

The Interaction of Anxiety, Stress, and Family Functioning in Families of Young  
Children with a Chronic Illness

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## ABSTRACT

The current study investigated the relationship between child behavior, parent anxiety, and family functioning in families with young children with a chronic illness compared to those with healthy children. Participants included 30 parents who completed questionnaires assessing parent, child, and family factors. Results indicate a difference between the chronic illness and healthy groups for child somatization, child withdrawal, parent anxiety, and parent stress. Additionally, for the full sample, significant correlations were found between parent anxiety and child internalizing behaviors, but not for externalizing behaviors. Within the chronic illness group, parent anxiety was significantly correlated with child anxiety, but it was not for the healthy group. Finally, within the chronic illness group, an increase in the frequency of role function and medical care activities was associated with higher parent anxiety. These data further demonstrate the complexity of dynamics in the lives of families with a young child with a chronic illness.

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## Chapter I

### INTRODUCTION

Chronic illness in children is defined in various ways, but is consistently considered to include health conditions that last for longer than 3 months and involve some impact on the functioning of the child and/or family (van der Lee, Mookink, Lidwine, Grootenhuis, Heymans, & Offringa, 2007). Some of the more common chronic illnesses in children include asthma, allergies, diabetes, epilepsy, chronic pain, and juvenile arthritis. The prevalence rates vary by condition and some data suggest that the number of young children with chronic illnesses is rising. For example, estimates indicate that 14% of children under 18 have asthma (Center for Disease Control (CDC), 2012). The CDC also reports that about 4% of children have a food allergy, and that this rate is about 18% higher than in was in 1997 (CDC, 2012). The incidence of diabetes in children under age 20 was estimated at 215,000 in the United States in 2010 (CDC, 2011). Hyams, Burke, Davis, Rzepski, and Adrilonis (1996) reported that 14% of high school students and 6% of middle school students have chronic abdominal pain and/or irritable bowel syndrome. These data demonstrate that many children are affected by chronic illnesses. Children with chronic illnesses and their families also may experience disruptions in their daily life due to these health conditions. The CDC reported that approximately 8% of school age children with chronic illnesses were limited in daily activities due to their health, as indicated by their parents (National Center for Health Statistics, 2007). Given these data, it is apparent that research is needed to explore the impact of these health

conditions on the child's emotional health as well as that of the parent and the family. This literature review will examine research specifically related to how chronic illness can affect the emotional health of children and their caregivers. It will also review research related to how these families function when facing a chronic illness and how the stress and emotional strain can impact the family in a multitude of ways. The review is divided by constructs assessed and by age of the children due to potential methodological and developmental differences.

### **Chronic Illness and Emotional Health in Young Children**

Chronic illness in young children is often accompanied by anxiety. Wolff et al. (2012) found that 3-year-olds with new-onset chronic pain had more anxious-depressed symptoms, sleep problems, somatic symptoms, and aggressive behavior than children without pain, as reported by their mothers. Chronic pain was most often ear-related, followed by abdominal (Wolff et al., 2012). Gortmaker, Walker, Weitzman, and Sobol (1990) identified chronic health conditions as a significant risk factor for behavioral problems such as anxiety, hyperactivity, and peer related issues in 4- to 11-year olds. Also examining anxiety in chronically ill children, Fielding and Brownbridge (1999) found that in children between the ages of 2 and 21, higher levels of functional impairment due to renal failure were significantly associated with higher anxiety scores and behavioral problems. Rask, Elberling, Skovgaard, Thomsen, and Fink (2012) assessed health anxiety specific symptoms in 5- to 7-year-olds. Their results suggest that health related anxiety symptoms make their first appearance in early childhood as

opposed to older children (Rask et al., 2012). Gortmaker et al. (1990) assessed behavioral concerns in chronically ill 4- to 17-year olds, but they divided the sample into two groups, 4 to 11 and 12 to 17. The 4- to 11-year olds showed significantly higher scores than the adolescent group on the Anxious/Depressed Mood and Peer Conflict/Social Withdrawal subscales of the Behavior Problem Index scale (Gortmaker et al., 1990). These studies all demonstrate a significant relationship between chronic illnesses and anxiety in young children.

An important issue to address when examining studies of anxiety in chronically ill children such as these is that parents are the most common source of information. Parental mental health status and perceptions of child behavior could affect their interpretation of their children's behavior. Wolff et al. (2012) found a significant discrepancy between reports of child anxiety by mothers and fathers. Although mother-reported data showed that child chronic illness was an indicator for child anxiety, the father-reported data showed no significant relationship between chronic pain and anxious-depressed symptoms (Wolff et al., 2012). Similarly, Rask et al. (2012) reported that child health anxiety (i.e., child's worrying about his/her own health) was significantly correlated to parent-reported presence of their child's physical health problem, such as diabetes, asthma, or epilepsy and to the child's general internalizing behavior (i.e., not health specific). Fielding and Brownbridge (1999) reported that parents of younger children were more likely to report child behavior problems and had higher levels of depression than parents of adolescents with chronic illnesses. These

studies suggest that the gender of the reporting parent, the age of the child, and the level of anxiety in the child may all be factors that influence parental assessment of the child. This is a critical assessment issue, especially in preschool age children, because the communication skills of the children are not as advanced as those of older children and parent report is more heavily relied upon for our understanding of the preschool child's symptoms.

These studies suggest that there are several difficult issues surrounding preschool age children who are suffering from anxiety and chronic illness. First, the research relies heavily on parent report, which can be affected by numerous extraneous variables such as the parent's mental health status, level of parental involvement, and individual parenting styles that may affect their perceptions and interpretations of their child's behavior (Wray & Sensky, 2004; Svavarsdottir & Rayens, 2004; Mednick et al., 2007; Hilliard, Monaghan, Cogen, & Streisand, 2010; Rouf, White, & Evans, 2011). Second, anxiety is difficult to define with this age group since developmental factors play a role and a preschool age child may not be able to clearly define their emotions. Because of these factors, anxiety can show itself in many different forms at this age, including aggression, sleeping issues, hyperactivity, and immature dependency. A final difficulty is that the current research shows that parents of younger children with chronic illness tend to have more anxiety and depression themselves and that these parents also tend to report more problematic behavior in their children. These tendencies lead to the empirical question of whether young children with chronic illness actually are experiencing more anxiety or if

parents of these children are just more likely to perceive it that way and/or to report it if they are anxious themselves.

### **Chronic Illness and Family Functioning in Young Children**

Impairment in family functioning is a common issue of concern with families of preschool age children who experience chronic illnesses. Families dealing with chronic illness not only face difficulties in daily routine, but in parental mental health, which may also affect the family's overall quality of life. Spieth et al. (2001) found that families of children ages 2 to 6 years old with cystic fibrosis had significantly lower overall scores on the Mealtime Family Interaction Coding System (MICS), a measure of families' functioning during a meal in their natural environment. The authors noted that the families who had a child with cystic fibrosis scored significantly lower than families of children without a chronic illness on five of the six dimensions: communication, interpersonal involvement, affect management, behavior control, and roles (Spieth et al., 2001). Osman, Baxter-Jones, and Helms (2001) assessed children of an average age of 3 years old with asthma and found that a change in a child's asthma symptoms significantly affected family quality of life, which included family activity and parental anxiety. They measured each child's symptom change over three months and found that as symptoms worsened or improved, so did family quality of life (Osman et al., 2001).

Even when symptoms of a chronic illness are mild, research shows that they still have a significant effect on family functioning. Spieth et al. (2001) found that even when a child with cystic fibrosis was functioning at a healthy weight and symptoms were well-

managed, family functioning at meal times was still negatively affected. Osman et al. (2001) also found that mild symptoms also were related to significant changes in overall family quality of life, including scores on family activity and parental anxiety. Wray and Sensky (2004) compared the levels of distress, coping styles, and marital relationships of parents of children with congenital heart disease to those with other health conditions and with parents of healthy children. They found that the severity of disease did not seem to affect levels of family functioning, including psychological distress, marital happiness, beliefs about control, or coping (Wray & Sensky, 2004). Otherwise stated, parents of children with manageable heart conditions showed the same amount of distress and family functioning impairment as parents of children with life threatening heart conditions. These findings suggest that mild conditions or severe conditions that are well managed can be associated with significant impairment in family functioning.

As a component of family functioning, parental mental health is a particularly important factor to consider. A parent or caregiver's mental health not only affects his/her own well-being, but potentially the family's quality of life and overall functioning. Wray and Sensky (2004) found that both fathers and mothers of children aged from birth to 16 with congenital heart problems had higher levels of psychological distress when compared to parents of healthy children. Cheshire, Barlow, and Powell (2010) compared the psychological well-being of parents of children with cerebral palsy (CP) to a control group. They found that parents of children with CP had significantly

higher scores of anxious and depressed mood and lower overall satisfaction with life compared to parents of healthy children.

It is also important to note that while having a child with a chronic illness may put parents at increased risk for mental health impairment, this also can affect family functioning, which can impact the child in many ways. Svavarsdottir and Rayens (2004) completed a study involving functioning in families with 2- to 3-year old children with asthma. They found that a parent's sense of coherence, depression, and sense of well-being all made significant contributions to overall family functioning. The authors also noted that a parent's perception of their family's coherence and partner's anxiety were predictive factors of family functioning (Svavarsdottir & Rayens, 2004).

Existing literature supports the idea that, in general, mothers of young children with chronic illness appear to show more emotional impairment than fathers. Svavarsdottir and Rayens (2004) found that mothers had lower scores than fathers on the well-being scale. Additionally, they noted that mothers were more likely to be depressed and have poorer general health, vitality, and self-control than fathers. Also related to self-control, Wray and Sensky (2004) noted that mothers were more external in their locus of control, meaning that they felt less control over their child's health when compared to mothers of healthy children. Mednick et al. (2007) conducted a study involving mothers of children ages 2 to 5 with Type 1 diabetes. They measured levels of hope and anxiety in the mothers and found a significant inverse relationship between hope and psychological distress; mothers with higher levels of hope reported lower levels

of anxiety. Mednick et al. (2007) also reported that if the mother was the only parent responsible for glucose monitoring and if she received no help in overall caretaking, she was likely to have less hope and be more anxious than if she had a partner to share the responsibility.

When specifically considering preschool aged children, it is important to remember that patterns of activity and behavior are sometimes inconsistent and this can be extremely challenging for a family when also coping with a chronic illness. Monaghan, Hilliard, Cogen, and Streisand (2009) conducted a study with families of 2- to 6-year olds with type 1 diabetes. They found that young children with diabetes are at a high risk for nighttime hypoglycemia because of a more erratic eating schedule and insulin regimen, which requires nighttime glucose monitoring (NGBM) while the child is asleep. In fact, one third of the parents in their study performed at least one nighttime glucose check (Monaghan et al., 2009). The authors also found that the parents who reported that they “sometimes” have to perform NGBM scored higher on the state anxiety measure when compared to parents who did not have to monitor glucose at night. More NGBM also was associated with higher levels of parental stress and general worry. Monaghan et al. (2009) also found that longer illness duration was associated with more frequent NGBM, which means that the higher levels of parental anxiety and stress most likely persist over time.

These studies suggest that families who have a young child with a chronic illness are more likely to face impairment in parental mental health and family functioning than

families of healthy children. This is true for a wide range of chronic illnesses ranging from more common, treatable conditions like asthma to life threatening heart conditions. Additionally, parental mental health and family functioning show a positive correlation with one another, so support and intervention with these families is vital. Overall, mothers tend to show more emotional impairment than fathers, but it is unclear whether this is due to lack of research on fathers, the possibility that mothers are truly more commonly the caretakers, or that they actually do suffer more emotionally than fathers as a result of their children's health conditions. Although these studies suggest a connection between a child chronic illness and family functioning, they do not address the potential role of the child's emotional health, especially anxiety, in this relationship. A few studies, however, have investigated the connections between these three factors in older children with chronic illnesses.

### **Chronic Illness, Emotional Health, and Family Functioning in Adolescents**

Current research has presented convincing evidence that parents of children with chronic illness experience high levels of stress and anxiety. Patino-Fernández et al. (2008) found that 51% of mothers and 40% percent of fathers of children newly diagnosed with cancer met criteria for acute stress disorder. The majority of parents reported at least one episode of acute stress and the authors found that general anxiety was a strong predictor of symptoms of acute stress. Otherwise stated, the parents who were more anxious were more likely to display significant stress. Williams, Laffel, and Hood (2009) conducted a study with families who had a child between the ages of 10 and

17 with type 1 diabetes. They found that 16% of children scored above the clinical cutoff for the Childhood Depression Inventory (CDI) and 24% of parents reported state or trait anxiety above the clinical cutoff (Williams et al., 2009). It was also noted that diabetes-specific family conflict was significantly associated with the occurrence of psychological distress in parents and children (Williams et al., 2009). Mandell, Curtis, Gold, and Hardie (2005) found that in parents of children (ages 6-18) with severe food allergies, nearly all of them reported feeling anxious, fearful, and unclear about how to manage their child's safety due to a lack of information given by medical professionals. The stress and anxiety that these parents experience can be due to a variety of factors and can negatively impact the family in numerous ways. Mandell et al. (2005) also noted that children with life threatening food allergies reported feeling restricted from a wide range of activities and felt negative feelings associated with their allergy. The authors note that children's anxiety appeared to be mediated by overall personality, attitudes, and vividness of the memory of the last allergic episode (Mandell et al., 2005).

Parental perceptions of child vulnerability play a vital role in the child's mental health functioning. Anthony, Bromberg, Gil, and Schanberg (2011) studied families of children ages 8 to 16 diagnosed with arthritis. They found that higher parental perceptions of child vulnerability, health status, and possibility of illness complications were significantly associated with higher levels of child anxiety. This strengthens the argument that the parent's state of mind and perceptions about their child's health can have a meaningful effect on the child's anxiety level. Lopez, Mullins, Wolf-Christensen,

and Bourdeau (2008) also found that parental psychological distress and perceived child vulnerability predict anxiety in adolescents with type 1 diabetes or asthma. The authors reported that perceived child vulnerability is the mediator between parental psychological distress and adolescent anxiety (Lopez et al., 2008).

Anthony et al. (2011) noted that parental stress not only predicted child anxiety, but also child reported pain for children ages 8 to 16. Feldman, Ortega, Koinis-Mitchell, Kuo, and Canino (2010) also assessed the link between parental stress and physical health problems in children. They found that parental stress was associated with higher probability of asthma, abdominal pain, and headaches in children ages 5 to 13. These findings suggest that parental stress could affect how children experience their illnesses and possibly puts them at a higher risk for developing health problems. In addition to increased risk for health related problems, parental stress and anxiety can affect a child's level of medically related fears. Dolgin, Phipps, Harow, and Zeltzer (1990) found that higher maternal anxiety was significantly associated with increased force used in punishment and more medically related fears in chronically ill children ages 5 to 13.

Current research shows that parental stress and anxiety tend to be prevalent in families of older children with chronic illnesses and that this can affect the child's mental health. It is necessary to explore how this may affect overall family functioning and adherence to medical treatment, since these factors are vital in a child's physical and mental health. Everhart (2010) conducted a study with families who had children between 8 and 19 diagnosed with cystic fibrosis. In this study, family functioning was

measured using the Mealtime Interaction Coding System (MICS) to evaluate family behavior during a meal in the natural home setting. Additionally, the Family Assessment Device (FAD) was a questionnaire used to assess family communication, roles, affective responsiveness, affective involvement, and behavioral control (Everhart, 2010). Results from the study showed that higher levels of family functioning predicted better treatment adherence to the cystic fibrosis treatment regimen which can encompass several facets including airway clearance, antibiotics, dietary restrictions, and other medications. It was also reported that social anxiety in children with cystic fibrosis negatively affected treatment adherence (Everhart, 2010). Fiese, Winter, Anbar, Howell, and Poltrock (2008) used the Family Routines Questionnaire – Asthma Version (FRQ-A) to evaluate burden associated with asthma management in families with children between the ages of 5 and 13. The authors found that mothers who had higher levels of perceived burden were more likely to demonstrate the rejection/criticism parenting style, which significantly predicts higher child anxiety levels (Fiese et al., 2008). Dolgin et al. (1990) reported that the quality of the child's health also influences parenting behavior, which impacts family functioning. They noted that parents of more medically fragile children were less likely to enforce punishment and more likely to promote dependency, which could negatively impact family functioning in a variety of ways (Dolgin et al., 1990).

The emotional status of parents of chronically ill children is a complex issue and there are many factors to consider, including whether their coping mechanisms are effective or maladaptive. Wong and Heriot (2007) studied families of children with

cystic fibrosis between the ages of 5 and 12. They found that parents who used self-blame and behavioral disengagement more often as coping mechanisms showed higher rates of depression and anxiety. These coping mechanisms were also correlated with poorer child mental health and higher parental emotional impact on the child. Emotional support and vicarious hope as coping mechanisms showed the opposite effect (Wong & Heriot, 2007). Maternal worry did not, however, correlate with teacher and child reports of child behavioral problems (DeVet & Ireys, 1998). This indicates that a parent's amount of worry can greatly affect their perception of their child's behavior, which could affect the child's mental health, parenting styles, and overall family functioning.

These studies examining the effects of chronic illness on the mental health of adolescents and their families may be predictive of some of the patterns that may be present in families who have a younger child with a chronic illness. Developmental factors, however, should be considered with younger children as the maladaptive behavior may manifest differently in these children and families. Unfortunately, studies of children under the age of 5 with chronic illnesses and their families are sparse, and those that have targeted this population focus on one or two factors (child anxiety, parent anxiety, parent stress, family functioning) but not how all four may be related in the same family.

### **Chronic Illness, Emotional Health, and Family Functioning in Young Children**

Families of preschool-aged children who are suffering from a chronic health condition face some of the same challenges as families of adolescents with chronic

illnesses. Research is more limited in this age group and the developmental and behavioral differences (e.g., language and cognitive skills, variability in behavioral expression of anxiety symptoms) result in a strong focus on parental report measures. In many cases, younger children also are recently diagnosed with a health condition, which can compound the complex issues of assessing these families. Child and parental mental health, overall family functioning, and problematic child behavior are the key themes addressed in current literature that focuses on this age group.

Like parents of older children with chronic illnesses, parents of chronically ill preschool children also show elevated levels of anxiety. Hilliard et al. (2010) studied children between the ages of 2 and 6 who were diagnosed with type 1 diabetes. They found that trait anxiety scores of mothers were significantly above average when compared to mothers of healthy children. Approximately one-fifth of parents were above the clinical cut-off level for state anxiety as well. Rouf et al. (2011) examined maternal emotional health of children between the ages of 3 and 5 with life threatening food allergies and reported that the three most prevalent areas of concern were parental adjustment, responsibility of living with the increased risk, and issues surrounding identity and social implications of their child's health. It is clear that concerns in these areas could heighten a parent's anxiety level in many ways.

Parental perceptions of child vulnerability resulting from a chronic illness play a major role in their ability to adapt to the situation, as well as on the child's adjustment to their illness. Since parent report is vital in research on young children with chronic

illness, it is important not to ignore the possibility that a parent's overall emotional health could affect their perception of their child's physical, emotional, and behavioral health. Anthony (2005) found that parents of children with arthritis between the ages of 5 and 7 who perceived their children as being more vulnerable also said that their child had more problems with internalizing behavior and pain as well as more difficulties functioning psychosocially. Higher levels of vulnerability perceptions also were significantly correlated with a lower parental psychosocial quality of life and increased use of health care services (Anthony, 2005). In this comparison of young children with arthritis with a group of healthy children, Anthony (2005) found that levels of perceptions of child vulnerability were significantly higher in the chronically ill group and suggests that they have "an important influence on adjustment in young children with arthritis."

Because it has been demonstrated that parental anxiety and perceptions of vulnerability are associated with the child's mental health and behavior, it is necessary to further examine how and why these factors have an influence on one another. Children with chronic illnesses may struggle with behavior related to their illness since, in many cases, intensive daily regimens of medication and treatments are required. This is in addition to the typical level of behavioral problems associated with this age group. Hilliard et al. (2010) used the Pediatric Inventory for Parents (PIP) to assess parenting stress in families of children with type 1 diabetes by rating the frequency and difficulty of stressful events associated with managing their illness. The overall PIP scores showed that parents of a young child with diabetes showed more parental stress when compared

to a group of older children between the ages of 9 and 17 with diabetes. The Eyberg Child Behavior Inventory (ECBI) was used to obtain data on parent reported problem behavior producing an intensity rating and a problem rating. The authors reported that while ECBI intensity ratings were similar to healthy preschool aged children, the report of problem ratings was significantly higher than healthy children (Hilliard et al., 2010). Calam et al. (2003) also used the ECBI in a study that focused on young children with asthma. They reported that parent ratings of problem behaviors were significantly correlated with parental mental health variables such as levels of conflict, anxiety, and depression. Calam et al. (2003) also found that as parent reported ECBI scores increased, the risk of having 3 or more asthma attacks also increased as well as the number of parent reported respiratory problems. It is unclear whether or not child behavior is truly a more prevalent issue in young children with chronic illness or if it is due to an increased level in parental stress and anxiety, which may influence parents to over-report problematic behavior or misinterpret behavior as problematic when it may not be.

Parental anxiety and child behavior problems also seem to be related to how the family functions with a young child with a chronic illness. Although parenting a healthy young child has its challenges, these challenges may be compounded when additional stress of a chronic illness is added to the family's everyday life. Morawska, Stelzer, and Burgess (2008) conducted a study on young children with asthma and found that parents who reported more child behavior problems also showed more difficulty in parenting tasks related to asthma and higher levels of dysfunctional parenting. Parenting style was

assessed using the Parenting Scale (PS) that measured three types of dysfunctional parenting styles: laxness, over-reactivity, and verbosity (Morawska et al., 2008). They also assessed parental asthma management tasks with the Asthma Parent Tasks Checklist (APTC), which addressed their confidence in dealing with their child's asthma and different ways of managing it and asthma behavior problems using the Asthma Behavior Checklist (ABC). The authors found that an increased number of asthma behavior problems was associated with lower levels of confidence in dealing with the illness (Morawska et al., 2008). Lower levels of confidence were also associated with an increased problem rating of parenting tasks related to asthma. The most commonly reported asthma related problem behaviors in children were anxiety, oppositional behavior, aggression, and hyperactivity (Morawska et al., 2008). Calam et al. (2003) also found that family functioning and parenting variables were significantly associated with each other and with ECBI intensity scores. It is also possible that impairment in family functioning can cause an increase in problematic child behavior and that these two factors have a reciprocal effect. Morawska et al. (2008) found that higher levels of ineffective, dysfunctional parenting were associated with higher levels of asthma related behavior and task difficulties.

Calam et al. (2003) found no significant differences in child behavior or family variables in the high, medium, or low asthma risk groups. This indicates that psychosocial risk factors are prevalent in families of young children with chronic illness, even when the disease is well-managed. Rouf et al. (2011) described the intense anxiety

and trauma experienced by mothers of children with severe food allergies. Participants in the study described severe emotional reactions associated with witnessing a severe reaction and fear of future social, emotional, and physical problems in adolescent years. Other prevalent issues for this group of mothers included living with the continued risk, responsibility and control over allergens, trusting others, teaching the child about their allergy, and social discomforts (Rouf et al., 2011). Regardless of the intensity or type of health condition, it is clear that parents of young children with chronic health problems are at higher risk of stress-inducing anxiety, parenting style issues, and are more likely to deal with behavior problems and anxiety in their children. These factors, in turn, may affect the family's day to day functioning.

### **Summary and Purpose of the Current Study**

Research with young children with chronic illnesses and their families is complex because it involves numerous factors including parental anxiety, child anxiety, frequency and intensity of required health care, overall family functioning abilities, parenting styles, and child behavior problems. These factors are not acting as static independent entities, as they are constantly changing and potentially influencing one another. Research shows that chronic illness is more strongly associated with anxiety and behavior problems in younger children than older children (Gortmaker et al., 1990; Rask et al., 2012). Most research in this area is based on parent report, so it is unclear if a true picture of the child's anxiety has been established. Additionally, not only do chronic illnesses in children affect the child's mental health, but also the entire family's ability to function

and the caregivers' mental health as well. Research suggests that families of a child with a chronic illness often report an overall lower quality of life, more conflict, and issues with communication and daily functioning compared to families of healthy children (e.g., Cheshire et al., 2010; Osman et al., 2001; Spieth et al., 2001; Wray & Sensky, 2004). Studies examining child and parent mental health and family functioning in families with older children with chronic illnesses report a strong correlation between these variables (e.g., Anthony et al., 2011; Lopez et al., 2008; Mandell et al., 2005; Williams et al., 2009). These factors also may have a cyclical effect, which can have a negative impact on the family as a whole. Research involving these factors in families of young children with chronic illness is very limited. The few studies including preschool age children suggest that child anxiety, parental anxiety, and family functioning may impact these families more negatively than families of older children (e.g., Gortmaker et al., 1990; Wolff, 2012). Further research is needed, however, to clarify these relationships and to determine the role of the chronic illness during this crucial developmental stage.

The purpose of the current study was to evaluate the relationship among child anxiety, parental anxiety, parental stress, and family functioning in families with young children with a chronic illness. The primary goal of the study was to assess these factors comparably in families with children with and without chronic illnesses. Specifically, we expected the chronic illness group to report more distressed parent, child, and family functioning compared to the healthy controls. Further, we hypothesized that family functioning would be predicted by perceived child anxiety, parental anxiety, and parental

stress in his/her role as a parent. We also expected a positive correlation between parental anxiety and perceived child anxiety. Finally, we predicted that parental anxiety would be positively correlated to their perceived stress specifically related role function and day to day care responsibilities.

## Chapter II

## METHOD

**Participants**

Participants in this study were 30 parents of children ages 2 through 7 years. The first group included 14 parents (Mean age = 37.6 yrs;  $SD = 7.40$ ) of children (Mean age = 4.30 yrs;  $SD = 1.80$ ) diagnosed with a chronic illness. Chronic illnesses included renal failure, supraventricular tachycardia, asthma, Hashimoto's thyroiditis, congenital heart disease, mastocytosis, Celiac Disease, and food allergies. The comparison group included 16 parents (Mean age = 35.4 yrs;  $SD = 5.62$ ) of children (Mean age = 3.65 yrs;  $SD = .94$ ) not diagnosed with a chronic illness (i.e., "healthy group"). The participants were recruited from an outpatient pediatric rehabilitation clinic, a pediatric medical clinic, a pediatric physical therapy clinic, an early intervention center, two preschools, and a disease-specific foundation in the Southeastern United States. Table 1 presents the demographic data for each group. The chronic illness group did not differ from the healthy group on child age,  $t(28) = -1.27, p = .23$ , parent age,  $t(27) = -.93, p = .36$ , number of children in the home,  $t(28) = -1.52, p = .14$ , or number of adults in the home,  $t(27) = .00, p = 1.00$ . Chi-square analyses also show no differences between groups on child gender ( $X^2 = 1.27, p = .26$ ), ethnicity of the child ( $X^2 = 1.88, p = .39$ ), ethnicity of the parent ( $X^2 = 1.88, p = .39$ ), household income ( $X^2 = 1.26, p = .53$ ), child's typical child care ( $X^2 = 3.21, p = .20$ ), or reporting parent's role ( $X^2 = 1.36, p = .51$ ).

Table 1

*Percentages for Demographic Variables by Child Illness Group*

	Healthy Group <sup>a</sup>	Chronic Illness Group <sup>b</sup>
Child Gender		
Male	56.2	35.7
Female	43.8	64.3
Parent Gender		
Male	12.5	7.1
Female	87.5	92.9
Child Ethnicity		
Caucasian	87.5	100
Biracial	6.3	0
Other	6.3	0
Parent Ethnicity		
Caucasian	87.5	100
Biracial	6.3	0
Other	6.3	0
Family Income		
\$14,999 or less	0	7.1
\$30,000-59,999	18.8	21.4
\$60,000 or more	81.3	71.4
Child's Typical Week		
1-2 days of preschool	6.3	14.3
3-5 days of preschool	93.8	71.4
5 days elementary	0	14.3
Parent Role		
Biological mother	87.5	85.7
Biological father	12.5	7.1
Adoptive mother	0	7.1

<sup>a</sup>N = 16. <sup>b</sup>N = 14.

## Measures

**Demographics and history of chronic illness.** The demographics questionnaire included information such as the child's date of birth, family structure, living arrangements, ethnicity, primary language spoken in the home, income, and the child's daily routine. Regarding the chronic illness, the questionnaire assessed medical diagnoses, child's age at diagnosis, and the average number of doctor's or service provider visits per month (see Appendix A).

**Impact on Family Scale.** The Impact on Family Scale (IFS; Stein & Riessman, 1980) was used to assess the impact of the child's chronic illness on the family. This tool is a 27-item scale that can be completed in approximately ten minutes. It is a parent-report measure that is designed for use with parents or caregivers of children with medical conditions. The response format is a 4-point Likert scale (1 = *strongly agree* to 4 = *strongly disagree*). The four descriptive scales on the IFS are Financial Impact, Familial-Social Impact, Personal Strain, and Mastery. These scales are summed for a total impact score. Internal consistency and construct validity are both well-established for this scale in samples that include children and families who are facing various chronic illnesses (e.g., Hanson, Lapidus, Zuniga & Murphy, 2000; Stein & Riessman). This scale was administered only to the chronic illness group, as the questions are not relevant to the parents of healthy children.

**Generalized Anxiety Disorders 7-Item Scale.** A 7-item anxiety scale (GAD-7; Spitzer, Kroenke, Williams, & Lowe, 2006) was used to assess parental general anxiety

in both the chronic illness and healthy groups. This tool has seven items, each rated on a 4-point Likert scale (1 = *not at all* to 7 = *nearly every day*). The score for each question is added to calculate a total score. Reliability for the GAD-7 is 0.86; it also has good convergent validity with the HADS anxiety scale ( $r = 0.82$ ), Beck Anxiety Inventory ( $r = 0.72$ ), and the anxiety subscale of the Symptom Checklist-90 ( $r = 0.74$ ; Donker, Van Straten, Marks, & Cuijpers, 2011; Spitzer et al., 2006). The GAD-7 also has demonstrated criterion, construct, factorial, and procedural validity as well as significant agreement between self-report and interviewer-administered versions of the scale (Spitzer et al., 2006). All parents completed the GAD-7.

**Pediatric Inventory for Parents.** The Pediatric Inventory for Parents (PIP; Streisand, Braniecki, Tercyak, & Kazak, 2001) was used to assess parenting stress and is specifically designed for use with parents caring for a child with a chronic illness. It was, however, administered to both the chronic illness and the healthy groups as a measure of parental stress. Questions on this measure apply to parents of children with or without a chronic illness. This tool has 42 items that each use two 5-point Likert scales for responses: the frequency domain (i.e., how often an event happens) and the difficulty domain (i.e., how difficult the parent feels the event is to handle if/when it occurs). The items are divided into four subscales: Communication, Emotional Functioning, Medical Care, and Role Function, for a total of 8 subscale scores (i.e., frequency and difficulty for each of the 4 content scales). These scales are then added together to form a total frequency score (PIP-F) and a total difficulty score (PIP-D). Reliability coefficients for

all individual scales are above .80 and for the total scores are .95 for PIP-F and .96 for PIP-D. Regarding construct validity, strong associations were found among PIP scores and state anxiety scores on the State-Trait Anxiety Inventory (Streisand et al., 2001).

**Behavior Assessment Scale for Children.** The preschool form of the Behavior Assessment System for Children, Second Edition (BASC-2) was used to assess the child's adaptive and problem behaviors. This scale has 134 items with a 4-point Likert type response (1 = *never* to 4 = *almost always*) and was completed by all parents. The BASC-2 has 10 clinical scales including hyperactivity, aggression, conduct problems, anxiety, depression, somatization, attention problems, learning problems, atypicality, and withdrawal. Adaptive scales include adaptability, social skills, and functional communication. These scales are grouped into composites including externalizing problems, internalizing problems, adaptive skills, and the behavioral symptoms index. According to Reynolds and Kamphaus (2004), internal consistency is in the low to middle .90s for adaptive skills and in the middle .80s to middle .90s for externalizing and internalizing problems. Reliability coefficients for the individual scales range from .80 to .83 for the preschool BASC. Median test-retest reliabilities for the preschool level are .77, .84, and .81, and median interrater reliabilities are .74, .69, and .77. The BASC-2 correlates in the .70s and .80s with the ASEBA Child Behavior Checklist for Ages 1-5, the Conners' Parent Rating Scale-Revised, and the Behavior Rating Inventory of Executive Functioning (BRIEF) and in the .90s with the previous BASC (Reynolds & Kamphaus, 2004).

**Procedure**

A packet of the tools was distributed to families at the clinics and preschools who were eligible for the study. Each packet included the informed consent letter (see Appendix B), the demographics questionnaire, the Behavior Assessment System for Children (BASC-2), the Impact on Family Scale (IFS), the Pediatric Inventory for Parents (PIP), and the Generalized Anxiety Disorder 7-item Scale (GAD-7). The order of the BASC, IFS, PIP, and GAD-7 was pseudo-randomized in the packets to control for potential order effects. Parents were instructed in the packets not to provide answers for the Impact on Family Scale if their child did not have a chronic illness. The parent/caregiver who completed the assessment did not include their name or any other identifying information in the packet which allowed anonymity. Packets were given to the eligible families by the researcher or by staff at the clinics. Completed packets were returned to the researcher via a self-addressed stamped envelope that was in the packet.

## Chapter III

## RESULTS

Table 2 includes descriptive statistics for all dependent variables by group. It was predicted that the two groups (i.e., healthy and chronic illness) would differ on child anxiety and child somatization, with the chronic illness group reporting higher child internalizing behavior problems. A one-way ANOVA (see Table 3) indicated that child anxiety was not significantly different between groups  $F(1, 27) = .75, MSE = 101.54, p = .39$ . There were significant differences, however, between groups for child somatization behavior,  $F(1, 27) = 7.44, MSE = 85.80, p = .01$  and withdrawal behavior,  $F(1, 27) = 5.57, MSE = 62.46, p = .03$ . Although not predicted, the groups did not differ on reports of externalizing problems,  $F(1, 27) = .81, MSE = 63.29, p = .38$ . Mean scores for all of these BASC-2 scales for both illness groups were within typical (i.e., non-clinical) range compared to age and gender norms.

Secondly, it was hypothesized that parents of children with chronic illness would report higher general anxiety and higher parental stress as measured by the PIP when compared to parents of healthy children. One way ANOVAs (see Table 3) indicate a significant difference between groups for GAD-7 scores,  $F(1, 29) = 16.51, p < .001$ , with parents of children with chronic illnesses reporting higher anxiety. Also, these parents reported significantly higher stress on the PIP frequency score,  $F(1, 27) = 19.17, MSE = 383.41, p < .001$ , and PIP difficulty score,  $F(1, 27) = 30.57, MSE = 427.15, p < .001$ .

Table 2

*Dependent Variables by Child Illness Group*

	Healthy Group <sup>a</sup>	Chronic Illness Group <sup>b</sup>
	<i>M (SD)</i>	<i>M (SD)</i>
GAD - 7	1.44 (2.19)	7.79 (5.580)
PIP		
Total Frequency Score	57.14 (14.51)	89.55 (23.59)
Communication - Frequency	11.57 (3.03)	19.45 (5.97)
Emotional Functioning – Frequency	19.64 (4.57)	32.64 (10.97)
Medical Care – Frequency	11.00 (3.88)	16.18 (5.88)
Role Function - Frequency	14.93 (5.17)	19.61 (6.00)
Total Difficulty Score	49.93 (8.90)	93.12 (27.84)
Communication - Difficulty	10.14 (1.56)	18.27 (7.14)
Emotional Functioning - Difficulty	18.50 (4.52)	36.94 (13.59)
Medical Care – Difficulty	8.79 (1.48)	16.00 (5.90)
Role Function - Difficulty	12.50 (3.01)	19.94 (6.11)
BASC-2		
Behavioral Index	48.69 (6.56)	51.08 (13.50)
Internalizing Problems	49.31 (9.58)	51.83 (7.98)
Externalizing Problems	47.94 (5.70)	50.67 (10.23)
Anxiety	49.75 (10.74)	46.42 (9.09)
Depression	50.25 (7.10)	49.33 (7.91)
Somatization	48.44 (8.72)	52.50 (12.12)
Hyperactivity	48.06 (5.20)	52.44 (10.61)
Aggression	47.94 (7.13)	48.67 (7.78)
Atypicality	50.88 (9.39)	52.92 (13.64)
Attention Problems	51.06 (6.31)	49.17 (13.60)
Withdrawal	45.63 (4.82)	52.75 (10.77)
IFS		
Total Score		45.00 (12.71)
Financial Impact		8.08 (3.32)
Familial-Social Impact		17.17 (5.84)
Personal Strain		10.92 (4.06)
Mastery		8.83 (1.90)

Note. The IFS was completed only by the Chronic Illness group.

<sup>a</sup>*N* = 16. <sup>b</sup>*N* = 14.

Table 3

*One-Way ANOVA for Child Anxiety, Parent Anxiety, PIP Total Frequency, and PIP Total Difficulty*

		Df	Mean Square	F	Sig.
Anxiety (BASC)	Between Groups	1	76.19	0.75	.39
	Within Groups	26	101.54		
	Total	27			
Total F	Between Groups	1	7351.56	19.17	.00**
	Within Groups	26	383.41		
	Total	27			
Total D	Between Groups	1	13059.36	30.57	.00**
	Within Groups	26	427.15		
	Total	27			
GAD-7	Between Groups	1	300.91	16.51	.00**
	Within Groups	28	18.23		
	Total	29			

\*\* $p < .001$

Table 4

*Results of the Stepwise Regression Analyses Predicting Family Functioning*

Model	R	R <sup>2</sup>	AdjR <sub>2</sub>	SE	ΔR <sup>2</sup>	ΔF	df1	df2	Sig F
1	.81	.66	.39	10.46	.66	2.45	4	5	.18

\* $p < .05$

For the families of children with chronic illnesses, it was hypothesized that family functioning would be predicted by a combination of parental general anxiety, child anxiety, and parental stress related to the child's illness. The IFS overall score was the outcome variable (i.e., family functioning). Predictor variables were the GAD-7 total score, the BASC-2 internalizing scale score, the PIP total frequency, and the PIP total difficulty scores. A forward stepwise regression analysis was conducted (see Table 4). Regression analysis did not support this hypothesis,  $R^2 = .66$ ,  $F(4, 5) = 2.45$ ,  $p = .18$ .

It was predicted that there would be a significant positive correlation between parental general anxiety and parental stress related to the frequency of activities and sacrifices made due to the child's illness. The GAD-7 and the PIP frequency scores for the Role Function scale (tasks that affect the individual's ability to function in everyday life) and Medical Care scale (medically related events such as procedures, appointments, and medial regimens) were used to test this hypothesis. Pearson correlation coefficients were calculated and an alpha of .05 was used. For the full sample ( $N = 30$ ), there were significant positive correlations between parent anxiety and PIP Role Function frequency,  $r^2 = .25$ ,  $p = .004$ , and between parent anxiety and PIP Medical Care Frequency,  $r^2 = .28$ ,  $p = .004$ .

Finally, it also was predicted that parent reported child anxiety scores and overall child internalizing problems (i.e., anxiety, somatization, depression and withdrawal) would be positively correlated with parent anxiety scores for all parents, regardless of child health status. For the full sample ( $N = 30$ ), there was no significant correlation

between parent anxiety and child anxiety specifically,  $r^2 = .12$ ,  $p = .07$ , but parent anxiety and child internalizing problems were significantly positively correlated,  $r^2 = .23$ ,  $p = .01$ . When correlating these measures separately for each child illness group, a different pattern emerges. In the chronic illness group ( $N = 14$ ), the correlation between parent anxiety and parent-reported child anxiety was significant,  $r^2 = .53$ ,  $p = .007$ , and parent anxiety and child internalizing problems also were significantly positively correlated,  $r^2 = .44$ ,  $p = .02$ . For the healthy group there was a significant positive correlation between parent anxiety and parent-reported child anxiety,  $r^2 = .26$ ,  $p = .045$ , but not for parent anxiety and internalizing problems,  $r^2 = .17$ ,  $p = .116$ .

## Chapter IV

### DISCUSSION

The purpose of this study was to compare parent, child, and family functioning in families with young children with and without chronic illnesses. The secondary goals were to identify specific relationships among parent anxiety and child anxiety, child somatization, child overall internalizing behaviors, and parental stress as it relates to factors associated with caring for health and well-being of their children. Thirty parents reported on these factors.

Comparing the healthy group to the chronic illness group, it was predicted that the chronic illness group would have higher child anxiety, child somatization, and other internalizing behavior. Results indicated, however, that the two groups were significantly different on child somatization behavior and child withdrawal behavior but not child anxiety. This finding means that children with chronic illnesses are more likely to present somatization and withdrawal symptoms, but are not necessarily more likely to be anxious when compared to healthy peers. These findings are consistent with the predictions for somatization and withdrawal, but not for anxiety. This lack of difference between groups on the child anxiety scale is inconsistent with previous research findings. For example, Wolff et al. (2012) found that 3-year-olds with new-onset chronic pain had more anxious-depressed symptoms, sleep problems, somatic symptoms, and aggressive behavior than children without pain, as reported by their mothers. Gortmaker et al. (1990) assessed behavioral concerns in chronically ill 4- to 17-year olds and found that the 4- to 11-year

olds showed significantly higher scores than the adolescent group on the Anxious/Depressed Mood and Peer Conflict/Social Withdrawal subscales (Gortmaker et al., 1990). These studies demonstrate a significant relationship between chronic illnesses and child anxiety, specifically. A number of factors potentially could have contributed to this inconsistency with previous findings and the current study such as the measures used to assess child anxiety in each study and the type of chronic illnesses represented in the samples. For example, Wolff et al. (2012) included a sample of children with chronic pain, who might experience higher anxiety than children with other illnesses such as asthma or food allergies which were more prevalent in the current study sample.

It also was predicted that the two groups would differ on the frequency and difficulty scales of the PIP (which measures parental stress) and parent anxiety. Results indicated that the two groups (healthy and chronic illness) were significantly different for both parent stress and parent anxiety, with parents in the chronic illness group reporting higher anxiety and higher levels of stress in their roles related to caretaking. These findings are consistent with the current literature in this area, as Powers et al. (2002) also found that parents of children with Type 1 diabetes reported higher stress levels than parents of children in the healthy control group. Additionally, Patino-Fernández et al. (2008) found that 51% of fathers and 40% of mothers of children newly diagnosed with cancer met criteria for acute stress disorder. These rates are more elevated than the prevalence of acute stress disorder in the general population, illustrating that parental stress is higher in those who have a child newly diagnosed with a chronic illness.

Mandell, Curtis, Gold, and Hardie (2005) found that in parents of children with food allergies, nearly all of them reported high levels of anxiety, but they were not compared to healthy controls. The higher rates of anxiety and stress in the care taking roles for these parents in the current and previous studies suggest a pattern of high demand for the parents' time and efforts as well as a feeling of worry and dread. What we don't know is if their anxiety is general or more specific to the child's health status or provoked by a specific health incident. We also don't know if the parent's anxieties were evident prior to the children's illnesses. Further investigation is needed to address these questions.

In addition to predicting group differences, we also hypothesized about the relationship between parent, child, and family factors. It was hypothesized that, regardless of illness status, there would be a positive correlation between parental anxiety and child anxiety, meaning that the more anxious the parent, the more anxious he/she would report the child as being. Interestingly, we found that parental general anxiety did *not* correlate with child anxiety in the full sample, but there was a positive correlation between parental general anxiety and child somatization behavior. This finding suggests that parent anxiety may be related more specifically to the child's health related symptoms than to the child's anxious symptomology. Further correlational analyses within each health group showed a slightly different pattern, though. For the chronic illness group, child anxiety and parent anxiety were significantly positively correlated, as were parent anxiety and child somatization. In the healthy group, parent anxiety and child anxiety were significantly positively correlated, but parent anxiety and child

somatization were not. Collectively these findings suggest a strong link between the child's health-related behavior and parent anxiety when child health issues are more prevalent (i.e., in the chronic illness group) than when the child is generally healthy. This link is possibly more influential than the child anxiety – parent anxiety correlation, which is significant in both subgroups. Previous research has not focused on these relationships in young children with chronic illnesses.

Because having a child with a chronic illness can impact the daily functioning of families, the next prediction was that the frequency of activities that affect the parent's ability to function in everyday life and the frequency of medically-related events (such as visits to the hospital, procedures, daily regimens, etc.) would have strong positive correlations with parent anxiety. These hypotheses were supported; both of these factors had a significant positive correlation with parent anxiety. As the frequency of activities that affect functioning and medical events increases, the higher the parent's reported anxiety. Lewin et al. (2005) also found that the PIP Role Functioning scale was highly correlated with maternal anxiety. These findings suggest that the higher anxiety among parents of children with chronic illnesses may be a function of the demands of the illness on family time and family activities. This connection is a critical one to consider in terms of services needed for parents and families of these children.

Finally, it was hypothesized that parent stress, parent anxiety, and child anxiety (combined) would predict overall family functioning in the chronic illness group. We found that these factors did not significantly predict family functioning in families who

have a child with a chronic illness. Studies examining child and parent mental health, family functioning, and chronic illness in older children report that there is a strong correlation between these variables (Anthony et al., 2011; Lopez et al., 2008; Mandell et al., 2005; Williams et al., 2009). The lack of significance in the regression analysis in the current study may be due to the strong intercorrelations between these factors and also the small sample size (i.e., 14).

### **Limitations and Future Directions**

In discussing strengths and limitations of this study, it is important to first note that the sample size was relatively small ( $N = 30$ ). It was more difficult than expected to recruit participants for the chronic illness group, especially with such a narrow age range. Approximately 200 packets were dispersed to the recruitment sites, with only 30 being returned. Accessing this population is difficult when not a staff member of a clinic providing services. Also, it might have been more helpful to have face-to-face contact with participants and have them fill out the packets and hand in personally rather than mailing them in. One direction for future research would be to replicate the study using a larger sample size. An additional sample characteristic that limits the generalizability of these results is that most of the participants were Caucasian and had middle to upper class income levels. Future research could attempt to replicate this study with different ethnic groups and/or socio-economic status groups.

Another factor for consideration is the method in which the parent's anxiety was assessed. The GAD-7 was used partially because it is a short, easy tool used to assess

generalized anxiety in adults. However, it does not take into consideration state/trait factors, so it cannot be said with certainty whether the anxiety the parents were reporting was due to their own anxious tendencies that may have been present even before their child was born (or diagnosed), or if it was due to anxiety-producing events currently occurring in their lives due to their child's illness. It would be interesting to take a closer look at the parent's anxiety, possibly with a state/trait measure. It also would be helpful to have the parents provide other information that may shed light on whether they have a history of any type of anxiety disorders or if they are currently experiencing any negative emotional reactions due to their own health, finances, relationships, and/or occupation.

An initial goal of this study was to compare children of various different illness groups, but we did not have enough participants in any particular group to make any comparisons. Another direction for future research would be to replicate this study with several illness groups (e.g., food allergies, heart conditions, and asthma), recruiting a substantial number of participants in each group, and then comparing groups to identify parent, child, and family differences and patterns by illness group. Whether an illness is terminal in nature could make a significant difference in the parents' and child's emotional state, as well as the frequency of medically related daily tasks required. These factors would be interesting to analyze when comparing one illness group to another.

Despite the methodological limitations of this study, the findings do suggest that families who have a young child with a chronic illness are experiencing more stress and anxiety than families of healthy children. It would be helpful for medical personnel and

the mental health field to be aware of these issues when serving these families. If possible, it would be beneficial if there were more providers available who understood the physical and emotional facets of a disease and were able to assist these families in learning ways to cope with their child's illness, both emotionally and physically. The number of children with chronic illnesses, like those in this study, is increasing each year. The mental health of these children and their caregivers is an area that should not be ignored, as it has major implications for their physical health as well. Additional research is needed with this young age group so we can more adequately develop support services for these families.

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## Appendix A

**MTSU IRB Approval Letter**

November 12, 2013  
Molly Boyce, Dr. Kim Ujcich Ward  
Psychology  
mrk2y@mtmail.mtsu.edu, kimberly.ward@mtsu.edu

Protocol Title: “Anxiety, Stress, and Family Functioning in Families of Young Children with a Chronic Illness” Protocol Number: 14-146

Dear Investigator(s),

The MTSU Institutional Review Board, or a representative of the IRB, has reviewed the research proposal identified above. The MTSU IRB or its representative has determined that the study poses minimal risk to participants and qualifies for an expedited review under 45 CFR 46.110 and 21 CFR 56.110.

Approval is granted for one (1) year from the date of this letter for 100 participants. Please note that any unanticipated harms to participants or adverse events must be reported to the Office of Compliance at (615) 494-8918. Any change to the protocol must be submitted to the IRB before implementing this change. You will need to submit an end-of-project form to the Office of Compliance upon completion of your research located on the IRB website. Complete research means that you have finished collecting and analyzing data. Should you not finish your research within the one (1) year period, you must submit a Progress Report and request a continuation prior to the expiration date. Please allow time for review and requested revisions. Failure to submit a Progress Report and request for continuation will automatically result in cancellation of your research study. Therefore, you will not be able to use any data and/or collect any data. Your study expires November 12, 2014. According to MTSU Policy, a researcher is defined as anyone who works with data or has contact with participants. Anyone meeting this definition needs to be listed on the protocol and needs to complete the required training. If you add researchers to an approved project, please forward an updated list of researchers to the Office of Compliance before they begin to work on the project.

All research materials must be retained by the PI or faculty advisor (if the PI is a student) for at least three (3) years after study completion and then destroyed in a manner that maintains confidentiality and anonymity.

Sincerely,  
Kellie Hilker  
Compliance Officer/ MTSU Institutional Review Board Member

## Appendix B

**Cover Letter**

Dear Parent/Guardian,

First of all, thank you for your interest in this project. We realize that as the caregiver of a young child, your time is limited and we appreciate your participation.

I am Molly Boyce, a graduate student in Clinical Psychology at MTSU. I am working on a research project about families who have young children *with* and *without* chronic health conditions like diabetes, food allergies, asthma, and others. The purpose of my project is to better understand what families of young children experience emotionally, and how a child's health condition might impact parents, families, and the child himself or herself.

This project is for families that have a child who is between the ages of 2 and 5 years old. We need families with children who have a chronic health condition AND families whose children do not have a chronic health condition. We hope that this project will help professionals gain a better understanding of what you and your families go through on an everyday basis. Also, we hope it will contribute to the development of useful services for children with chronic illnesses and their families. The only risk involved in participating is the possibility of an emotional reaction to some of the questions because they have to do with your child's health and your family.

Your help with this project will take about 15 minutes of your time. If you would like to participate, please fill out the attached questionnaires, place them in the envelope, and return the packet to your preschool/day care provider **or** mail it back to MTSU in the self-addressed envelope if one is provided. Please do not include your name or your child's name, or any other information regarding your identity on any of the questionnaires.

By returning your completed packet, you are giving your consent to be a part of the project and for your responses to be used as a part of the results. If you have any questions, please contact me at [mrk2y@mtmail.mtsu.edu](mailto:mrk2y@mtmail.mtsu.edu), or you can contact my research supervisor at MTSU, Dr. Kim Ujcich Ward at [Kimberly.ward@mtsu.edu](mailto:Kimberly.ward@mtsu.edu) or 615.898.2188. For additional information about giving consent or your rights as a participant in this study, please feel free to contact the MTSU Office of Compliance at (615) 494-8918.

If you decide not to participate, that is not a problem at all. We would still like for you to put the blank questionnaires in the envelope and bring or mail them back to us.

Again, thank you for your participation. We truly appreciate your time and the valuable information and insight you can offer to help us better understand families who have young children.

Sincerely,

Molly Boyce  
Graduate Student, Clinical Psychology  
Middle Tennessee State University  
mrk2y@mtmail.mtsu.edu

## Appendix C

**Demographic Questionnaire**

1. Your child's gender: \_\_\_\_\_ Male \_\_\_\_\_ Female
2. Your child's current age: \_\_\_\_\_ years and \_\_\_\_\_ months
3. Your current age: \_\_\_\_\_
4. How many children (17 or younger) live in your home? \_\_\_\_\_
5. How many adults (18 or older) live in the home? \_\_\_\_\_
6. Ethnicity of the child:  
African American \_\_\_\_\_ Caucasian \_\_\_\_\_ Hispanic \_\_\_\_\_ Biracial \_\_\_\_\_ Other: \_\_\_\_\_
7. Ethnicity of the parent/caregiver:  
African American \_\_\_\_\_ Caucasian \_\_\_\_\_ Hispanic \_\_\_\_\_ Biracial \_\_\_\_\_ Other: \_\_\_\_\_
8. Primary language spoken in the home:  
English \_\_\_\_\_ Spanish \_\_\_\_\_ Other: \_\_\_\_\_
9. Please estimate your family's approximate yearly income:  
\_\_\_\_\_ \$14, 999 or below  
\_\_\_\_\_ \$15,000 – 29,999  
\_\_\_\_\_ \$30,000 – 59,999  
\_\_\_\_\_ \$Over 60, 000
10. Which of the following best describes a typical week for your child:  
\_\_\_\_\_ Does not attend preschool or daycare outside of our home  
\_\_\_\_\_ Attends a preschool, daycare or Mother's day out 1-2 times a week  
\_\_\_\_\_ Attends preschool or daycare 3-5 days a week
11. Which of the following best describes your relationship with this child?  
\_\_\_\_\_ Biological mother  
\_\_\_\_\_ Biological father  
\_\_\_\_\_ Adoptive mother  
\_\_\_\_\_ Adoptive father  
\_\_\_\_\_ Step-mother

- Step-father  
 Grandparent  
 Other relative (please describe): \_\_\_\_\_  
 Foster parent  
 Other (please describe): \_\_\_\_\_

12. Has your child been diagnosed with any of the following health conditions? Please indicate "yes" if so, and note the age at which he/she was diagnosed.

	Child Diagnosed?	Age at Diagnosis
ADHD	Y N	Age:
Asthma	Y N	Age:
Autism Spectrum Disorder	Y N	Age:
Cerebral Palsy	Y N	Age:
Chronic Pain	Y N	Age:
Congenital Heart Disease	Y N	Age:
Crohn's Disease	Y N	Age:
Cystic Fibrosis	Y N	Age:
Developmental Disability	Y N	Age:
Diabetes (Type 1)	Y N	Age:
Diabetes (Type 2)	Y N	Age:
Epilepsy	Y N	Age:
Food Allergy Which food(s):	Y N	Age:
Irritable Bowel Syndrome	Y N	Age:
Juvenile Arthritis	Y N	Age:
Migraines	Y N	Age:
Sickle Cell Anemia	Y N	Age:

13. Has your child been diagnosed with any other chronic health conditions? If so, please list them:

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14. Considering all of your child's health care providers (physicians, nurse practitioners, physical therapists, occupational therapists, speech therapists, mental health counselors, etc.), approximately how many appointments per month does he/she have? \_\_\_\_\_

