
   - Yes → Go to Question 1a
   - No → Go to Question 2

   1a. Is this because of ANY medical, behavioral or other health condition?
       - Yes → Go to Question 1b
       - No → Go to Question 2

   1b. Is this a condition that has lasted or is expected to last for at least 12 months?
       - Yes
       - No

2. Does your child need or use more medical care, mental health or educational services than is usual for most children of the same age?
   - Yes → Go to Question 2a
   - No → Go to Question 3

   2a. Is this because of ANY medical, behavioral or other health condition?
       - Yes → Go to Question 2b
       - No → Go to Question 3

   2b. Is this a condition that has lasted or is expected to last for at least 12 months?
       - Yes
       - No

3. Is your child limited or prevented in any way in his or her ability to do the things most children of the same age can do?
   - Yes → Go to Question 3a
   - No → Go to Question 4

   3a. Is this because of ANY medical, behavioral or other health condition?
       - Yes → Go to Question 3b
       - No → Go to Question 4

   3b. Is this a condition that has lasted or is expected to last for at least 12 months?
       - Yes
       - No

4. Does your child need or get special therapy, such as physical, occupational or speech therapy?
   - Yes → Go to Question 4a
   - No → Go to Question 5

   4a. Is this because of ANY medical, behavioral or other health condition?
       - Yes → Go to Question 4b
       - No → Go to Question 5

   4b. Is this a condition that has lasted or is expected to last for at least 12 months?
       - Yes
       - No

5. Does your child have any kind of emotional, developmental or behavioral problem for which he or she needs or gets treatment or counseling?
   - Yes → Go to Question 5a
   - No

   5a. Has this problem lasted or is it expected to last for at least 12 months?
       - Yes
       - No
Scoring the Children with Special Health Care Needs (CSHCN) Screener®

The CSHCN Screener® uses consequences-based criteria to screen for children with chronic or special health care needs. To qualify as having chronic or special health care needs, the following criteria must be met:

a) The child currently experiences a specific consequence.
b) The consequence is due to a medical or other health condition.
c) The duration or expected duration of the condition is 12 months or longer.

The first part of each screener question asks whether a child experiences one of five different health consequences:

1) Use or need of prescription medication.
2) Above average use or need of medical, mental health or educational services.
3) Functional limitations compared with others of same age.
4) Use or need of specialized therapies (OT, PT, speech, etc.).
5) Treatment or counseling for emotional or developmental problems.

The second and third parts* of each screener question ask those responding “yes” to the first part of the question whether the consequence is due to any kind of health condition and if so, whether that condition has lasted or is expected to last for at least 12 months.

*NOTE: CSHCN screener question 5 is a two-part question. Both parts must be answered “yes” to qualify.

All three parts of at least one screener question (or in the case of question 5, the two parts) must be answered “yes” in order for a child to meet CSHCN Screener® criteria for having a chronic condition or special health care need.

The CSHCN Screener® has three “definitional domains.”

1) Dependency on prescription medications.
2) Service use above that considered usual or routine.
3) Functional limitations.

The definitional domains are not mutually exclusive categories. A child identified by the CSHCN Screener® can qualify on one or more definitional domains (see diagram).

© CAHMI: The Child and Health Measurement Initiative
ACKNOWLEDGEMENTS

The following people participated in the Child and Adolescent Health Measurement Initiative (CAHMI) Living with Illness Task Force and contributed to the development and/or testing of the Children with Special Health Care Needs (CSHCN) Screener:

Christina Bethell, CAHMI- The Child and Adolescent Health Measurement Initiative
Stephen Blumberg, Centers for Disease Control and Prevention
Julie Brown, RAND
Trebbe Brown, Association of Maternal and Child Health Plans
Paul Cleary, Harvard Medical School
Christine Crofton, Agency for Healthcare Research and Quality
Susan Epstein, New England SERVE
Jack Fowler, University of Massachusetts
Shirley Girouard, Southern Connecticut State University
Maxine Hayes, Washington State Department of Health
John Hochheimer, formally with the National Committee for Quality Assurance
Charles Homer, National Initiative for Child Healthcare Quality, Institute for Healthcare Improvement
Alice Lind, Washington State Medical Assistance Administration
Margaret McManus, Maternal & Child Health Policy Research Center
Merle McPherson, Federal Maternal and Child Health Bureau
John Neff, Center for Children with Special Needs
Paul Newacheck, University of California, San Francisco
James Perrin, Massachusetts General Hospital
Debra Road, CAHMI- The Child and Adolescent Health Measurement Initiative
Donald Steinwachs, Johns Hopkins University
Ruth Stein, Albert Einstein College of Medicine
Joe Thompson, Arkansas Children’s Hospital
Deborah Klein Walker, Massachusetts Department of Public Health
Nora Wells, Family Voices
# APPENDIX B

## DEMOGRAPHIC INVENTORY

### DEMOGRAPHIC INFORMATION

#### AFFECTED-child

<table>
<thead>
<tr>
<th>Age: _____</th>
<th>Gender:</th>
<th>The child lives with:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>One parent</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>Both parents</td>
</tr>
<tr>
<td></td>
<td></td>
<td>A non-parent guardian</td>
</tr>
</tbody>
</table>

#### Which of the following diagnoses does your child have? (check all that apply)

- ☐ I don’t know
- ☐ Anal Stenosis
- ☐ Currarino Triad
- ☐ Renal Defects
- ☐ Bladder Exstrophy
- ☐ Down Syndrome
- ☐ Sacral Agenesis
- ☐ Caudal Regression
- ☐ Hirschsprung’s Disease
- ☐ Cloaca
- ☐ Imperforate Anus
- ☐ VATER/VACTERL
- ☐ Cloacal Exstrophy
- ☐ Neuropenic Bladder
- ☐ Tracheo-Esophageal
- ☐ Fistula/Esophageal Atresia
- ☐ Crohn’s Disease
- ☐ Spina Bifida
- ☐ Tethered Spinal Cord
- ☐ Scoliosis
- ☐ Other (please describe) __________

#### Does your affected child have any of the following educational plans? (check all that apply)

- ☐ IEP (individualized education plan/special education)
- ☐ Accommodations Plan (504 plan/not special education)
- ☐ IHP (individualized health care plan)

#### How much school did your child miss last school year (2010-2011) because of his/her condition?

- ☐ None
- ☐ 1-3 days
- ☐ 1-2 weeks
- ☐ 2 weeks – 1 month
- ☐ 3-5 days
- ☐ More than 1 month
- ☐ My child doesn’t attend school, but a teacher comes to our house to teach him/her
- ☐ I homeschool my child because of his/her condition

#### Is your affected child covered by any of the following types of insurance?

- ☐ Private insurance
- ☐ Public insurance (i.e. Medicaid or CHIPS)
- ☐ No, he/she has no insurance

#### A medical home is defined as an environment through which to receive acute, chronic, and preventive services. The services should be accessible, accountable, comprehensive, integrated, patient-centered, safe, scientifically valid, and satisfying to both patients and their physicians.

#### Do you consider your child to have a medical home?

- ☐ Yes
- ☐ No

#### How far away is the provider you consider to be your child’s BEST provider of care related to his/her illness?

- ☐ Less than 20 miles
- ☐ 21-40 miles
- ☐ 41-60 miles
- ☐ 61-80 miles
- ☐ 81-100 miles
- ☐ More than 100 miles

#### How many days during the last school year (2010-2011) did your child spend in the hospital?

- ☐ None
- ☐ 1-3 days
- ☐ 1-2 weeks
- ☐ 2 weeks – 1 month
- ☐ More than 1 month
- ☐ My child doesn’t attend school, but a teacher comes to our house to teach him/her
- ☐ I homeschool my child because of his/her condition
It is the intent of this research to study the affected child and his/her primary caregivers. Most traditionally, this is the mother and father. Please provide the following information regarding the caregivers participating.

### CAREGIVER 1

<table>
<thead>
<tr>
<th>Age: _______</th>
<th>Role:</th>
<th>Does this caregiver live in the household with the affected child for the majority of the time?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>[ ] Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>[ ] No</td>
</tr>
</tbody>
</table>

**Gender:**
- [ ] Male
- [ ] Female

**Does this caregiver receive counseling or other professional mental health support?**
- [ ] Yes
- [ ] No

**Does this caregiver receive support through non-professional groups (i.e., support groups, etc.)?**
- [ ] Yes
- [ ] No

### CAREGIVER 2

<table>
<thead>
<tr>
<th>Age: _______</th>
<th>Role:</th>
<th>Does this caregiver live in the household with the affected child for the majority of the time?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>[ ] Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>[ ] No</td>
</tr>
</tbody>
</table>

**Gender:**
- [ ] Male
- [ ] Female

**Does this caregiver receive counseling or other professional mental health support?**
- [ ] Yes
- [ ] No

**Does this caregiver receive support through non-professional groups (i.e., support groups, etc.)?**
- [ ] Yes
- [ ] No

### What is your total household income per year?

- [ ] Less than $25,000
- [ ] Between $25,000 and $49,999
- [ ] Between $50,000 and $74,999
- [ ] $75,000 or more
- [ ] I do not wish to report
APPENDIX C

IRB APPROVAL FORM

THE UNIVERSITY OF SOUTHERN MISSISSIPPI

INSTITUTIONAL REVIEW BOARD
118 College Drive 2047 | Hattiesburg, MS 39406-0091
Phone: 601.266.4330 | Fax: 601.266.4377 | www.usm.edu/irb

NOTICE OF COMMITTEE ACTION

The project has been reviewed by The University of Southern Mississippi Institutional Review Board in accordance with Federal Drug Administration regulations (21 CFR 26, 111), Department of Health and Human Services (45 CFR Part 46), and university guidelines to ensure adherence to the following criteria:

- The risks to subjects are minimized.
- The risks to subjects are reasonable in relation to the anticipated benefits.
- The selection of subjects is equitable.
- Informed consent is adequate and appropriately documented.
- Where appropriate, the research plan makes adequate provisions for monitoring the data collected to ensure the safety of the subjects.
- Where appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of all data.
- Appropriate additional safeguards have been included to protect vulnerable subjects.
- Any unanticipated, serious, or continuing problems encountered regarding risks to subjects must be reported immediately, but not later than 10 days following the event. This should be reported to the IRB Office via the “Adverse Effect Report Form”.
- If approved, the maximum period of approval is limited to twelve months. Projects that exceed this period must submit an application for renewal or continuation.

PROTOCOL NUMBER: 11111602
PROJECT TITLE: Anxiety in Children/Youth with Bowel and/or Bladder Dysfunction and Their Parents: Impact of Medical, Educational, and Psychological Factors
PROJECT TYPE: Dissertation
RESEARCHER(S): Leslie LaVergne
COLLEGE/DIVISION: College of Education & Psychology
DEPARTMENT: Curriculum, Instruction, & Special Education
FUNDING AGENCY: N/A
IRB COMMITTEE ACTION: Expedited Review Approval
PERIOD OF PROJECT APPROVAL: 11/17/2011 to 11/16/2012

Lawrence A. Hosman, Ph.D.
Institutional Review Board Chair
REFERENCES


framework, issues and applications for school nursing practices (pp. 59-68).

North Branch, MN: Sunrise River Press.


doi: 10.1300/J019v2804_04


Child and Adolescent Health Measurement Initiative (CAHMI), 2002


Harrigan, D. Zaiger (Eds.), *Individualized healthcare plans for the school nurse: Concepts, framework, issues and applications for school nursing practices* (pp. 7-10). North Branch, MN: Sunrise River Press.


