

Parent-Child Interactional Factors that Mediate Medical Adherence
Behaviors in Children with Atopic Dermatitis

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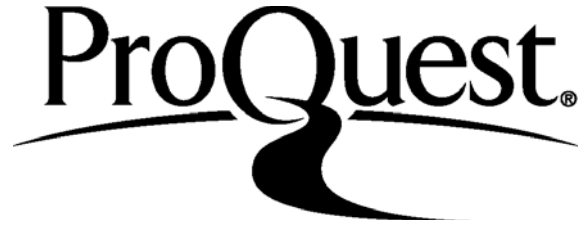
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DEDICATION

This project is dedicated to the children suffering from Atopic Dermatitis as well as the family members attempting to comfort, heal and soothe their children. It is true torture to watch your child suffer with painful rashes, sleepless nights and endless distress for years on end with no way to provide long-lasting relief. This disease robs children of a carefree childhood while scratching is substituted for spontaneous play and constant distress is exchanged for creativity and growth. I was lucky enough to find an extraordinarily talented team of physicians and nurses to diagnose the underlying causes of my children's eczema and to find effective treatments, but many families aren't nearly as fortunate. My hope is that this dissertation will add to the understanding of the pain and suffering of families and spur on more effective, relational-based interventions to provide a relief from suffering.

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First, I would like to acknowledge Dr. Siegfried and her entire office for their tireless pursuit of treatments for this horrible disease. Not only have they saved the life of my daughter and provided brilliant and compassionate care to my two sons, they work daily to do the same for other children and their families. They continue to do this work despite a void of effective treatments, families that do not follow protocols, and a medical community that does not give them the support they need. Their dedication and perseverance inspired me to do this study.

Second, I would like to thank my dissertation chair Dr. Pettinelli for his clinical guidance and mentoring throughout the program. You have greatly added to my clinical development and constantly challenged me to think in more creative, attuned ways.

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CHAPTER I

INTRODUCTION

Quotes from Parents of Children with AD:

“He scratches through the night, disfiguring himself. His sheets are bloody.”

“She is miserable. Nothing you can do will comfort her.”

“When my husband sees dried blood on her face he cries.”

“I blame myself for passing it on to him.”

“Everyone wants a perfect infant. I miss touching his face because of his eczema.”

“I am being cheated out of part of motherhood. I don’t want to take pictures.”

(Chamlin, Frieden, Williams & Chren, 2004, pp. 608-610):

Purpose of the Study

This study sought to examine the effect of parent-child interactional factors on medical adherence behavior in children with Atopic Dermatitis. AD, commonly referred to as eczema, is a chronic, remitting skin disease that causes an itchy rash. AD often begins in infancy or early childhood and has been shown to have an impact on both physiological and psychological development (Chamlin, Frieden, Williams & Chren, 2004). Although effective medical treatments exist, adherence rates are consistently found to be below 50%, leaving many children with higher levels of disease severity than necessary (Ou, Feldman & Balkrishnan, 2010). Existing theoretical frameworks for medical adherence in children with AD have focused on internal and external factors regarding the parent and family since the duty of treatment in young

children falls primarily on the parents (Chisolm et al., 2009). This study sought to add to those frameworks by exploring parent-child interactional factors such as stress, attunement, and contingent communication as predictors for medical adherence. Finally, the current study also attempted to understand how adherence behaviors vary in different areas of treatment protocols and to discover reasons behind non-adherence behaviors. These goals were accomplished by surveying parents and children with AD seeking outpatient medical treatment from a pediatric dermatologist with scales regarding disease severity, medical adherence and parental stress. Physicians were also surveyed for disease severity, disease improvement, and overall global functioning.

This chapter will outline the theoretical frameworks that informed the development of the study. A cursory explanation of the symptoms, effects and treatment of Atopic Dermatitis will be discussed. Existing frameworks for medical adherence for children with AD will be described. Finally, an overview of attachment theory and interpersonal neurobiology will be included.

Brief Overview of the Literature

Atopic Dermatitis: Disease and Treatment

Atopic dermatitis (AD) is the most common skin condition of childhood, affecting approximately 17% of children in the United States (Balkrishnan, Housman, Carroll, Feldman & Fleischer, 2003; Chamlin, Frieden, Williams & Chren, 2004). Atopic dermatitis involves an itchy rash located typically in the folds of the elbows, behind the knees, ankles, under the buttocks, or in the neck, eyes and ears area (Spergel, 2010). It is a chronic, remitting disorder that can vary from mild to severe depending on the area of skin involved, the distress caused by

intense itching (also referred to as pruritis), and the severity and duration of flare-ups of the condition (Novak, 2009). While children may have mild rashes at times of chronic disease, flare-ups involve increased rashes over larger parts of the body that can become inflamed and infected, intensifying the child's level of distress (Schafer, 2006).

The effects of AD on both children and their families have been well documented (Ben-Gashir, Seed & Hay, 2004; Chamlin, Frieden, Williams & Chren, 2004; Krakowski, Eichenfield & Dohil, 2008; Lewis-Jones, 2006; Chamlin, 2006). Children with AD have been found to be at increased risk for difficulties in physical, emotional and social functioning (Chamlin, Frieden, Williams & Chren, 2004). The effect of the disease on quality of life continues even when there is no visible evidence of eczema rash (Ben-Gashir, Seed & Hay, 2004). Children with AD have higher rates of problematic behaviors, attention deficits, emotional sensitivity, clinginess and fearfulness (Roth, Beyreiss, Schlenzka & Beyer, 1991; Chamlin, Frieden, Williams & Chren, 2006). Sleep disturbances have been found in both children and families with AD (Dahl, Bernhisel-Broadbent, Scanon-Holdford, Sampson & Lupo, 1995; Moore, David, Murray, Child & Arkwright, 2006). AD in children has been found to affect the emotional, financial, physical and social well-being of parents (Chamlin, Frieden, Williams & Chren, 2006; Su, Kemp, Varigos & Nolan, 1997). Parents also report increased sadness and blame around their child's disease as well as concern for their child's development (Chamlin & Chren, 2010). Overall, the family impact of AD has been found to be comparable to children with insulin-dependent diabetes (Su, Kemp, Varigos & Nolan, 1997).

Approximately 90% of cases of AD begin in either infancy or the first five years of life which places the responsibility of medical adherence primarily in the hands of the parents (Chamlin, Frieden, Williams & Chren, 2004). Medical adherence, though expensive and time-

consuming, can lessen the effects of the disease on both the child and family. Medical adherence is defined as an agreement between the patient and physician on a set of rules, behaviors or mode of conduct to achieve an optimal treatment outcome (Hodari, Nanton, Carroll, Feldman & Balkrishnan, 2006; Cork, Britton, Butler, Young, Murphy & Keohane, 2003). Treatment protocols typically include “avoidance of irritants and specific triggers, repair and maintenance of the skin barrier, interruption of the itch-scratch cycle, and reduction of inflammation” (Boguniewicz, Eichenfield & Hultsch, 2003, p. S140). For children with Atopic Dermatitis, medical protocols typically include six main categories: bleach baths, application of moisturizers, topical creams, application of topical medications such as steroids, wet wraps around effective areas, and the removal of allergens and dust mites from the home environment. Poor adherence may cause failure of topical treatments, leading to the use of more dangerous systemic medications (Ou, Feldman & Balkrishnan, 2010). These medical protocols, though time consuming, are effective at controlling or minimizing the disease in most children with AD (Krakowski, Eichenfield & Dohil, 2008). Despite the effectiveness of existing treatments, lack of adherence leaves many children to suffer with more disease severity than necessary (Ou, Feldman & Balkrishnan, 2010). Research has continually shown adherence rates with AD to be below 50% (Krejci-Manwaring, et al., 2007; Nolan & Feldman, 2009). Studies have looked into various causes for lack of medical adherence by primary caregivers to children with AD and have so far found internal factors such as maternal self-efficacy, trust in physician and perceived risk of treatment and external factors such as access to care and socioeconomic status effect adherence rates (Nolan & Feldman, 2009; Ou, Feldman & Balkrishnan, 2010; Ohya, et al., 2001).

Frameworks aimed at understanding adherence behaviors have focused on parental factors such as socioeconomic status, access to care, self-efficacy and trust in physician. The focus on these factors led to the development of intervention strategies aimed at educating parents around treatment protocols with some success in improving adherence rates (Krejci-Manwaring, et al., 2007). However, this sole focus on parental factors neglected the impact the relationship between parent and child may have on adherence behaviors. For instance, some parents report children running away from baths and refusing ointments (Ou, Feldman & Balkrishnan, 2010). Other studies have found that hypersensory sensitivity, which impairs the child's ability to respond appropriately to sensory cues, are common in children with AD (Engel-Yeger et al., 2007). Therefore, parents who attempt adherence behaviors may find it difficult to identify the current severity of the child's disease, gain cooperation from the child, or may fear that they are causing the child added distress or pain. Understanding how the parent and child interact around adherence behaviors is therefore an essential piece in developing interventions aimed at increasing adherence.

Theories of Attachment and Interpersonal Neurobiology

Infants are biologically predisposed to develop an attachment to a primary caregiver in order to provide protection and care (Bowlby, 1982; Cassidy & Shaver, 1999). Attachment behaviors such as smiling, vocalization, and crying are signals to the primary attachment figure to remain close and provide the interaction necessary for development and protection in times of distress (Bowlby, 1969). Bowlby argued that interactional patterns between the primary caregiver and infant created internal working models of self and others in the child. These internal models then help the child and parent to anticipate and interpret interactions with their attachment partners (Bowlby, 1988). An infant is biologically programmed to develop a select

few attachment relationships in which the infant will seek 1) proximity to the attachment figure; 2) a sense of safe haven that the relationship will soothe his or her distress; and 3) develop an internal schema of him or herself and of others. The consistent meeting of these needs enable the child to possess a sense of safety and well-being that will allow him or her to explore the world and self-soothe in times of distress (Bowlby, 1969). Bowlby labeled this internal model of security in both self and others as a secure attachment (Bowlby, 1969).

Children who learn to feel secure in an attachment figure's ability to comfort and soothe them in times of distress develop a realistic appraisal of stressors and self-efficacy in the management of the threat (Bowlby, 1969). Insecurity regarding the ability of an attachment figure to soothe and comfort during times of distress can be the effect of that caregiver responding inconsistently, intrusively or in non-effective ways. An insecure model of self or others is related to a hypervigilant response which may include exaggerated perception of threats, excessive dependency and clinginess. Internal models that view the attachment figures as unreliable may also create avoidant strategies including downplaying of threats and compulsive self-reliance (Mikulincer & Shaver, 2003; Porter, Davis & Keefe, 2007).

Early attachment relationships are crucial in the emotional, social and brain development of young children (Siegel, 2001). Brain structures that mediate social and emotional functioning develop in the first years in a way that appears to be dependent on interpersonal experience (Siegel, 2001). An overproduction of neurons before birth and synapses during the first three years allows the brain to develop in response to environmental stimulation, including interpersonal experiences (Siegel, 2001). Environmental stimulation can cause the establishment of new synaptic connections that are then strengthened by repeated experiences (Siegel, 2001).

The absence of environmental stimulation or the presence of toxic conditions (such as

psychological or physical distress) can lead to the elimination of existing synapses (Siegel, 2001). The circuits of the brain that develop during these early years of life include regulation of emotion, memory, the capacity for response flexibility and memory (Schore, 1994, 1996; Siegel, 1999). Response flexibility is the result of the brain's ability to take in information, attach meaning to incoming cues and internal responses that these cues provoke, and apply logical thought to possible responses based on previous lessons (Van der Kolk, 2006). Patterns of interaction between attachment figures and the child appear to have a crucial role in the development of these processes throughout childhood (Cassidy & Shaver, 1999).

Before children have the ability to integrate their own flexible responses, the onus is on the caregiver to accurately assess when the child is experiencing distress and to change the conditions in order to restore homeostasis for the child (Van der Kolk, 2006). The child's repeated experience of having attachment figures correctly identify and provide relief from distress has a profound effect on modulation of autonomic arousal (Porges, Doussard-Roosevelt, Portales, & Greenspan, 1996). Cases where the attachment figure does not provide relief from distress can disrupt the child's ability to appraise his or her own internal state and execute actions necessary to restore his or her own homeostasis (Van der Kolk, 2006). An inability to identify physical and emotion sensations can then cause incongruent external responses and block the child's ability to receive comfort and support from caregivers (Van der Kolk, 2006).

The role of the Autonomic Nervous System in early brain development has been well documented (Van der Kolk, 2006). Consistent experiences of being comforted and soothed by a primary caregiver allows a child to quickly move from states of distress to emotional regulation. Exposure to physical or emotional threats or distress early in life, combined with a lack of soothing from caregiving responses, significantly influence the ability of the sympathetic and

parasympathetic nervous systems to modulate subsequent stress (Porges, Doussard-Roosevelt, Portales, & Greenspan, 1996). The sympathetic nervous system is responsible for the preparation of action in the body by increasing heart rate, blood flow, stimulating sweat glands and inhibiting gastrointestinal functions (Van der Kolk, 2006). The prolonged activation of the sympathetic nervous system can cause difficulty in one's ability to attend to inner sensations and perceptions and flexibly and logically respond to stimuli (Van der Kolk, 2006; Siegel 2011). The parasympathetic nervous system, by contrast, serves to inhibit sympathetic responses (Van der Kolk, 2006). The parasympathetic nervous system is comprised of two branches: the Ventral Vagal Complex (VVC) and the Dorsal Vagal Complex (DVC). While the DVC is primarily linked with digestion and taste in mammals, the VVC appears to be implicated in inhibiting the sympathetic nervous system response. Lack of VVC, therefore, is linked to lack of internal awareness of sensations as well as a lack of ability to respond to interpersonal comfort (Van der Kolk, 2006).

Memory is the vehicle through which the brain encodes past experiences and shapes future functioning (Milner, Squire & Kandel, 1998). Although explicit memory, or the ability to intentionally recall information, does not begin to develop until the middle of the second year of life, infants do have implicit memory that involves behavioral, perceptual, and somatosensory memory (Bauer, 1996). Implicit memory also includes the formation of mental models, or schemas that prime the brain for future response to specific cues (Schacter & Buckner, 1998). These primes can influence behavior and emotions in the present without conscious awareness of their connection to past experience (Siegel, 2001).

Children who develop a secure attachment to primary caregivers have been found to have many positive developmental outcomes including increased emotional regulation, response

flexibility, social functioning and cognitive abilities (Cassidy & Shaver, 2008). Children with insecure attachment styles, in contrast, are at risk for emotional rigidity, and problems with social functioning (Rosenblum, Coplan, Freidman, Basoff, Gorman & Andrews, 1994).

Health Behavior Frameworks for Studying Adherence in Children with AD

The development of a framework is a necessary tool for the scientific study of phenomena. The complex nature of adherence in AD creates difficulties in developing effective strategies to overcome adherence problems. A better understanding of the components of adherence behaviors can help to guide research in developing evidence-based interventions aimed at increasing adherence and thereby improving medical and psychological outcomes for both children with AD and their families.

Treatments for children with AD have many unique features. First, the cost and time associated with the arduous protocols in treatment of the disease places a significant amount of stress on the family unit with family's reporting a time investment of up to three hours per day (Kaugars et al., 2003; Kelsay, Klinnert & Bender, 2010). Also, the loss of sleep, fatigue and psychological distress on the child and parents may impact a family's ability to remain compliant (Carroll, Balkrishnan, Feldman, Fleischer & Manuel, 2005). Because responsibility falls to the parents in the majority of young children with AD, parental factors that inhibit or promote adherence behaviors must be considered. Finally, the child may interfere with the parent's ability to follow treatment protocols by such acts as refusing to allow the medicine to be applied or refusing bleach baths (Chisolm et al., 2009). Although adherence can be time consuming and expensive, poor adherence has been linked to both treatment failure and future issues with

treatment effectiveness (Feldman et al., 2007). Therefore, Chisolm et al. sought to develop a framework to better understand adherence behavior in children with AD (2009).

The Chisolm, et al. model of adherence integrates the major models used to describe patient health behaviors: the Health Belief Model, the Health Behavior Model, and Social Cognitive Theory. Each of these models seeks to describe factors that can influence adherence so that this information can inform treatment protocols. A description of each of these models and a review of the current literature regarding their efficacy will be further discussed in Chapter II. The Chisolm, et al., model outlines factors that influence adherence behaviors into external and internal factors (2009). This model assumes that people make rational choices based on an assessment of known or presumed costs associated with adherence behaviors relative to anticipated benefits. External factors contributing to the rational cost-benefit analysis made by families of children with atopic dermatitis include family employment, socioeconomic status, reminder systems, access to care, and education and communication. These external factors include contextual barriers in accessing care and can be good targets for adherence interventions.

Internal factors include perceived severity of illness, perceived benefits of treatment, perceived cost of treatment, trust in physician, and self-efficacy. These internal factors combine to shape individual assessments and appraisal of potential costs and benefits to adherent behaviors. The Chisolm model also takes into account the dynamic process of adherence behaviors in the context of reciprocal determinism which is a continuous interaction between the individual the environments and the behavior. Outcome of previous treatment may therefore effect subsequent adherence behavior. For instance, better initial outcomes of treatment may predict future adherent behaviors. Due to the unique nature of barriers in the treatment of children with AD, a specific health behavior model can help further guide adherence

interventions to deal with those specific barriers and thereby improve treatment outcomes (Chisolm et al, 2009).

Parent-Child Interactional Factors that Mediate Adherence Behaviors

As portrayed in the beginning quotes, AD affects the parent-child relationship in numerous ways. Parents discuss challenges disciplining their children, feelings of helplessness around their ability to soothe the child, and struggles with applying medication or giving baths that the child experiences as painful (Daud, Garrald & David, 1993; Chamlin, Frieden, Williams & Chren, 2004). The presence of AD in young children can make bonding experiences through touch be experienced as painful (Arndt, Smith & Tausk, 2008). Research has proposed that the decreased quantity and quality of maternal touch due to AD may effect child development (Balkrishnan, Housman, Carroll, Feldman & Fleischer, 2003; Howlett, 1999). The distress from intense itching causes disruptions in the sleep, development and emotional regulation of the children (Kelsay, Klinnert & Bender, 2010; Chamlin, Frieden, Williams & Chren, 2004). Families report higher stress levels due to sleep disturbances, expensive and time consuming medical protocols, and worry over the pain and distress of their children (Arndt, Smith & Tausk, 2008). Sleep disruptions alone have been demonstrated to have a direct correlation with maternal anxiety and depression scores (Moore, David, Murray, Child & Arkwright, 2006). Practical issues such as increased house cleaning to avoid allergens and extra laundry due to weepy and bleeding skin and greasy ointments further tax parents' limited time resources (Arndt, Smith & Tausk, 2008). Furthermore, parents report that their children with AD are more anxious, upset, dependent and demanding than other children (Faught, Bierl, Barton & Kemp, 2007). Parents discuss having to constantly hold the child's hands to avoid scratching and feeling unable to soothe the child's distress. They report feeling unable to discipline the child

due to the fear that upsetting the child will lead to scratching behavior (Chamlin, Freiden, Williams & Chren, 2004). And yet there has been no exploration to date of how these factors may affect a parent's ability to be aware of the child's medical regimen, recognize the importance of adherence, consistently invest in the time and finances to remain adherent, and compel the child to cooperate with treatment. There has also been no study of the interactional effects on the child's ability to trust parents in potentially painful procedures such as topical steroid application, behavioral management and ability to self-soothe that may play a role in the interactional process. Therefore, a greater understanding of the interactional factors affecting adherence behaviors needs to be developed and explored to further understand the impact they may have on medical adherence.

Atopic Dermatitis, like many other chronic illnesses in children, may serve to hamper the process of bonding between parent and child. Every child is born with the innate desire to be connected with others in order to provide the safety and security necessary for development (Bowlby, 1988). The attachment system between parent and child influences the child's ability to "regulate internal and external stimuli" (Ogden, Minton & Pain, 2006). An essential piece to the process of attachment is the primary caregiver's ability to modulate the child's arousal, ie. calming the child when the child is in distress (Schore, 1994). In children with chronic illness, especially those with chronic pain or distress, the ability of a caregiver to modulate the child's arousal may be severely limited, thereby impairing the attachment process. Also, a main vehicle used by primary caregivers in modulating the child's arousal is through holding and physical soothing (Brazelton, 1989). However, in the case of children with AD, physical touch may cause increased pain and discomfort to the child, thereby limited the caregiver's ability to soothe the child (Arndt, Smith & Tausk, 2008). There are parental factors that can also block the parent's

ability to remain attuned enough with his or her child in order to perceive information about the child's AD. Families with children with AD report increased stress due to many circumstances including increased parental responsibilities (ie. co-sleeping, hypervigilance in watching the child to prevent scratching, and increased financial and time burdens due to the condition) (Warschburger, Buccholz & Petermann, 2004; Balkrishnan, Housman, Carroll, Feldman & Fleischer, 2003).

The parent-child attachment has been linked to developmental factors such as emotional intelligence, self-esteem, cognitive abilities and social skills (Siegel, 2003). A sensitive parent-child bond that includes contingent communication and a sense of safety allows the child to grow and develop in optimal ways. With all children, but especially children with chronic, remitting diseases such as AD, flexible responding by parents is an essential tool to responding to varying situations. Parents with children of AD need to be able to decipher the child's current level of disease severity and distress as well as to decipher defiant or learned behaviors from those that are disease induced. For instance, sleep disturbances in children with AD are quite common during times of disease severity due to distress, but often remain long after the disease is in remission (Chamlin et al., 2005). This leads physicians to believe that although the sleep disturbances may begin out of need for comfort due to the distress of AD, they become a learned behavior that then must be managed. Response flexibility can be impaired at times of increased stress, tiredness, or anger (Siegel, 2003). Therefore, many conditions inherent in the childhood disease of AD may actually impede a parent's ability to respond flexibly and appropriately to medical protocols. The Parenting Stress Index (PSI) is used in this study to quantify the three separate domains of Difficult Child, Parental Distress and Parent-Child Dysfunctional

Interactions (Abidin, 1990; 1995). Each of these scales can then be assessed independently for their relationship to medical adherence behaviors.

Rationale for the Study

Numerous studies have focused on the parental characteristics that impact adherence behaviors, and yet adherence rates remain below 50%, with some studies showing mean rates of adherence at only 32% (Chisolm, Taylor, Grywacz, O'Neill, Balkrishnan and Feldman, 2009). Poor medical adherence has been linked to higher disease severity and can result in failure of topical treatments, leading to the use of more dangerous systemic medication (Ou, Feldman & Balkrishnan, 2010). Increasing adherence behaviors has been shown to decrease severity of disease and increase quality of life for both child and family (Nolan & Feldman, 2009; Greenlaw, Yentzer, O'Neill, Balkrishnan & Feldman, 2010). A clearer understanding of adherence behaviors can help guide clinical interventions to promote adherence behaviors (Chisolm et al., 2009; Nolan & Feldman, 2010).

Focus of the Study

The aim of this study was to develop a more in-depth understanding of the interactional factors that influence adherence behaviors. It sought to view adherence behavior as an interactional, dynamic process in order to change the dynamics necessary to increase medical adherence rates. Previous interventions seeking to effect adherence rates have focused exclusively on parent factors such as providing support groups or education (Blessmann Weber, Prati, Soirefman, Mazzotti, Barzenski, & Cestari, 2008; Staab et al., 2006). Studies such as this

one are seeking to understanding adherence as a dynamic and interactional process may help to guide interventions that can affect the parent-child interaction.

Need for the Study

Atopic Dermatitis is the most common inflammatory skin disorders in children in the U.S. with approximately 17% of children affected (Chamlin, Frieden, Williams & Chren, 2004). The prevalence of AD in children parallels similar increases in asthma, allergic rhinoconjunctivitis and gastroenteritis and is frequently the first disorder in the “atopic march.” Current studies are investigating the idea that prompt intervention of early AD in children may improve outcomes and decrease the clinical course of the atopic march (Boguniewicz, Eichenfield & Hultsch, 2003; Krakowski, Eichenfield & Dohil, 2008). Poor adherence to medical advice is common in families with children with AD, with average adherence rates being below 50% (Feldman, Camacho, Krejci-Manwaring, Carroll & Balkrishnan, 2007; Brown, Krejci-Manwaring, Tusa, Camacho, Alan, Balkrishnan & Feldman, 2008).

Despite the existence of many effective treatments for AD, low adherence rates result in poorly controlled disease in many children with AD (Chisolm, Taylor, Gryzwacz, O’Neill, Balkrishnan & Feldman, 2009). Poor adherence also leads to higher healthcare expenditures, more frequent hospitalizations, poorer quality of life for the children with AD and their family, and potential treatment failure, leading to potentially toxic systemic treatments (Feldman, Camacho, Krejci-Manwaring, Carroll & Balkrishnan, 2007). A greater understanding of the issues surrounding adherence in children with AD can serve to increase the quality of life for children and families with AD, decrease health expenditures, and possibly disrupt the atopic march.

Research Questions

Research Question I: What is the relationship between Difficult Child, Parental Distress, Dysfunctional Interaction and Total Parental Stress Scores and each of the six rates of medical adherence (Bleach baths, moisturizers, topical medications, wet wraps, other medications, removal of allergens)?

Research Question II: What is the relationship between Difficult Child, Parent Distress, Dysfunctional Interactions and Total Parental Stress scores and reasons for non-adherence behaviors?

Research Question III: Is there a correlation between parental rating of severity and physician rating of severity?

Research Question IV: Will the reasons provided by parents for medical non-adherence vary according to parent's rating of disease severity?

Research Question V: What is the relationship between physician-reported disease improvement and medical adherence rates on each of the six scales (Bleach baths, moisturizers, topical medications, wet wraps, other medications, and removal of allergens).

Research Question VI: What is the relationship between physician rating of adherence and parent-reported medical adherence rates on each of the six scales (Bleach baths, moisturizers, topical medications, wet wraps, other medications, and removal of allergens).

Operational Definitions and Measurements

Difficult Child: In this study, Difficult Child was defined as the parental perception of child characteristics that influence overall parental stress. Difficult Child Characteristics portrays parental ease or difficulty in gaining cooperation of the child as well as the child's ability to self-regulate emotions. Child characteristics are measured in 6 subscales: distractibility/hyperactivity, adaptability, reinforces parent, demandingness, mood, and acceptability. This was measured by 12 questions in one of four scales found in the Parenting Stress Index (Abidin, 1995).

Parent Distress: In this study, Parent Distress was defined as the parental perception of personality and situational factors that contribute to overall parental stress. The parent variables include 7 subscales: competence, isolation attachment, health, role restriction, depression, and spouse. This was measured by 12 questions in one of four scales found in the Parenting Stress Index (Abidin, 1995).

Parent-Child Interactional Stress: In this study, Parent-Child Interactional Stress was defined as the amount of emotional tension felt by the parent due to the relationship with the child. This was measured by the 12 question Dysfunctional Interaction Scale of the Parenting Stress Index-Short Form (Abidin, 1995).

Parent Total Stress: In this study, Total Parent Stress was defined as the sum total of the scores of the Difficult Child, Parent Distress, and Dysfunctional Interaction scale of the Parenting Stress Index-Short Form (Abidin, 1995).

Medical Adherence: For the purposes of this study, medical adherence referred to the extent to which the patient's (or caregiver's) treatment-related behavior is in concordance with

the provider's recommendation (Serup, Lindblad, Maroti, Kjellgren, Niklasson, Ring & Alner, 2006). The definition of medical adherence for Atopic Dermatitis was broken down into several categories typical for management of AD: bleach baths, application of moisturizers, application of topical medications, application of wet wraps, and other prescribed medication. Each subcategory included a question asking if the physician has prescribed these treatments and includes a Likert Scale measuring the amount of adherence to that particular category.

Chronic Disease vs. Acute Disease: Whether the disease is currently in a chronic or acute state was measured by two parent-reported Likert scale questions involving the degree of severity of the child's current condition (ranging from "None" to "Extreme Severity") and a question regarding the current state of the eczema ranging from "Better than Normal" to "At Its Worst". Also, chronic disease vs. acute disease was also indicated by the parental report of the reason for the doctor's visit as being "scheduled" or "emergency."

Summary

Atopic Dermatitis in children has significant impact on quality of life for both the child and family (Balkrishnan, Housman, Carroll, Feldman & Fleischer, 2003; Chamlin, Frieden, Williams & Chren, 2004). Despite the existence of effective treatments, low medical adherence rates prevent optimal management of the disease (Nolan & Feldman, 2007). Existing studies on adherence behaviors have viewed these behaviors in a linear manner, focusing exclusively on parental factors. This study sought to add to the current understanding of medical adherence behaviors by looking at the dynamic process of interaction between parent and child that can affect adherence behaviors.

CHAPTER II

LITERATURE REVIEW

The current study focused on the effect of parent-child interactional factors on medical adherence rates in children with Atopic Dermatitis. The purpose of this chapter is to provide an overview of the research on Atopic Dermatitis, medical adherence factors, and parent-child attunement. Current research on the diagnosis, causes and treatment of Atopic Dermatitis will be discussed as well as the impact of the disease on children and families. Also, existing literature on frameworks on medical adherence in children with AD will be provided. Finally, a review of current literature on attachment and interpersonal neurobiology will be discussed, including the effects of attunement on medical adherence and emotional regulation as well as the impact a chronic illness may have on the attunement process.

Atopic Dermatitis

Atopic dermatitis, or eczema, is often called the “itch that rashes” (Boguniewicz, 2005; Kelsay, Klinnert, Bender, 2010). It is an inflammatory skin disease that affects nearly one in five U.S. children (Chamlin, Frieden, Williams & Chren, 2004; Laughter, Istvan, Tofte & Hanifin, 2000; Asher, Montefort, Bjorksten, Lai, Strachen & Weiland, 2006). Although previously viewed as a minor skin disorder, it has now been labeled a global health concern due to the impact on quality of life for the child and the family as well as the financial costs to health systems (Shaw, Currie, Koudelka & Simpson, 2010). The misery of living with atopic dermatitis greatly affects quality of life for children and their families, with the family impact being greater than that of childhood-onset, insulin-dependent diabetes mellitus (Su, Kemp, Varigos & Nolan, 1997; Lewis-Jones, 2006). Most children with AD (approximately 85%) develop the disease

within the first 5 years of life during a critical time of physical and psychosocial development. AD has been found to cause psychosocial, behavioral and emotional disturbances that last long past the disease's remission (Chamlin & Chren, 2012; Krakowski, Eichenfield & Dohil, 2008).

Atopic Dermatitis is an itching skin condition in which at least five of the following five criteria have been met: 1) Involvement of skin creases (or flexoral folds) including elbows, ankles, knees or neck; 2) History of asthma or hay fever; 3) History of generally dry skin lasting at least one year; 4) Visible rash or dermatitis in the cheeks, forehead or out limbs if child is under age 4 and 5. Typical onset under the age of 2 (Schafer, 2006). About 60% of cases begin within the first year of life and 90% begin within the first five years (Laughter, Istvan, Tofte & Hanifin, 2000). AD is viewed as a chronic relapsing disease with three stages: acute, subacute and chronic. The acute stage includes red, scaly skin with vesicles that rupture and weep from scratching (Raimer, 2000). The subacute stage involves skin with mild scaling and lichenification (thickening or hardening of the skin). Finally, the chronic stage includes prominent scaling with lichenification (Raimer, 2000; Carroll, Balkrishnan, Feldman, Fleischer & Manuel, 2005). The severity of the disease can vary from mild to severe. While patients with mild disease are more likely to experience remission, patients with moderate to severe disease have a greater chance of experiencing long-term, remitting symptoms (Kelsay, Klinnert & Bender, 2010).

Pruritis, or intense itch, is the most common symptom of children with AD presenting to dermatology clinics (Weisshaar & Dalgard, 2009). Pruritis is typically experienced as incredibly distressing and shares similar neural passageways with chronic pain (Latremoliere & Woolf, 2008). The itch then provokes scratching, especially in young children. This scratching can cause trauma to the skin, damaging the epithelial barrier and its function (Kircik, 2011). The

epithelial barrier controls the entry of external irritants and allergens into the system (Spergel, 2010). This damage to epithelial barrier leads to greater exposures to irritants, intensifying pruritis and creating the “itch-scratch cycle” (Kircik, 2011, p. 48). Pruritis has also been associated with sleep disruption, decreased attention, poor academic performance and a decrease in overall quality of life (Kelsay, Klinnert & Bender, 2010). Scratching can cause ruptures and disfigurement to the skin as well as decreasing the skin’s ability to ward off infection (Sack & Hanifin, 2010). The ruptures in the skin have been found to increase the risk of colonization of the *Staphylococcus Aureus* bacteria in children with AD (Hauser, Wuethrich, Matter, Wilhelm, Sonnabend & Schopfer, 1985). Scratching behavior tends to increase at night, causing sleep disturbances as the child, either consciously or unconsciously, scratches so intensely that the skin excoriates and bleeds (Sack & Hanifin, 2010). The parental rating of intensity of pruritis has been negatively correlated with ratings of quality of life for both children and parents (Kelsay, Klinnert & Bender, 2010).

The causes of AD are not well understood. The prevailing view is that multi-factorial causes such as genetic predispositions, environment, immunologic functioning and psychological components underlie the development of AD (Novak, 2009; Arndt, Smith & Tausk, 2008). The largest risk factor for the development of AD appears to be family predisposition, which seems to be transmitted through expression of multiple genes (Novak, 2009; Schafer, 2006). A study from a national survey conducted in 2003 found single mother households, higher socioeconomic status, and African American race are all risk factors for the disease (Shaw, Curris, Koudelka & Simpson, 2010).

Several environmental factors have been shown to predict AD. Higher prevalence rates of AD have been found in metropolitan or urban areas (Shaw, Currie, Koudelka & Simpson,

2010). Potential explanations for this include environmental pollution (Asher, et al. 2006), lack of exposure to microorganisms as compared to rural farming areas (von Hertzen & Haahtela, 2006) and increased hygiene such as increased washing and bathing of young children (Sherriff & Golding, 2002). Exposure to air-born allergens such as pets, dust mites and pollen has also been shown to increase severity of AD (Capristo, Romei, Boner, 2004).

Several new studies have shown a link between several innate immune system defects and the development of AD (DeBenedetto, Agnihotthri, McGirt, Bankova & Beck, 2009). AD consists of an overactive immune response to nonspecific stimuli (ie. non-harmful environmental factors) (Leung & Bieber, 2003). This immunological hyper-reactivity to environmental triggers is considered the first step in an Atopic March that can result in asthma and allergies (Arndt, Smith & Tausk, 2008). The severity of AD was found to be positively correlated with future development of asthma and allergic rhinitis. Gustaffson et al. showed that 50% of children with severe AD eventually developed asthma and 75% developed allergic rhinitis (Gustaffson, Sjoberg & Foucard, 2008). Ricci et al. found similar results, with 59% of children with severe AD developing asthma throughout childhood (2006). However, the percentage dropped to 25% of those with moderate AD and 33% of those with mild AD developing asthma (Ricci, Patrizi, Baldi, Menna, Tabanelli & Masi, 2006). There is some evidence that the defect in the epithelial skin barrier in AD can initiate systemic sensitization to external allergens, thereby contributing the onset and progression of the atopic march (Spergel, 2010). It is hypothesized that treatment aimed at better maintenance of the epithelial barrier in AD can minimize or halt the progression of the atopic march (Spergel, 2010).

Psychological factors have been proposed to play a causal factor in the development of AD. One current theory posits that AD is a stress-responsive disorder that involves automatic

nervous system dysfunction (Tran et al., 2010). Laboratory studies found that subjects with AD showed overactive sympathetic response to itch compared to healthy controls (Tran et al., 2010). Also, patients with AD have been shown to have altered heart rate and vagal tone dysfunction even in the absence of acute stressors (Boettger, Bar, Dohrmann, Muller, Mertins, Brockmeyer & Agelink, 2009). Although a single, causal relationship was assumed between AD and psychological dysfunction wherein the disease was presumed to cause psychological symptoms, recent theories argue for a more interactive relationship (Kelsay, Klinnert & Bender, 2010). Although it remains clear that AD causes burden and stress to both children and families with the disease, stress, in turn, has shown to have an impact on disease severity and symptomatology (Kelsay, Klinnert & Bender, 2010; Arndt, Smith & Tausk, 2008). Stressful events have been found to precede exacerbations of flare-ups and increased scratching behavior (Arndt, Smith & Tausk, 2008). Patients with AD have been found to have a persistent sensitization of the HPA axis, leading to an exaggerated cortisol response to stress (Wright, Cohen & Cohen, 2005). The hypothalamic-pituitary-adrenal axis (HPA axis) controls the body's response to stress and regulates many body functions including digestion, mood, and automatic nervous system functioning. Exposure to stressors early in life have been theorized to lead to persistent sensitization of the HPA axis, which then increases vulnerability to stressful events later in life (Heim et al. 2000). The impact of chronic stress on the HPA axis has been linked to anxiety, depression and immunoregulatory responses (Leonard, 2005; Buske-Kirschbaum, Geiben, Hollig, Morschhauser & Hellhammer, 2002). HPA axis responsiveness has been linked to increased susceptibility of allergic inflammation (Buske-Kirschbaum, Geiben, Hollig, Morschhauser & Hellhammer, 2002). In this way, it is theorized that increased HPA axis

responsiveness may explain the positive correlation between psychological stress and flare-ups, which can influence the course of the disease (Blessman-Weber et al., 2008).

Although the causes of AD are complex and poorly understood, it is clear that AD is a chronic, remitting disease that requires consistent management in order to reduce disease severity and possibly limit the progression of the atopic march (Spergel, 2010). Maintaining epithelial barrier integrity, decreasing pruritis, and limiting the amount of allergens that invade the epithelial barrier are all key components of treating AD.

Treatment of Atopic Dermatitis

There are six main areas included in medical protocols for the treatment of Atopic Dermatitis: bleach baths, moisturizers, topical steroids, removal of triggers including dust mites and allergens in the environment, wet wraps, and other medications. Each of these protocols serve independent functions in decreasing the severity of the Atopic Dermatitis by reducing symptoms of the disease, decreasing the degree and frequency of flares, and possibly slowing the progression of the atopic march (Ellis et al., 2003).

Bleach bath regimens include adding $\frac{1}{4}$ to $\frac{1}{2}$ cup of common bleach to bath water and having the child soak in the bath for 15 to 20 minutes. The purpose of bleach baths are to decrease the number of local skin infections in order to reduce the need for systemic antibiotics used to treat these infections (Krakowski, Eichenfield & Dohil, 2008). Patients with AD have a high risk of Staphylococcus Aureus infections that can also serve to cause a sudden flare-up of AD symptoms (Metry, Browning and Rousseau, 2007).

Moisturizers are prescribed at least twice per day after topical medications. (Krakowski, Eichenfield & Dohil, 2008). They should be dye-free and fragrance-free. Daily moisturizers are

thought to improve AD symptoms by retaining moisture in the skin. Atopic skin typically has impaired functioning of the water permeability barrier (Boguniewicz, Eichenfield & Hultsch, 2003). Moisturizer use has been shown to decrease the need for topical steroids (Lucky, Leach, Laskarzerwski & Wench, 1997).

Topical corticosteroids are used to control flare ups due to their anti-inflammatory and immunosuppressive responses (Bewley, 2008). Corticosteroid medications vary in potency and can be tailored to the current state of the skin barrier, the current severity of the disease, the age of the patient and the duration of treatment needed (Krakowski, Eichenfield & Dohil, 2008). Possible side effects of topical steroids are numerous, including skin atrophy and thinning, HPA axis suppression, growth retardation and reduced bone density (Hanifin et al., 2004). Another concern is a risk of flare-up after discontinuation of treatment (Krakowski, Eichenfield & Dohil, 2008). However, these risk factors have been found to be rare when the medications are used properly (Callen et al., 2007). Physicians tailor quantity, frequency, and duration of steroid treatments to the specific case.

The avoidance of triggers and removal of allergens can help to eliminate certain specific triggers that can exacerbate AD symptoms. Triggers vary from patient to patient and the role of aeroallergens, such as dust mites or animal dander, remains unclear (Dohil & Eichenfield, 2005). However, potential triggers may include toiletries containing alcohol or fragrances, wool or synthetic clothing, carpets, dander-producing pets, and some food allergens such as soy or eggs (Krakowski, Eichenfield & Dohill, 2008). Also, removal of carpets, cleaning rooms daily, and use of anti-mite bedding for the child are typical mite-avoidance protocols (Ohya et al., 2001).

Wet wraps are typically prescribed following the application of topical steroids. The wet wraps consist of a bottom (wet) and top (dry) layers. The bottom layer of gauze is soaked in warm water and wrapped over the affected area(s). The top layer, which can be clothing, is immediately placed over the wet layer. The wraps can be left on overnight and applied daily when needed. Wet wraps aid in maintaining skin hydration as well as serving as a barrier to scratching (Krakowski, Eichenfield & Dohill, 2008).

Finally, other medications can be used in the treatment of symptoms for AD. Failure of topical steroids can result in use of systemic medications. Immunomodulatory agents such as cyclosporine intravenous Ig and methotrexate are used in the treatment of severe AD (Boguniewicz, Eichenfield & Hultsch, 2003). These systemic agents have significant risk factors and require consistent monitoring (Boguniewicz, Eichenfield & Hultsch, 2003).

The above combination of treatment protocols has been found to be quite effective in the management of AD. For example, topical corticosteroids have been found to be highly effective in clinical trials (Krakowski, Eichenfield & Dohil, 2008). However, AD in many children remains poorly controlled, leading to higher levels of distress for both the child and caregivers (Chisolm, Taylor, Grywacz, O'Neill, Balkrishnan & Feldman, 2009). Once these children are admitted to a hospital where medication is applied in adherence with medication protocol and triggers such as dust mites and other allergens are successfully avoided, the skin rapidly clears, leading providers to question the reasons for poor adherence at home (Ohya, et al., 2001). Poor adherence is common due to a variety of possible factors, including lack of time, financial resources or social support to follow through with the protocol, fear of side effects of medication, or a lack of understanding regarding the application of the medication (Fenerty, O'Neill, Gustafson & Feldman, 2013). Also, children may refuse to allow the application of the

medication which can sometimes be uncomfortable or painful (Chisolm, Taylor, Grywacz, O'Neill, Balkrishnan & Feldman, 2009).

Medical Adherence

Atopic dermatitis is a chronic relapsing disease which can be exacerbated by poor adherence to medical advice (Ben-Gashir, Seed & Hay, 2004; Ohya, et al., 2001). Adherence refers to the extent to which the patient's (or caregiver's) treatment-related behavior is in concordance with the provider recommendations (Serup et al., 2006). Treatment protocols for children with AD take a great deal of time and energy. Parents of children with moderate to severe AD report spending approximately 3 hours per day caring for their child's skin (Su, et al., 1997; Kelsay, Klinnert & Bender, 2010).

Lack of adherence to treatment protocols for AD cause a poorer prognosis not only for the skin but also for the physical, psychological and socioemotional disturbances it causes in children and families. Higher levels of adherence have been found to correlate with a reduction in severity of the disease, especially in initially severe cases (Krejci-Manwaring et al., 2007). Ben-Gashir et al. found a positive correlation between the child's quality of life score and improvements in disease severity (Ben-Gashir, Seed & Hay, 2004). Better control of AD symptoms at the onset of the disease has also been hypothesized to reduce the chances of the atopic march (Spergel, 2010). Therefore, increasing adherence behaviors is a key component in improving the physical and psychological health for children with AD and their families.

Despite the clear benefits of medical adherence in children with AD, the rates of adherent behavior have been labeled "abysmal" (Fenerty, O'Neill, Gustafson & Feldman, 2013, p. 229).

Approximately one-third to one-half of patients prescribed medication for chronic

dermatological conditions are non-adherent (Serup et al., 2006). Poor adherence to protocols can result in failure of topical treatments, leading to use of more dangerous systemic medications (Ou, Feldman & Balkrishnan, 2010). Research has continually shown adherence rates with AD to be below 50%, with some studies reporting rates as low as 32% (Krejci-Manwaring, et al., 2007; Nolan & Feldman, 2009). Traditional methods for measuring adherence have included patient self-report, physician estimates, pill counts, and electronic monitoring (Osterberg & Blaschke, 2005). The Medication Electronic Monitoring System (MEMS) documents actual use patterns by recording the date and times at which the medication is opened. MEMS is considered the gold-standard of monitoring patient adherence, however it is expensive and not always practical (Osterberg & Blaschke, 2005). MEMS also does not identify barriers to adherence behaviors because it simply measures usage. Self-report measures are quick and inexpensive, but consistently showed that patients and caregivers over-report adherence behaviors (Hodari, Nanton, Carroll, Feldman & Balkrishnan, 2006). However, self-report measures also have the added benefit of identifying barriers to adherence that are currently poorly understood (Greenlaw, Yentzer, O'Neill, Balkrishnan, & Feldman, 2010).

Given the importance of adherence to medical protocol for the treatment of AD as well as the quality of life for the child, assessing impediments to medical adherence is crucial to promoting optimal outcomes to the health and well-being of children with AD. Medical protocols can be time-consuming with skin care routines, extra housekeeping and laundry to avoid potential allergens and irritants, and life-style constraints such as special diets or avoidances of situations that could increase allergen exposures such as pets (Lawson, Lewis-Jones, Finlay, Reid & Owens, 1998).

Reasons for non-adherence have been historically broken into three groupings: socioeconomic, cognitive and psychological factors (Hodari, Nanton, Carroll, Feldman & Balkrishnan, 2006). Socioeconomic factors include the costs of medications, disruptions in social functioning due to time-consuming protocols and cultural factors. Cognitive factors include lack of understanding the treatment plan or lack of baseline knowledge of the disease. Psychological factors include a sense of helplessness due to previous treatment failures or a state of apathy on the part of the patient or family (Hodari, Nanton, Carroll, Feldman & Balkrishnan, 2006). Quality of life has been shown to be negatively correlated with adherence behaviors (Renzi et al., 2002). Specifically in children with AD, mother's perception of the severity of the disease has been shown to be a strong predictor of medical adherence (Fischer, 1996). Although parents report fear around the side effects of steroid use, studies have shown that the anxiety does not interfere with adherence behaviors (Charman, Morris & Williams, 2002). Finally, the loss of sleep, fatigue and psychosocial distress for both the child and caregiver has also been cited as obstacles for medical adherence (Chisolm, Taylor, Gryzwacz, O'Neill, Balkrishnan & Feldman, 2009; Carroll, Balkrishnan, Fleischer, & Manuel 2005).

Frameworks for Adherence Behaviors

Treatments for children with AD have many unique features. First, the cost and time associated with the arduous protocols in treatment of the disease places a significant amount of stress on the family unit with family's reporting a time investment of up to three hours per day (Kaugars et al., 2003; Klinnert, Price, Kelsay, Klinnert & Bender, 2010). Also, the loss of sleep, fatigue and psychological distress on the child and parents may impact a family's ability to remain compliant (Carroll, Balkrishnan, Feldman, Fleischer & Manuel, 2005). Because responsibility falls to the parents in the majority of young children with AD, parental factors that

inhibit or promote adherence behaviors must be considered. Finally, the child may interfere with the parent's ability to follow treatment protocols by such acts as refusing to allow the medicine to be applied or refusing bleach baths (Chisolm et al., 2009). Although adherence can be time consuming and expensive, poor adherence has been linked to both treatment failure and future issues with treatment effectiveness (Feldman et al., 2007). Therefore, Chisolm et al. sought to develop a framework to better understand adherence behavior in children with AD (2009).

The Chisolm, et al. model of adherence integrates the major models used to describe patient health behaviors: the Health Belief Model, the Health Behavior Model, and Social Cognitive Theory (2009). Each of these models seeks to describe factors that can influence adherence so that this information can inform treatment protocols. Due to the unique nature of barriers in the treatment of children with AD, a specific health behavior model can help further guide adherence interventions to deal with those specific barriers and thereby improve treatment outcomes (Chisolm et al, 2009).

The Health Belief Model (Table 1) argues that patients (or caregivers) make a rational assessment regarding adherent behavior based on their assessment of perceived costs and benefits. Inherent in this assessment is 1) the patient's perception of his or her susceptibility to a disease (or, when the diagnosis has already been made, the estimate of the susceptibility of the consequences of the disease), 2) the patient's perception of the severity of the illness, 3) the effect on his or her quality of life, 4) the perception of the potential benefit of prescribed treatment, 5) and the perception of the barriers to that treatment (including cost and time constraints) (Champion & Skinner, 2008). Later Health Belief Models also included self-efficacy (the extent to which the patient believes him or herself to be capable of performing the

prescribed tasks) and cues to action (strategies that activate readiness to complete tasks) (Chisolm et al., 2009).

Several critical reviews of Health Belief models were conducted between 1974 and 1984 (Champion & Skinner, 2008; Becker, 1974; Janz & Becker, 1984). These reviews showed significant support for the model in both retrospective and prospective studies with perceived barriers being the single most powerful predictor of behavior across all studies (Champion & Skinner, 2008). The construct of self-efficacy was found to be predictive of breast mammography use (Champion, Skinner and Mennon, 2004) as was perceived susceptibility, lower benefits, higher barriers, and action cues (Champion, 1984; Champion & Menon, 1997; Champion, Ray, Heilman & Springston, 2000; Friedman, Neff, Webb & Latham, 1998).

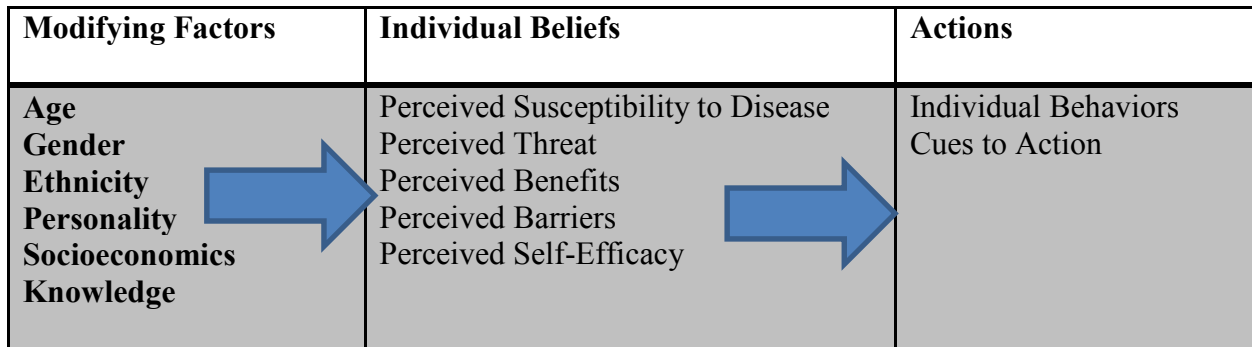


Figure 1: Health Belief Model

While the Health Belief Model concentrates on the internal factors that may predict adherence, the Health Behaviour Model emphasizes the external factors at play in adherence (Chisolm et al., 2009). These contextual factors include characteristics of the patient and caregiver as well as factors in the healthcare system that may promote or suppress patient adherence (Aday & Andersen, 1974). Patient characteristics involve resources specific to the

individual or family (such as education, income or insurance) as well as resources available in that patient's community (such as access to care) (Aday & Andersen, 1974). These external factors may be especially good targets for adherence interventions due to the feasibility of changing them at a practice level (Chisolm et al., 2009). Therefore, it is necessary to consider both internal (Health Behavior Model) and external (Health Belief Model) factors when attempting to understanding adherence behaviors (Figure 2).

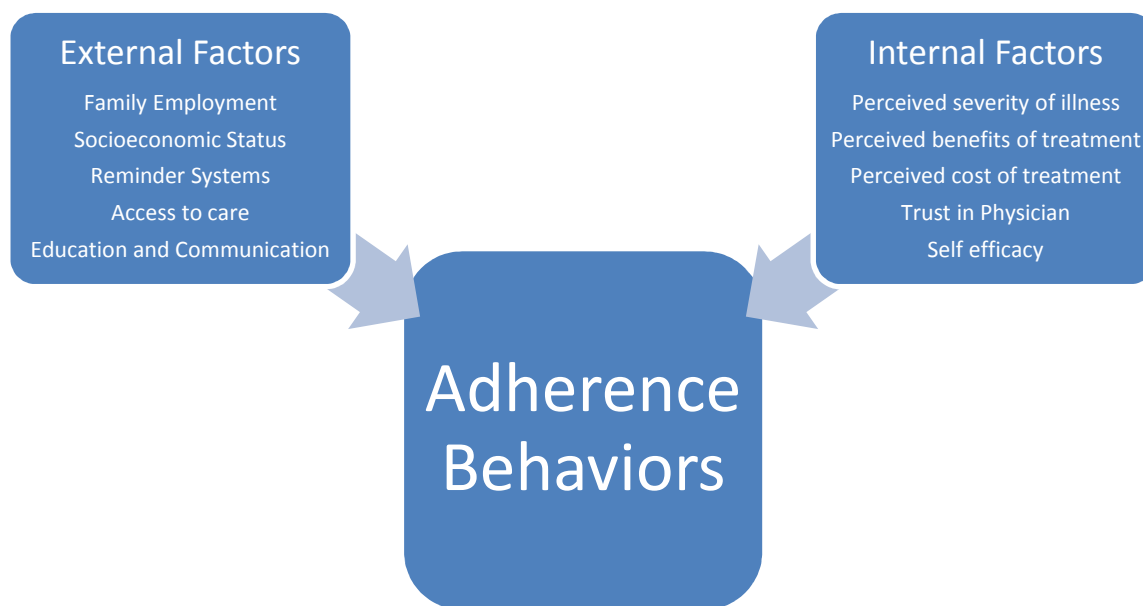


Figure 2. Integration of Health Belief Model and Health Behavior Model

Finally, Chisolm, et al. includes Social Cognitive Theory (Figure 3), which focuses on the dynamic relationship between person, environment and behavior (Chisolm et al., 2009; Bandura, 1986). In the specific case of medical adherence, Social Cognitive Theory helps to explain the reciprocal relationship between treatment outcomes and adherence behavior. Specifically, initial successes or failures in treatment may predict subsequent adherence behavior. Initial successes, for instance, may increase adherence behaviors despite time and

financial costs. Initial failures, on the other hand, may decrease adherence behaviors when time and financial costs outweigh expected benefits, thereby limiting the effectiveness of later treatment protocols. Due to the chronic and remitting nature of AD, the dynamic and reciprocal relationships between behavior, outcome and future behavior must be taken into account. Also, the effect that initial successes may have on internal (parental self-efficacy, perceived benefit of treatment, trust in physician) and external factors (parent's ability to work to maintain income and health insurance) are also important.

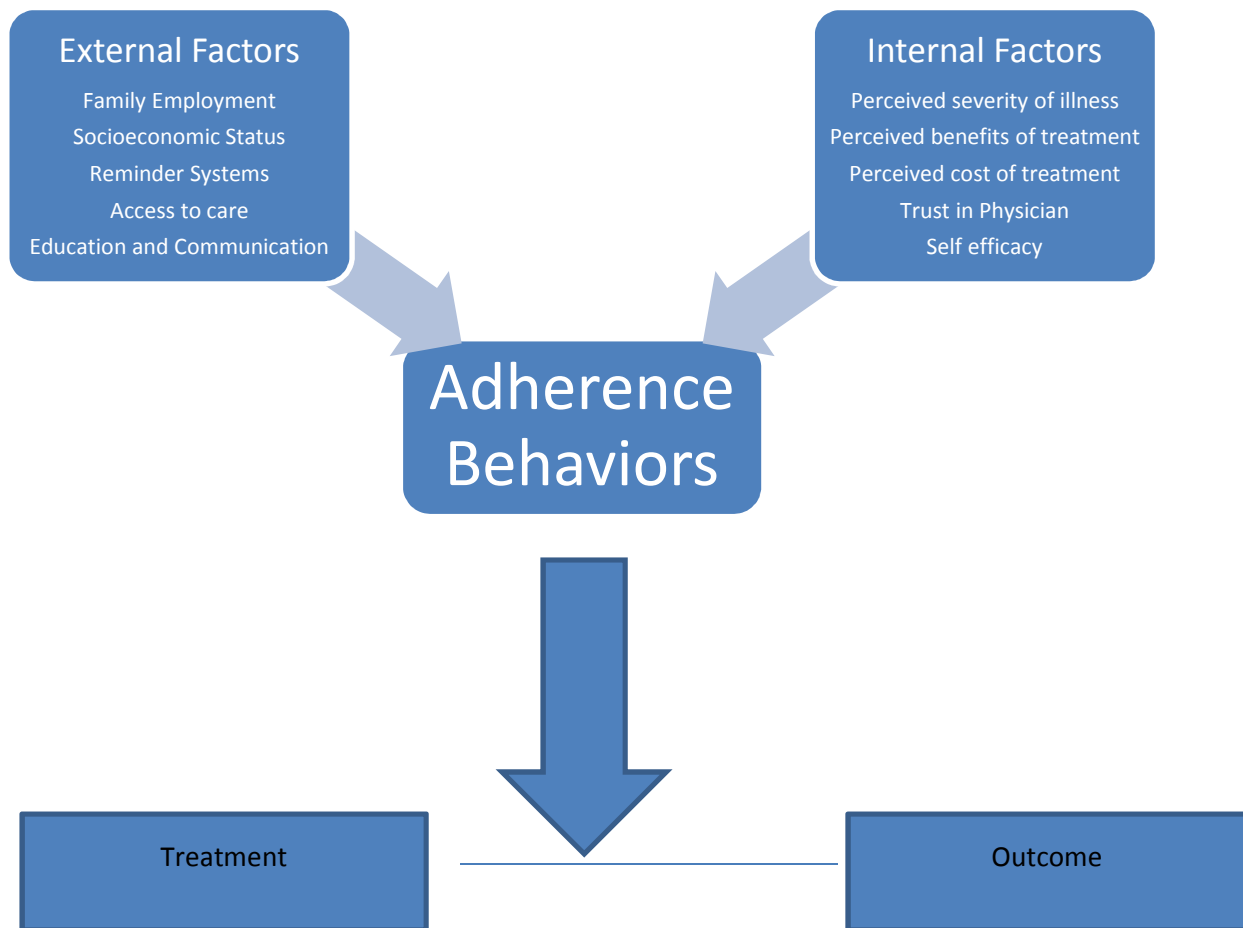


Figure 3. Integration of Health Belief Model, Health Behavior Model and Social Cognitive Theory (Chisolm et al., 2009)

Chisolm et al.'s model integrates internal and external parental factors as well as addressing the reciprocal nature of previous outcomes and future adherence behaviors. The awareness of these factors have allowed for tailored interventions in education and support groups for the parents (Blessmann Weber et al., 2008). Specific child factors such as child's level of discomfort, sensory hypersensitivity or sleep disruptions may influence the parent's ability to compel the child to participate in treatments. This study seeks to explore additional factors affecting medical adherence that are not currently identified in existing models. Despite anecdotal support that parent-child interactions impact medical adherence, these factors are not included in the Chisolm et al. model (2009). Parents report several interactional reasons for non-adherent behaviors, including "[I] resent child lay attitude about his/her own treatment", "My child is reluctant to take a bath", and "I can do nothing without my child's own coping" (Ohya, et al., 2001). Difficulties in parenting strategies and anxiety around ineffective parenting have been found in multiple studies but have never been linked to adherence behaviors (Daud, Garralda & David, 2003; Balkrishnan, Housman, Carroll & Feldman, 2003). Age has begun to be discussed as a possible factor discussing that as a child becomes more mobile or oppositional, parents may experience more difficulty in compelling the child to participate in adherent behaviors (Ou, Feldman & Balkrishnan, 2010) Therefore, the addition of parent-child interactions can provide a more comprehensive view of the nature of adherence behaviors (Figure4).

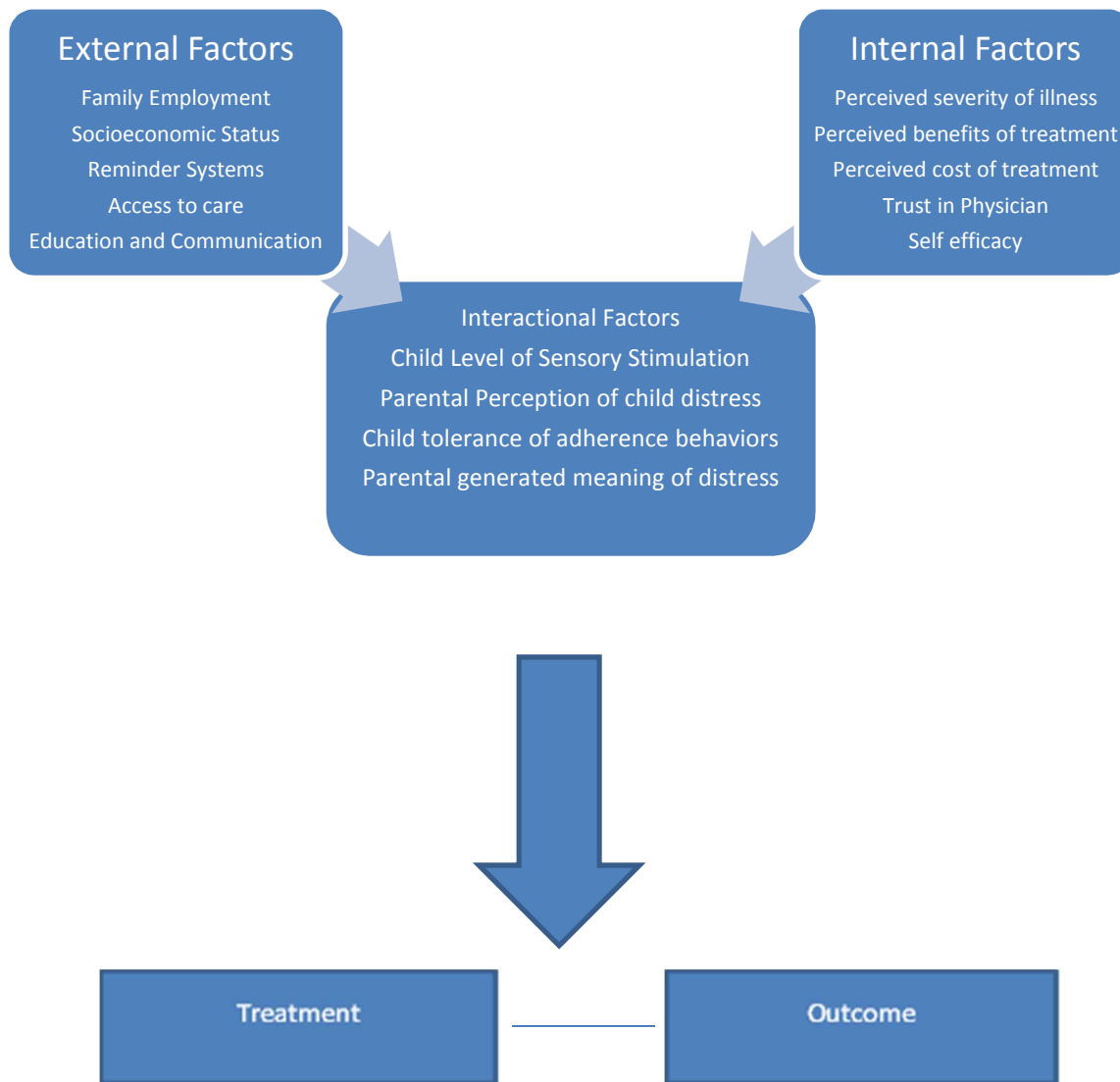


Figure 4: Proposed Comprehensive Model of Adherence Factors

Finally, the existing framework for medical adherence does not account for any differences that may occur in adherence behaviors during times of stable disease versus ‘flare-ups’ (Chisolm et al., 2009). This absence remains despite parental responses that parents report an influence of overall disease severity on disease management (Warschburger, Buchholz &

Petermann, 2004). A greater understanding of how adherence behavior changes during the different stages of this chronic, remitting disease can help further guide interventions tailored to each level of disease severity.

Child Impact of Atopic Dermatitis

Studies using the Children's Dermatology Life Quality Index (CDLQI) have shown that the majority of children with AD are affected by the disorder and that their quality of life continues to be impacted even when no visible evidence of the eczema exists (Ben-Gashir, Seed & Hay, 2004). Children with AD have been shown to have an increased risk of difficulties in the development of physical, emotional and social functioning (Chamlin, Frieden, Williams & Chren, 2004). This disruption in development is most often attributed to pruritis that is experienced as intense and distressful (Krakowski, Eichenfield & Dohil, 2008). Pruritis has also been linked to diminished sleep and disturbed sleep patterns in up to 60% of children with AD (Lewis-Jones, 2006). Sleep disturbances include difficulty in getting the child to sleep, frequent night-wakening, and reduced overall sleep (Reid & Lewis-Jones, 1995). These sleep disturbances persist during times of disease remission, leading to a hypothesis that these sleep disturbances may become a learned pattern (Reuveni, Chapnick, Tal & Tarasiuck, 1999). AD in children can disrupt the development of sleep patterns, emotional development, behaviors and relationships (Chamlin, 2006). Parents of young children with AD describe excessive dependency, hyperactivity and scratching to get attention (Chamlin, Frieden, Williams & Chren, 2004; Daud, Garralda & David, 1993). Children with AD display problems with attention, disruptive behaviors, emotional sensitivity and restlessness in accordance with ADHD symptomatology (Roth, Beyreiss, Schlenzka & Beyer, 1991). Psychosocial issues include excessive clinginess, dependency and fearfulness (Chamlin, Frieden, Williams & Chren, 2006).

Sleep disturbances have been positively correlated with behavior and discipline problems in children with AD (Dahl, Bernhisel-Broadbent, Scanlon-Holdford, Sampson, & Lupo, 1995).

Family Impact of Atopic Dermatitis

The effects of childhood AD expand to affect the well-being of parents in the dimensions of emotional, financial, physical and social well-being (Chamlin, Frieden, Williams & Chren, 2006; Su, Kemp, Varigos & Nolan, 1997). Mothers with young children with AD report a decrease in ability to work outside of the home as well as poor social support and difficulty with discipline (Daud, Garralda & David, 1993). Mothers caring for children with AD lose approximately 39 minutes of sleep per night while fathers lose approximately 45 minutes per night. This loss of sleep is positively correlated with anxiety for fathers and anxiety and depression for mothers (Moore, David, Murray, Child, & Arkwright, 2006). Parents report increased sadness, crying and blame toward self or their atopic spouse for their child's illness (Chamlin & Chren, 2010). Parents worry about medical costs as well as the changes to environment and lifestyle that are necessary in the treatment of AD. Parents express concern that covering or holding the child's hands as a way to prevent scratching may impede normal development activities (Chamlin, Frieden, Williams & Chren, 2004). Additionally, they voice concern about the use and side effects of using topical steroids to treat the condition (Charman, Morris & Williams, 2002). Negative reactions of family, friends and the public to the child with AD can serve as another emotional stressor and often evoke feelings of sadness, helplessness and frustration and can cause social isolation. Parents describe accusations of child abuse and neglect from strangers along with unsolicited advice (Chamlin, 2006). Psychological distress and parenting difficulties are the common causes of concerns for parents, with positive

correlations between parental concern and parental perception of severity (Balkrishnan, Housman, Carroll & Feldman, 2003).

Parent-Child Interactional Impact of Atopic Dermatitis

Although many studies have examined the effects of AD on both children and caregivers, very few have focused on the impact of AD on the parent-child relationship. However, mothers of children with AD report greater amounts of stress in parenting and being less effective in their parenting strategies (Daud, Garralda & David, 1993). They expressed concern about how the child's AD affects their relationship and their ability to parent their child (Kelsay, Klinnert & Bender, 2010). Mothers report these children as being clingy and fearful as well as having increased behavioral problems (Daud, Garralda & David, 1993; Faught, Bierl, Barton & Kemp, 2007). Parents describe the child with AD as often being naughty, distressed and irritable with less positive behaviors (Lawson, Lewis-Jones, Finlay, Reid & Owens, 1998; Pauli-Pott, 1999). Most mothers rated their children as being very demanding (67%) as well as inadaptable (56%) in infancy (Pauli-Pott, 1999). Parents of children with moderate to severe atopic dermatitis consistently report high levels of stress related to the treatment as well as intense feelings of helplessness (Lawson, Lewis-Jones, Finlay, Reid & Owens, 1998). Also, parental mental health and family functioning have been found to explain 10% to 36% of variation in disease management (Warschburger, Buccholz & Petermann, 2003).

Effects of Illness on Process of Attunement

Connection with others is not only necessary for language and cognitive development, it is also crucial for the development of emotional regulation and modulation of internal stimuli (Siegel & Bryson, 2011). Parent-child attunement requires alignment, or the empathetic

mirroring of a parent's state to that of the child. Parents are then able to provide a holding environment in which the parent can demonstrate recognition of the child's physiological state and can convey his or her ability to manage the child's needs adequately (Winnicott, 1990). In order to effectively create this holding environment, a parent needs to be able to "stay with" the child in his or her state of distress and dysregulation (Schore, 2003). This process is necessary for parents to be able to match their child's level of voice tone, volume, touch, expression, etc. and then bring the child "down to a calmer state" (Siegel, 1999, pp. 280-281). However, for children with chronic distress due to pruritis, the ability of the parent to calm the child may be severely hampered due to the chronic state of the distress, the limitations to physical soothing, and the parent's ability to tolerate such long term distress.

Healthy parent-child relationships have cycles of attunement and misattunement that are adapted to the needs of the child (Siegel & Hartzell, 2003). However, sometimes misattunement happens at times when the child needs connection. Bowlby theorized that children sought proximity to caregivers during times of increased danger or threat (Bowlby, 1977). Chronic illnesses, especially those that include chronic pain or distress, may serve to increase a child's need for attunement and proximity seeking. Parents report experiencing their children with AD as clingy, dependent and fearful (Faught, Bierl, Barton & Kemp, 2007) Misattunement, in these situations, can serve to hyper-activate the attachment system of the child. Parent-child relationships can be incredibly resilient to periods of misattunement when repair is made quickly and consistently. However, several factors may block either person's ability to repair the relationship and return to a state of attunement. Specific to children with AD, the parent may be unable to tolerate the increased needs and distress of the child. The child with AD may also experience sensory processing issues that block his or her ability to regain attunement.

The hampering effects a disease such as childhood AD can have on the process of parent-child attunement along with the added stress to the family can set up interactional patterns that are less positive or satisfying to both parent and child. Although much of the research regarding the attachment process of children with AD has focused on parental stress and response, it is important to note that the process of attunement is a two-way process defined as mutual emotional regulation ((Daud, Garrald & David, 1993; Tronick, 1989). Attunement can be defined by Stern as the intersubjective sharing of affect wherein the parent and child must work together to understand each other's verbal and non-verbal cues (1985). Understanding both sides of the attunement process can aid in a better understanding of ways to develop healthier attunement and regulation.

Child Factors

Recent findings in the area of attachment and interpersonal neurobiology support the idea that all childhood experiences, including parent-child interactions, shape brain development in young children (Siegel, 2011). Compared to health controls, young AD patients were found to have an increased avoidance of intimacy, social or sport activities. Up to 70% of patients suffered from feelings of shame surrounding peers that continued into primary and secondary school (Brennikmeijer, et al., 2009). Key components of psychosocial development such as emotional regulation and attachment behaviors occur during the first five years of life (Chamlin, Frieden, Williams & Chren, 2004). Chronic distress in AD may cause disruptions in a child's ability to regulate his or her emotions as well as to accurately respond to sensory cues. This may be the result of an overfunctioning fight or flight response by the autonomic nervous system (Shani-Adir, Rozenman, Kessel, Engel-Yeger, 2009). The effects of the chronic itching, scratching and mental stress to overactive the autonomic nervous system in AD has been

documented (Tran et al., 2010). Becoming overwhelmed with emotion in ways that overactive the autonomic nervous system decreases the brain's ability to have integrated, informed responses.

Children with AD have been found to over-respond to itch cues when presented and then take longer to soothe (Tran, et al., 2010). Chronic itch has been found to share similar neural passageways with chronic pain (Latemoliere & Woolf, 2008). Studies have shown that patients with AD have an altered heart rate and dysfunctional vagal tone even in the absence of acute stressors (Boettger et al., 2009; Sieffert, Hilbert, Schaechinger, Zouboulis & Deter, 2005). Therefore, a child with AD who has an overfunctioning autonomic response may excessively respond to minor levels of distress in a way that hampers the parent's ability to discern if they are simply uncomfortable or in dire pain. This hypersensory sensitivity will impair the ability of a parent to soothe the child even after the distress is reduced due to the overfunctioning autonomic response.

The hypersensory sensitivity may also impair the degree to which a child is cooperative with treatment protocols. Treatment protocols such as bleach baths and ointments that are applied to eczematous skin may be uncomfortable, but children with hypersensory sensitivity may not be able to tolerate even mild discomfort without a "fight or flight" response by kicking, screaming, or running away from the parent who is attempting to apply ointments or give the child baths. Parents have discussed these frustrations in qualitative studies (Ohya, et al., 2001) and yet the effect these factors have on adherence behaviors and the parent-child relationship has yet to be explored.

Parental Factors

Parents of children with AD report increased stress due to the disease. They report worry regarding the child's health, their emotional development and their ability to be accepted by peers (Lawson, Lewis-Jones, Finlay, Reid & Owens, 1988; Warschburger, Buccholz & Petermann, 2004). The parents face challenges regarding expensive and time-consuming treatment protocols, the increased needs and constraints of the child with AD, and overcoming the blame and shame associated with a disease of the skin (Chamlin, Frieden, Williams & Chren, 2004). They also report concern about how the AD is affecting their relationship with the child as well as their ability to parent. Parents of children with AD reported high levels of inadequate disease management including aggressive behavior toward scratching, overprotectiveness, and high levels of frustration with the illness (Warschburger, Buccholz & Petermann, 2004). Mothers of preschool children with AD report more stress regarding parenting and less efficient ways to manage discipline (Kelsay, Klinnert & Bender, 2010). The children themselves experience chronic distress from itching, sleep disturbances, and discrimination from peers and adults (Chamlin, Frieden, Williams & Chren, 2004). Unhealthy parental responses to issues such as self-soothing or recreating sleep after being awoken by pruritis can delay a child's ability to self-soothe (Burnham, Goodlin-Jones, Gaylor & Anders, 2002).

Responding to varying levels of a chronic, remitting disease such as childhood AD require that the parent be attuned to the child's level of distress and the current condition of the disease in order to provide appropriate medical treatment. Parental attunement to disease states and symptoms as well as the developmental and individual needs of the child has been found to have an impact in children and adolescents with Inflammatory Bowel Disease (Nicholas, Otley, Smith, Avolio, Munk & Griffiths, 2007). The mediating role of parental response to child's pain

has been shown to be substantial. Parents who responded to their child's pain with maladaptive parental responses including criticism, discounting of pain, increased attention due to pain or giving special privileges because of the pain were found to be associated with increased disability or somatization of the child (Claar, Simons & Logan, 2007). In comparison, attunement requires contingent communication. A contingent response includes a correct assessment of the child's experience and a response that correctly reflects the experience of the child. Over time, patterns of contingent communication by the parent can provide a sense of safety as well as allow a correct assessment of the child's current state of comfort or distress (Siegel, 2003). The ability of the parent and child to gain a state of attunement may be more difficult to achieve due to the amount of stress on both parent and child due to the effects of the illness. Research regarding parent-child attunement has placed an emphasis on the child's ability, with the help of the parent, to learn to self-soothe and correctly modulate responses to the environment (Schoore, 1994; Siegel, 1999). However, chronic diseases such as AD in children may disrupt the ability of the parent to promote self-soothing and emotional regulation due to issues such as distress due to pruritis, disrupted sleep for both parent and child, and the necessary application of medical ointments by the parent that the child may see as tedious, uncomfortable and even painful. The distress caused by the disease may serve as an impediment to the child's ability to accept parent's attempts at soothing the child. This cycle can lead to overall frustration as well as a lack of positive parent-child experiences necessary for healthy attachment.

Child Attunement Factors

An often overlooked aspect of the parent-child attachment process is the specific impact of child factors. Attachment is defined as the capacity of both parent and child to "regulate intense affect experience while simultaneously maintaining mutual connection." (Fosha, 2003, p.

226). Child temperament, once thought to influence the parent-child attachment, has not been shown to be a factor in attachment development (Siegel, 2001). In contrast, the emotional distress caused by child abuse has been shown to have an effect on the child's attachment security (Siegel, 2001). These events change the process of brain and neuroendocrine development in ways similar to the experience of the chronic pain and distress of AD. Chronic physical distress can also serve to activate similar stress responses in the body and brain, as shown by similar responses in the Autonomic Nervous System and HPA Axis (Van der Kolk, 2006; Tran et al., 2010). This physical distress, along with a parent's inability to bring relief, may have similar effects on the child's ability to accept comfort from caregivers and work toward modulation of emotional arousal (Van der Kolk, 2006).

The effects of AD on attachment formation have been studied with varying results in children with Atopic Dermatitis. Although one study did not find any difference in attachment style between children with AD and a control group, others have focused on the issues of parent-child dysfunctional interactions as both an instigating factor of flare-up and a reason for medically non-adherent behaviors (Koblenzer & Koblenzer, 1988; Daud, Garralda & David, 1993). The Daud, Garralda & David study, although reporting no significant difference between attachments styles in children with AD versus controls, found different attachment interactions at times of disease stability versus times of more intense severity (Daud, Garralda & David, 1993). Interventions aimed at improving the mother-child bond by providing parenting education to parents showed rapid and sustained improvement in skin, emotional development and social adjustment, but did not look specifically as to whether improved medical adherence was a possible intervening variable (Koblenzer & Koblenzer, 1988).

Chronic distress in AD can cause disruptions in a child's ability to regulate his or her emotions as well as to accurately respond to sensory cues. Children with AD have been found to over-respond to itch cues when presented and then take longer to soothe (Tran, et al., 2010). Studies have shown that patients with AD have an altered heart rate and dysfunctional vagal tone even in the absence of acute stressors (Boettger et al., 2009; Seiffert, Hilbert, Schaechinger, Zouboulis & Deter, 2005). This may be the result of an overfunctioning fight or flight response by the autonomic nervous system (Shani-Adir, Rozenman, Kessel, Engel-Yeger, 2009). The effects of the chronic itching, scratching and mental stress to overactive the autonomic nervous system in AD has been documented (Tran et al., 2010). Becoming overwhelmed with emotion in ways that overactivate the autonomic nervous system decreases the brain's ability to have integrated, informed responses (Siegel, 2011). This lack of integrative responses can hamper the child's ability to respond appropriately to choose and to regulate emotions. Therefore, a child with AD who has an overfunctioning autonomic response may over-respond to minor levels of distress in a way that hampers the parent's ability to discern if they are simply uncomfortable or in dire pain. This hypersensory sensitivity will impair the ability of a parent to respond in a contingent manner because the external cues of the child may be an over-response to what is being experienced internally.

The hypersensory sensitivity may also impair the degree to which a child is cooperative with treatment protocols. Treatment protocols such as bleach baths and ointments that are applied to eczematous skin may be mildly uncomfortable, but children with hypersensory sensitivity may not be able to tolerate even mild discomfort without a "fight or flight" response by kicking, screaming, or running away from the parent who is attempting to apply ointments or give the child baths. Parents have discussed these frustrations in qualitative data (Ohya, et al.,

2001) and yet the effect these factors have on adherence behaviors and the parent-child relationship has yet to be explored.

Parental Attunement Factors

Another crucial element in parent-child attachment is the parent's emotional state. A child will use the parent's emotional state of mind in order to regulate his or her own internal state. These periods of attunement, or mutual coregulation of emotion between parent and child, are the building blocks of the child's emotional self-regulation (Feldman, Greenbaum & Yirmiya, 1999). Patricia Crittenden, in her work on child-protective behavior, identifies the following psychological steps as necessary for the parents to initiate action to provide for child needs (2008). First, the information about the state of the child (ie. the condition of the child's skin in AD or the child's level of distress) must be perceived. Next, the information must be identified as relevant to both the parent and the child. The parent must then generate meaning about the information (ie. the cause of the flare up or the interpretation of the child's scratching as either "naughty" behavior or sympathetic behavior). Next, the parent considers alternative responses and selects a response. Finally, a parent decides whether or not to implement the response depending on their preexisting perceptions about the effectiveness of each response (Crittenden, 2008).

From the parental point of view, attunement requires parents to be able to distinguish their own emotions from those of the child's. This differentiation allows the parent to avoid being flooded by their own emotion and remain at a point of emotional equilibrium necessary to adhere to medical regimens (Siegel, 2012). The ability of parents to remain attuned to the child without being flooded with emotion is essential for parents to gain enough knowledge about the

child's internal state of distress and external state of disease severity in order to differentially respond to varying states of the recurring and remitting disease. Factors inherent in the management and treatment of AD may decrease parents' ability to maintain emotional equilibrium due to several factors. Parents report worry regarding the child's health, their emotional development and their ability to be accepted by peers (Lawson, Lewis-Jones, Finlay, Reid & Owens, 1988; Warschburger, Buccholz & Petermann, 2004). Parents face challenges regarding expensive and time-consuming treatment protocols, the increased needs and constraints of the child with AD, and overcoming the blame and shame associated with a disease of the skin (Chamlin, Frieden, Williams & Chren, 2004). They also report concern about how the AD is affecting their relationship with the child as well as their ability to parent. Parents of children with AD reported inadequate strategies for dealing with the disease including aggressive behavior toward scratching, overprotectiveness, and high levels of frustration with the illness (Warschburger, Buccholz & Petermann, 2004). Mothers of preschool children with AD report more stress regarding parenting and less efficient ways to manage discipline (Kelsay, Klinnert & Bender, 2010). The children themselves experience chronic distress from itching, sleep disturbances, and discrimination from peers and adults (Chamlin, Frieden, Williams & Chren, 2004). Unhealthy parental responses to issues such as self-soothing or recreating sleep after being awoken by pruritis can delay a child's ability to self-soothe (Burnham, Goodlin-Jones, Gaylor & Anders, 2002). Each of these factors may play a role in inhibiting the parent's ability to adequately attune to the child, correctly assess the current state of disease severity, and perform appropriate adherence behaviors.

The very nature of the increased stress may then cause parents to respond only when the intensity of need is high rather than responding at lower levels in order to prevent escalation of

symptoms (Crittenden, 2008). Specifically, parents of children with AD may only respond with adherence behaviors when the child's skin has reached a high level of flare up, therefore increasing the intensity of the situation and the severity of the child's illness (Ohya et al., 2001). Depending on the meaning that the parent generates of the child's increase signals of distress, he or she may select different responses. A parent who sees the child's increased crying and need for soothing as clinginess, for example, will choose a different response than a parent who sees the child's crying as a signal of increased disease severity. Parent's preexisting levels of guilt, frustration or helplessness may also factor into the type of meaning generated by the increasing signals of distress (Warschburger, Bucholz & Petermann, 2004). If a parent waits until the intensity of the child's signal is very high, the high arousal response in the parent may serve to limit that parent's ability to implement a response in a timely and consistent manner (Crittenden, 2008). Also, a parent's belief in the ability of the medical treatment to improve the child's condition may affect his or her decision about whether or not to remain adherent with the treatment (Chisolm, Taylor, Balkrishnan & Feldman, 2008).

The hypervigilance necessary for parents to avoid environmental triggers can impede the child's ability to develop independent self-soothing and social functioning. Attending preschool programs or sleep overs with family or friends may not be possible due to the necessity of skin care rituals and the avoidance of allergens (Howlett, 1999). Parents' needs for intrusive behaviors such as disrupting play and sleep for hand-holding in order to prevent scratching can also impede the child's ability to independently learn to experience and soothe emotions.

Response flexibility can be impaired at times of increased stress, tiredness, or anger (Siegel, 2003). As disease severity increases, distress on both caregiver and child may affect not only the child's ability to attach to the caregiver, but also the caregiver's ability to soothe and

comfort the child. Itching and scratching in subjects with atopic dermatitis has been shown to cause increase sympathetic nervous system response than control groups and to retain that heightened physiological response and heart rate longer than healthy subjects (Tran, Papoiu, Russoniello, Wang, Patel, Chan & Yosipovitch, 2010). This finding parallels studies in that attachment literature of extended heart rates for insecurely attached infants who were faced with parental separation as compared to securely attached infants (Sroufe & Waters, 1977; Zalenko, Kraemer, Huffman, Gschwendt, Pageler & Steiner, 2005). Chronic distress in patients with AD may, in effect, force the body into a “flooding” state, a state of diffuse physiological arousal that may impede attachment-related behaviors (Gottman, 2011). Therefore, at times of intense distress and need, caregivers may be actually placed in a helpless situation of not being able to remove the child’s distress while being rejected in their attempts to soothe and comfort the child. The tactile nature of the distress of AD may serve to further distance the child from any attempts by the caregiver to comfort and soothe the child (Balkrishnan, Housman, Carroll, Feldman & Fleischer, 2003; Howlett, 1999). The resultant interactional factors may then affect the caregiver’s ability to remain adherent to time-consuming, potentially painful and costly medical treatments.

Responding to varying levels of a chronic, remitting disease such as childhood AD require that the parent be attuned to the child’s level of distress and the current condition of the disease in order to provide appropriate medical treatment. Parental attunement to disease states and symptoms as well as the developmental and individual needs of the child has been found to have an impact in children and adolescents with Inflammatory Bowel Disease (Nicholas, Otley, Smith, Avolio, Munk & Griffiths, 2007). The mediating role of parental response to child’s pain has been shown to be substantial. Parents who responded to their child’s pain with “maladaptive

parental responses” including criticism, discounting of pain, increased attention due to pain or giving special privileges because of the pain were found to be associated with increased disability or somatization of the child (Claar, Simons & Logan, 2008). The ability of the parent and child to gain a state of attunement may be more difficult to achieve due to the amount of stress on both parent and child due to the effects of the illness.

Statement of Problem

Atopic Dermatitis is a common childhood disease affecting up to 17% of children in the United States with rising prevalence (Laughter, Istvan, Tofte & Hanifin, 2000). Although some patients may have mild disease that is quickly outgrown, a significant number of patients develop more severe and persistent disease (Chamlin, 2006; Boguniewicz, Nicol, Kelsay & Leung, 2008). Many children with AD go on to develop asthma and allergies in what is referred to as the “atopic march” (Kapoor, Menon, Hoffstad, Bilker, Leclerc, & Margolis 2008). Approximately 90% of cases appear in the first five years of life during a critical period of development (Chamlin, Frieden, Williams & Chren, 2004). The disease can have significant negative effects on both patients and their families (Kelsay, Klinnert & Bender, 2010). Although there are many effective treatments for AD, poor adherence rates are common and serve to increase the level of distress and healthcare expenditures in the treatment of AD (Chisolm, Taylor, Grywacz, O’Neill, Balrishnan & Feldman (2010). Many studies have attempted to assess psychosocial factors that influence medical adherence, however none have looked at the effects of the parent-child relationship on medical adherence. Therefore, it was the aim of this study identify what, if any, parent-child interactional factors influence medical adherence in children with AD and how disease severity may affect those factors.

Research Questions and Hypotheses

Research Question I: What is the relationship between Difficult Child, Parental Distress, Dysfunctional Interaction and Total Parental Stress Scores and each of the six rates of medical adherence (Bleach baths, moisturizers, topical medications, wet wraps, other medications, removal of allergens)?

Hypothesis I: Higher levels of child distress perceived by the parent, measured by the Difficult Child scale of the PSI will positively correlate with rates of medical adherence on each of the six scales (Bleach baths, moisturizers, topical medications, wet wraps, other medications, removal of allergens).

Hypothesis II: Higher levels of Parental Distress as measured by the Parental Distress scale of the PSI will negatively correlate with rates of medical adherence on each of the six scales (Bleach baths, moisturizers, topical medications, wet wraps, other medications, removal of allergens).

Hypothesis III: Higher levels of parent-perceived parent-child interactional stress as measured by the Dysfunctional Interaction scale of the PSI will negatively correlate with rates of medical adherence on each of the six scales (Bleach baths, moisturizers, topical medications, wet wraps, other medications, and removal of allergens).

Hypothesis IV: Higher levels of the total score of Parental Stress Index will negatively correlate with rates of medical adherence on each of the six scales (Bleach baths, moisturizers, topical medications, wet wraps, other medications, and removal of allergens).

Research Question II: What is the relationship between Difficult Child, Parent Distress, Dysfunctional Interactions and Total Parental Stress scores and reasons for non-adherence behaviors?

Hypothesis I: Parents who report high levels of child distress as measured by the Difficult Child scale of the PSI will report greater numbers of internal reasons for non-adherence behaviors.

Hypothesis II: Parents who report high levels of parent distress as measured by the Parent Distress scale of the PSI will report greater numbers of external reasons for non-adherence behaviors.

Hypothesis III: Parents who report high levels of parent-child interactional distress as measured by the Dysfunctional Interaction scale of the PSI will report greater numbers of interpersonal reasons for non-adherence behaviors.

Research Question III: Is there a correlation between parental rating of severity and physician rating of severity?

Hypothesis I: Parental rating of disease severity will positively correlate with physician rating of disease severity.

Research Question IV: Will the reasons provided by parents for medical non-adherence vary according to parent's rating of disease severity?

Hypothesis I: Parents who report lower levels of disease severity will report different reasons for medical non-adherence than parents who report higher levels of disease severity.

Research Question V: What is the relationship between physician-reported disease improvement and medical adherence rates on each of the six scales (Bleach baths, moisturizers, topical medications, wet wraps, other medications, and removal of allergens).

Hypothesis I: Physician's rating of disease improvement will positively correlate with parental rating of medical adherence on each of the six medical adherence scales (Bleach baths, moisturizers, topical medications, wet wraps, other medications, and removal of allergens).

Research Question VI: What is the relationship between physician rating of adherence and parent-reported medical adherence rates on each of the six scales (Bleach baths, moisturizers, topical medications, wet wraps, other medications, and removal of allergens).

Hypothesis I: Physician's rating of adherence will positively correlate with parental rating of medical adherence on each of the six medical adherence scales (Bleach baths, moisturizers, topical medications, wet wraps, other medications, and removal of allergens).

Conclusion

Not only does AD impact current quality of life for both the child and family, but also has been linked to long term behavioral and emotional disruptions in children. Medical compliance with AD can be time-consuming, expensive and complicated. Poor medical compliance has been found and linked to poorer prognosis. Therefore, it is important to understand the factors that inhibit medical compliance among parents with children with AD to promote better health and overall adjustment of these children. Studies have looked at various causes for non-compliance including parental self-efficacy, parental stress and relationship to doctor, but no

studies have specifically looked at the effect the level of distress in the child has on the parent-child relationship nor the effects of that relationship on medical compliance. Previous studies have looked at parental factors alone in attempting to answer questions surrounding poor adherence, however this study seeks to look at the relationship between the parent and child as a determining factor of medication compliance.

CHAPTER III

METHODOLOGY

This study sought to explore the parent-child interactional factors that influence medical adherence rates in children with Atopic Dermatitis. It further explored how those factors vary in times of chronic and acute disease states.

A cross-sectional survey research design was chosen for this study. Cross-sectional designs include “studying samples chosen from the population to discover the relative incidence, distribution, and interrelations of these variables” (Kerlinger, 1986, p. 378). Cross-sectional designs, therefore, can determine the prevalence of a particular variable in a population at a given point in time (Mann, 2003). Cross-Sectional studies may also be used to infer causation (Mann, 2003). These designs are effective at identifying associations to allow for future, more rigorous studies such as randomized controlled designs (Mann, 2003). Due to the exploratory nature of the study in assessing for the prevalence of a correlation between parent-child interactional factors and medical adherence, a cross-sectional survey was determined to be the most efficient design for the current study.

Surveys in cross-sectional designs can target a specific sample of a specialized group when the population is too large to directly observe (Fowler, 2002). The design process included a recursive procedure of revisiting decisions surrounding sample size, instruments and analysis throughout the study in order to minimize errors and produce reliable, valid data (Fowler, 2009). This design process was based on Fowler’s concept of a total design concept of survey research. Fowler’s concept acknowledges the importance of allowing each individual stage of the research to inform the others, thereby allowing a clear and unified process of data collection and analysis (Fowler, 2009).

Restatement of Research Questions and Hypotheses

Research Question I: What is the relationship between Difficult Child, Parental Distress, Dysfunctional Interaction and Total Parental Stress Scores and each of the six rates of medical adherence (Bleach baths, moisturizers, topical medications, wet wraps, other medications, removal of allergens)?

Hypothesis I: Higher levels of child distress perceived by the parent, measured by the Difficult Child scale of the PSI will positively correlate with rates of medical adherence on each of the six scales (Bleach baths, moisturizers, topical medications, wet wraps, other medications, removal of allergens).

Hypothesis II: Higher levels of Parental Distress as measured by the Parental Distress scale of the PSI will negatively correlate with rates of medical adherence on each of the six scales (Bleach baths, moisturizers, topical medications, wet wraps, other medications, removal of allergens).

Hypothesis III: Higher levels of parent-perceived parent-child interactional stress as measured by the Dysfunctional Interaction scale of the PSI will negatively correlate with rates of medical adherence on each of the six scales (Bleach baths, moisturizers, topical medications, wet wraps, other medications, and removal of allergens).

Hypothesis IV: Higher levels of the total score of Parental Stress Index will negatively correlate with rates of medical adherence on each of the six scales (Bleach baths, moisturizers, topical medications, wet wraps, other medications, and removal of allergens).

Research Question II: What is the relationship between Difficult Child, Parent Distress, Dysfunctional Interactions and Total Parental Stress scores and reasons for non-adherence behaviors?

Hypothesis I: Parents who report high levels of child distress as measured by the Difficult Child scale of the PSI will report greater numbers of internal reasons for non-adherence behaviors.

Hypothesis II: Parents who report high levels of parent distress as measured by the Parent Distress scale of the PSI will report greater numbers of external reasons for non-adherence behaviors.

Hypothesis III: Parents who report high levels of parent-child interactional distress as measured by the Dysfunctional Interaction scale of the PSI will report greater numbers of interpersonal reasons for non-adherence behaviors.

Research Question III: Is there a correlation between parental rating of severity and physician rating of severity?

Hypothesis I: Parental rating of disease severity will positively correlate with physician rating of disease severity.

Research Question IV: Will the reasons provided by parents for medical non-adherence vary according to parent's rating of disease severity?

Hypothesis I: Parents who report lower levels of disease severity will report different reasons for medical non-adherence than parents who report higher levels of disease severity.

Research Question V: What is the relationship between physician-reported disease improvement and medical adherence rates on each of the six scales (Bleach baths, moisturizers, topical medications, wet wraps, other medications, and removal of allergens).

Hypothesis I: Physician's rating of disease improvement will positively correlate with parental rating of medical adherence on each of the six medical adherence scales (Bleach baths, moisturizers, topical medications, wet wraps, other medications, and removal of allergens).

Research Question VI: What is the relationship between physician rating of adherence and parent-reported medical adherence rates on each of the six scales (Bleach baths, moisturizers, topical medications, wet wraps, other medications, and removal of allergens).

Hypothesis I: Physician's rating of adherence will positively correlate with parental rating of medical adherence on each of the six medical adherence scales (Bleach baths, moisturizers, topical medications, wet wraps, other medications, and removal of allergens).

Data Collection

The present study used a non-probability, convenience sampling method (Creswell, 2009). Convenience sampling was utilized in this study (Creswell, 2009). Due to the large number of children with Atopic Dermatitis in the general population, obtaining information from a subset of that population was an acceptable way of obtaining exploratory information (Nelson & Allred, 2005).

Sample

The data was collected from a total of 86 participants. This study initially sought a sample size of 120 participants. However, due to limitations with the size of the dermatological practice, the sample size was changed to 80 to 100 participants. This sample size is consistent with other studies completed on children with AD (Ohya, et al., 2001). The proposed sample size is based on a target p value of .05 (Cohen, 1988). The limitation of the lesser sample size is that it limits the study's ability to run each of the subscores of the PSI (ie. Parent Distress, Parent-Child Dysfunctional Interaction, and Difficult Child) within the target p value. According to Field (2005), a common rule for calculating sample size for regression analysis, there are two equations to consider when assessing a minimum sample size. One equation is $104 + k$ with k equaling the number of predictors in the study. The predictors for this study include Parenting Stress Index Total Score, Parent Rating of Disease Severity, Physician Rating of Disease Improvement, and Physician Rating of Adherence. The sample size for this study, then, according to this equation, would be $104 + 4 = 108$. The second equation Field discusses for computing minimum sample size is $50 + 8(k)$, which for the purposes of this study would be $50 + 8(4) = 82$. Therefore, a minimum sample size for this study is 80 to 100. The sample for this study met those criteria.

Participants were recruited from two pediatric dermatology clinics located in different regions of the Greater St. Louis Metropolitan area. The two regions of the Greater St. Louis Metropolitan area are generally perceived to possess very different demographic characteristics, including race, income and urban vs. suburban. By drawing a sample from these areas it is assumed that the sample will possess a broad range of socio-economics and racial characteristics.

Inclusion/Exclusion Criteria for Study

Patients who qualified for the study were primary caregivers of children with AD who accompanied a patient to an appointment at one of three pediatric dermatological offices in the St. Louis area. The age range of the diagnosed child was birth to 12 years. This limited age range is due to the limitations of the PSI which is designed for parents of children (ages birth to 12 years). Primary caregivers were defined as someone who participated in the adherence behaviors discussed in the study.

Inclusion Criteria:

- 1) Primary caregiver over the age of 18 must be present with child at the day of the visit.
- 2) Child is 12 years old or younger with a diagnosis of Atopic Dermatitis.
- 3) Child is a patient at the Pediatric Dermatology Practice at Cardinal Glennon and/or their satellite offices.
- 4) Primary caregiver and child have an appointment to see either a physician or physician's assistant at the Pediatric Dermatology Practice at Cardinal Glennon and/or their satellite offices.
- 5) Primary caregiver is willing and able to sign consent and participate in the study.

Exclusion Criteria:

- 1) Primary caregiver did not escort child to the appointment.

- 2) Child does not have a diagnosis of Atopic Dermatitis.
- 3) Child is over the age of 12.
- 4) Primary caregiver is not able or willing to fill out the Demographic/Medical Adherence Questionnaire and the PSI.

Procedure

For a period of two years, flyers were set up at each of the two dermatological practice sites inviting all primary caregivers who accompanied a child ages 12 and under with a diagnosis of Atopic Dermatitis to participate in the study. Subjects who requested to be in the study were then given a letter briefly explaining the study, inviting his or her participation, and an invitation to call the PI if further information is needed (Appendix A). Primary caregivers who agreed to participate were then given a packet by the receptionist at the clinic. The research packet contained: an informed consent, a short demographic questionnaire, the Parenting Stress Index, and the Medical Adherence Scale.

All patients with a diagnosis of Atopic Dermatitis in this practice were given a standard treatment protocol that includes wet wraps, topical moisturizers, bleach baths ointments, and removal of allergens. Topical medications and other medications are also typically added to the protocol as necessary. Therefore, all of the subjects in the study were given four out of the six areas of treatment listed within the Medical Adherence Scale.

Informed Consent (Appendix B)

The informed consent informed participants the study had received the approval of the Saint Louis University Institutional Review Board and that their responses to the questionnaires

would not be provided to the physician, physician assistant, or any other staff at the facility. The document also explained that their decision on whether or not to participate in the study would have no impact on their ability to continue under the care of the physician or physician's assistant. Identifying information such as names, social security numbers, or addresses were not obtained. Finally, they were informed that they had the right to quit the study at any point throughout the process.

Subjects returned the packet to the front desk either before or after their appointment with the physician or physician's assistant. The receptionist at the front desk then added the participant code onto a form for the physician that records each of the three physician's ratings (Appendix C). The physician or physician's assistant then recorded their ratings of severity, adherence and improvement (Appendix B) during the same visit under the participant's code which was also collected by the PI. The physician and physician's assistant were only given aggregate data of the research upon the completion of the study.

Measures

The packet of questionnaires completed by subjects who were primary caregivers, included: 1) a letter requesting participation in the study 2) a Demographic Questionnaire/Medical Adherence Scale; and 3) The Parenting Stress Index Short Form Fourth Edition.

The measures completed by the physician and physician's assistant included: 1) Physician Assessment of Adherence; 2) Physician Assessment of Response to Treatment; and, 3) Physician Assessment of disease severity.

Demographic Information/Medical Adherence Scale

Basic demographic information was obtained using a demographic form including age and race of the child, household income, marital status of child's parents and caregiver's relationship to the child. In addition, caregivers were asked about the length of time the child has had Atopic Dermatitis, the overall severity of the condition and the current severity of the AD. Finally, caregivers were asked whether the child has been diagnosed with allergies and asthma. (Appendix D).

The Medical Adherence Scale was developed as an adaptation of previous scales used in self-report assessments (Ohya et al., 2001; Krakowski, Eichenfield & Dohill, 2008). It focuses on the six main areas of medical treatment in AD: Bleach Baths, Moisturizers, Topical Medications, Wet Wraps, Topical Creams and allergen removal (Boguniewicz, Eichenfield & Hultsch, 2003; Krakowski, Eichenfield & Dohill, 2008). In each of the six categories, it asks how many times per day the treatment is prescribed, how often the parent follows this advice, and gives a list of reasons for non-adherence. The rate of medical adherence, or how often the parent follows the physician's advice, was broken down into a five-option likert scale with options of ">90%, 60-90%, 30-60%, 10-30%, and <10% for each of the six categories of medical adherence. The reasons for medical non-adherence were adapted from previous research on reported reasons for non-adherence behaviors and contained three main categories: external factors (EXT) (ie. "It costs too much"), internal factors "I don't know how to do it" (INT) and parent-child interactional factors (PCIF) (ie. "It upsets my child") (Chisolm et al., 2009; Hodari, Nanton, Carroll, Feldman & Balkrishnan, 2006; Nolan & Feldman, 2009). Each of these answers was scored as nominal data.

Although medication electronic monitoring systems (MEMS) are considered the gold-standard in accurately assessing medical adherence in AD, these tests only show the rates of medical adherence rather than the factors that may enhance or inhibit medical adherence rates (Balkrishnan, Carroll, Camacho & Feldman, 2003; Greenlaw, Yentzer, O'Neill, Balkrishnan & Feldman, 2010). Self-report measures on adherence have been found to consistently overestimate adherence rates, however their usefulness in identifying barriers to adherence behaviors is well-established (Greenlaw, Yentzer, O'Neill, Balkrishnan & Feldman, 2010; George, Mackinnon, Kong, & Stewart, 2006; Carroll, Feldman, Manuel & Balkrishnan, 2004). Therefore, a self-report medical adherence scale was used in this study to increase our awareness of the reasons behind non-adherence in chronic diseases such as AD and establish trends of use (Renzi, Picardi, Abeni, Agostini, Baliva, Pasquini, Puddu & Bragga, 2002; Grenlaw, Yentzer, O'Neill, Balkrishnan & Feldman, 2010).

The Parenting Stress Index Short Form Fourth Edition™

The PSI-SF (Appendix F) is an empirically validated instrument measuring the amount of stress within the parent-child system (Abidin, 1995). It was designed to measure the stable, enduring dynamics that include parental factors, child factors and interactional factors within the parent-child relationship (Abidin, 1995). The PSI can assess the parent's perceived level of satisfaction and adaptation to child behavior and temperament (Abidin, 1995). It includes three subscales of 12 items each including: Parental Distress (PD); Parent-Child Dysfunctional Interaction (PCDI) and Difficult Child (DC). The PD scale measures the amount of distress felt by the parent due to perceived parental incompetence, lack of support, or other parental factors. The PCDI scale focuses on stressors inherent in the parent's interactions with the child and the parent's perception of the child's response to the parent's attempts at connection. The DC scale

focuses on the stress resulting from the management of the child's behavior and temperament (Abidin, 1995). Each subscale can be independently scored with a minimum score of 12 and a maximum score of 60 for each subscale. Scores at or above the 85th percentile are considered high and scores at 15th percentile are considered low. Each subscale is composed of 12 likert-scale questions with options ranging from "strongly agree" (5 points), "agree" (4 points), "not sure" (3 points), "disagree" (2 points), and "strongly disagree" (1 point). A measure of overall parenting stress in the role of the parent can also be obtained by summing the cumulative score from each subscale, with a total stress score above 90 indicating a risk to the well-being of the parent and child (Abidin, 1990). The scale typically takes about 10 minutes to complete and all but two of the PSI scales collected in the study were completed in its entirety. One scale was missing one line of data, while the other was incomplete and was not included in the study.

The scale has been validated with parents of different racial and socioeconomic backgrounds (Reitman, Currier & Stickle, 2002; Haskett, Ahern, Ward & Allaire, 2006). It has been widely used and measured with average alpha reliability coefficients of $r=.79$ for Parental Distress, $r=.80$ for Parent-Child Dysfunctional Interaction, and $r=.78$ for Difficult Child (Abidin, 1995).

Studies assessing distress in families of children with AD have consistently used the Parenting Stress Index to self-report both child and parent stress levels (Faught, Bierl, Barton & Kemp, 2007; Yoo & Kim, 2004). However, these studies focused solely on the Total Scale Score and subscales of the PSI concerning parental or child stress and have neglected the Interactional Distress subscale of the Index. The original intent of the present study was to include the Parent-Child Dysfunctional Interaction (PCDI) subscale. However, due to the lower sample size the ability to gain the statistical power necessary for this subscale was

compromised. Although this data will still be reported, the statistical limitations will be discussed in Chapter 5.

Physician Assessment of Adherence

Upon each visit, the physician made an independent assessment of adherence for each child with AD based by completing a form with answers on a five point likert scale with options of “Perfect >90%”, “Excellent 60-90%”, “Good 30-60%”, “Fair 10-30%”, and “Poor <10%” (Appendix C). This assessment was based on the clinical judgment of the physician based on the parental report of medication/treatment adherence, observation of amount of medication used by parents (parents are asked to bring in all medication to each doctor’s visit) and the child’s report (if possible) about adherence behaviors. The scale attempts to assess the composite adherence of each of the six adherence categories listed above (M, BB, TM, WW, TC and ALL). Although this is not a standardized assessment scale, it is a standard tool used by the physician’s office to assess overall adherence.

Physician Assessment of Response to Treatment

The physician made an independent assessment of response to treatment for each child by completing a form with answers on a 5 point likert scale with options of “Worse”, “None”, “Minimal”, “Moderate”, and “Excellent” (Appendix C). Response to treatment assesses the overall degree of improvement in the severity, duration of flare ups, and overall impact to the child since the previous visit to the physician. Again, in the absence of a standardized scale for this assessment, this likert scale attempted to assess the response to treatment.

Physician Assessment of disease severity

The physician made an independent assessment of the overall condition of the child's current level of AD disease using the Investigator's Global Assessment Scale (Appendix C). The IGA is based on a 5 point likert scale with options of "Clear", "Almost clear", "Mild", "Moderate", and "Severe". Although there is no standardized assessment scale for disease severity in AD, the Investigator's Global Assessment scale has been found to be one of the most frequently used scales for this purpose (Rehal, B., 2011; Ashcroft, Dimmock, Garside, Stein & Williams, 2005).

Table 1: Summary of Research Design and Data Analysis

Hypothesis	Variables: (IV) and (DV)	Analysis
H ₁ : Higher levels of parent-perceived child distress as measured by the Difficult Child scale of the PSI will positively correlate with rates of medical adherence on each of the six scales	IV: PSI-DC Scale (continuous) DV: Medical Adherence Rates (continuous)	Spearman Correlation
H ₂ : Higher levels of Parental Distress as measured by the Parental Distress scale of the PSI will negatively correlate with rates of medical adherence on each of the six scales.	IV: PSI – PD (continuous) DV: Medical Adherence Rates (continuous)	Spearman Correlation
H ₃ : Higher levels of parent-perceived parent-child interactional stress as measured by the Dysfunctional Interaction scale of the PSI will negatively correlate with rates of medical adherence on each of the six scales.	IV: PSI-DI (continuous) DV: Rate of medical adherence (continuous)	Spearman Correlation

Table 1 Continued: Summary of Research Design and Data Analysis

Hypothesis	Variables: (IV) and (DV)	Analysis
<p>H₄: Higher levels of the total score of Parental Stress Index will negatively correlate with rates of medical adherence on each of the six scales.</p>	<p>IV: PSI-TS (continuous) DV: Rate of medical adherence (continuous)</p>	<p>Spearman Correlation</p>
<p>H₅: Parents who report high levels of parent-perceived child distress as measured by the Difficult Child scale of the PSI will have higher rate of responses of internal reasons for non-adherence behaviors.</p>	<p>IV: PSI-DC (dichotomous) DV: Reasons for Non-Adherence Behaviors - I (discrete)</p>	<p>Chi²</p>
<p>H₆: Parents who report high levels of parent distress as measured by the Parent Distress scale of the PSI will have higher rate of responses of external reasons for non-adherence behaviors.</p>	<p>IV: PSI-PD (continuous) DV: Reasons for Non-Adherence Behaviors E (discrete)</p>	<p>Chi²</p>

Table 1 Continued: Summary of Research Design and Data Analysis

Hypothesis	Variables: (IV) and (DV)	Analysis
H ₇ : Parents who report high levels of parent-child interactional distress as measured by the Dysfunctional Interaction scale of the PSI will have higher rate of responses of interpersonal reasons for non-adherence behaviors.	IV: PSI-DI (continuous) DV: Reasons for Non-Adherence Behaviors – PC (discrete)	Chi ²
H ₈ : Parental rating of disease severity will positively correlate with physician rating of disease severity.	IV: Parental Rating of Disease Severity (continuous) DV: IGA (continuous)	Spearman Correlation
H ₉ : Parents of children who report lower levels of disease severity will differ from parents of children with high levels of severity on categories of reasons for medical non-adherence.	IV: Parental Rating of disease severity (continuous) DV: Reasons for Medical Non-Adherence Behaviors (discrete)	Chi ²

Table 1 Continued: Summary of Research Design and Data Analysis

Hypothesis	Variables: (IV) and (DV)	Analysis
H ₁₀ : Rates of physician-reported disease improvement will positively correlate with parental-reported rates of medical adherence on each of the six scales.	IV: IGA (continuous) DV: Medical Adherence Rates (continuous)	Spearman Correlation
H ₁₁ : Physician's rating of adherence will positively correlate with parental rating of medical adherence on each of the six medical adherence scales (Bleach baths, moisturizers, topical medications, wet wraps, other medications, and removal of allergens).	IV: Physician's rating of Adherence (continuous) DV: Medical Adherence Rates (continuous)	Spearman Correlation

CHAPTER IV:

RESULTS

This chapter reports demographic information gathered on each of the surveys as well as the statistical analysis of each of the study's hypotheses. The chapter reports survey data collected from 86 participants who are parents of children visiting two different sites of a dermatological practice in the metropolitan St. Louis area. Additionally, data will be reported gathered through assessments completed by the physician and/or physician's assistant on each of the children. The measures completed by the parents included a Demographic Form, a Medical Adherence Scale and a Parenting Stress Index-Short Form. The scales completed by the physician and/or physician's assistant at the time of the visit included the Physician Assessment of Adherence, the Physician Assessment of Response to Treatment and the Physician Global Assessment.

Descriptive Statistics

The following tables present descriptive statistics computed on the categorical measures utilized in this study, focusing specifically on demographic and related measures. The first table (Table 2) provides demographic information collected included specific information about the primary caregiver: 1) is the primary caregiver accompanying the child to the appointment, 2) is the primary caregiver the legal guardian, 3) gender of the primary caregiver and, 4) the family income, marital status and additional financial support the primary caregiver may receive. The second table (Table 4) includes specific information regarding the child, which included: 1) was the visit a scheduled or emergency appointment, 2) age and race of the child, and 3) the duration of the Atopic Dermatitis. Table 3 is the average of responses to each subscale of the PSI

including Difficult Child (PSIDC), Parental Distress (PSIPD), Parent Child Dysfunctional Interaction (PSIPCDI), Total Score (PSITS) and Defensive Responding (PSIDR). Table 5 breaks down the percentage of “clinically significant” responses (ie. responses that fell into the range of “clinically significant” in the scoring guide for the PSI) in each of the subscales (PSIDCSIG, PSIDPDSIG, PSIPCDISIG, PSITSSIG and PSIDRSIG). Table 6 depicts the actual number of respondents that reported Parent-Child Interactional Factors (PCIF) as reasons for non-adherence for each of the six types of adherence behaviors: Bleach Baths (BB), Moisturizers (M), Topical Medications (TM), Wet Wraps (WW), Topical Creams (TC) and Allergen Removal (ALL). Finally, Table 6 includes the percentages of Reasons for Non-Adherence Behaviors (ie. External Reasons, Internal Reasons and Parent-Child Reasons) for each of the six types of adherence behaviors.

The demographic information shows that all but one of the 86 participants were both the primary caregiver and legal guardian (See Table 2). Seventy-eight of the visits were scheduled and eight were emergency appointments. Sixty-eight parents were females and fourteen were males, with 4 surveys missing data. For the children, 43 were male and 41 were female with two missing data points. Parents made up 81 of the survey sample, with 2 stepparents reporting, 2 grandparents and 1 foster parent. Forty-three of the children were Caucasian, thirty-one were African American, three were Asian, four were Hispanic, 3 were biracial and 2 reported “Other”. Family income break downs included 36 respondents reporting incomes under \$30,000 per year, 27 respondents reported \$30,000 to \$99,000 per year, and 23 respondents reported having a yearly income of \$100,000 or above. Fifty of the respondents reported being married, twenty-five were single, two respondents were remarried, one respondent was widowed and three indicated they were cohabitating. Financial support came from spouses in 49 responses, from

significant others in 16 responses, from relatives in 3 responses and from parents/grandparents in 8 responses. Ten of the surveys left this question blank.

Table 2: Descriptive Statistics: Demographic

<u>Measure</u>	<u>N</u>	<u>%</u>
<i>Primary Caregiver</i>		
No	1	1.2
Yes	85	98.8
Total	86	100.0
<i>Legal Guardian</i>		
No	1	1.2
Yes	85	98.8
Total	86	100.0
<i>Visit</i>		
Scheduled Visit	78	90.7
Emergency Visit	8	9.3
Total	86	100.0
<i>Parent Gender</i>		
Male	14	16.3
Female	68	79.1
Missing	4	4.7
Total	86	100.0
<i>Child Gender</i>		
Male	43	50.0
Female	41	47.7
Missing	2	2.3
Total	86	100.0
<i>Relationship to Child</i>		
Parent	81	94.2
Step-Parent	2	2.3
Grandparent	2	2.3
Foster Parent	1	1.2
Total	86	100.0

Table 2 Continued: Descriptive Statistics: Demographic

<u>Measure</u>	<u>N</u>	<u>%</u>
<i>Race of Child</i>		
African American	31	36.0
Caucasian	43	50.0
Asian	3	3.5
Hispanic	4	4.7
Biracial	3	3.5
Other	2	2.3
Total	86	100.0
<i>Family Income</i>		
Less than \$10,000	11	12.8
\$10,000 to \$29,999	25	29.1
\$30,000 to \$59,999	13	15.1
\$60,000 to \$99,999	14	16.3
\$100,000 and above	23	26.7
Total	86	100.0
<i>Marital Status of Parent</i>		
Single	25	29.1
Married	50	58.1
Divorced	5	5.8
Remarried	2	2.3
Widowed	1	1.2
Cohabiting	3	3.5
Total	86	100.0
<i>Household Support</i>		
Spouse	49	57.0
Significant Other	16	18.6
Relative	3	3.5
Parent/Grandparent	8	9.3
Missing	10	11.7
Total	86	100.0

The average age of children in the survey was 6.542 (SD 3.631). The average length of illness (how long the child has had AD) was 5.620 (SD 3.619) (Table 3).

Table 3: Descriptive Statistics: Demographic

<u>Measure</u>	<u>Mean</u>	<u>SD</u>
<i>Age of Child</i>	6.542	3.631
<i>Duration of AD</i>	5.620	3.619

Descriptive Statistics were performed on each subscale of the PSI (PSIDC, PSIPD, PSIPCDI, PSIDR and PSITS) for the mean and standard deviation of each subscale (Table 4). Possible scores for PSIDC, PSIPD and PSIPCDI range from 0 to 48. The PSITS is computed by adding the PSIDC, PSIPD and PSIPCDI. The PSIDR, or Defensive Responding Scale, ranges from a possible score of 0 to 28. The mean of the Difficult Child subscale (PSIDC) was 24.151; SD 9.270. The Parental Distress (PSIPD) was 23.081; SD 23.081. Parent-Child Dysfunctional Interaction was the lowest mean of the subscales at 18.861; SD 7.369. The mean of the Total Score was 65.791; SD 19.803. The Defensive Responding mean was 13.861; SD 4.681.

Table 4: Descriptive Statistics: PSI Subscale Means

<u>Measure</u>	<u>Mean</u>	<u>SD</u>
<i>PSIDC</i>	24.151	9.270
<i>PSIPD</i>	23.081	7.267
<i>PSIPCDI</i>	18.663	7.369
<i>PSIDR</i>	13.861	4.681
<i>PSITS</i>	65.791	19.803

Each subscale of the PSI has a validated “clinically significant” cut off score. Over 22% of respondents measured in the clinically significant range for the Defensive Responding scale, which infers that the responses may have intentionally been unreported. The Parental Distress subscale consisted of 10.5% of respondents having a “clinically significant” score (PSIPDSIG),

The Difficult Child subscale included 19.8% having a clinically significant score, and the Parent-Child Dysfunction subscale had 14% of respondents with clinically significant scores. This resulted in 17.4% of respondents having a clinically significant Total Score on the PSI.

Table 5: Descriptive Statistics: PSI Percentage of “Clinically Significant” Scores

<u>Measure</u>	<u>Percentage</u>
<i>PSIPDSIG</i>	10.5%
<i>PSIDCSIG</i>	19.8%
<i>PSIPCDISIG</i>	14.0%
<i>PSIDRSIG</i>	22.1%
<i>PSITSSIG</i>	17.4%

The results regarding Parent-Child Interactional Factors as a reason for non-adherence behaviors revealed that Bleach baths had the highest rating of Parent-Child Interactional Factors as a reason for non-adherence behaviors at 40.7% (see Table 4). Topical Medications had the second largest percentage of PCIF factors at 23.3%. Moisturizers and wet wraps were the next most common at moisturizers at 17.4% and 12.8% respectively. Finally, 5.8% of respondents reported PCIF reasons for non-adherence of topical creams while 3.5% reported PCIF reasons for non-adherence of allergen removal (see Table 5).

Table 6: Descriptive Statistics: PCIF Measures

<u>Measure</u>	<u>N</u>	<u>%</u>
<i>BBPCIF</i>		
No	51	59.3
Yes	35	40.7
Total	86	100.0
<i>MPCIF</i>		
No	70	81.4
Yes	15	17.4
Missing	1	1.2
Total	86	100.0
<i>T MPCIF</i>		
No	66	76.7
Yes	20	23.3
Total	86	100.0
<i>WWPCIF</i>		
No	75	87.2
Yes	11	12.8
Total	86	100.0
<i>TCPCIF</i>		
No	81	94.2
Yes	5	5.8
Total	86	100.0
<i>ALLPCIF</i>		
No	83	96.5
Yes	3	3.5
Total	86	100.0

The average rates of adherence of all respondents in each category break down as follows: Wet Wraps, Bleach Baths and Allergen Removal had the lowest adherence rates at 53%, 55% and 65% respectively. Adherence to Moisturizers and Topical Creams averaged at 71.4% and 74%. Adherence to Topical Medications showed the highest average rates of adherence with an average of 90% (See Table 7).

Table 7: Rates of Adherence by Type of Adherence

<i>Type of Adherence</i>	<i>Percentage of Rate of Adherence</i>
Bleach Baths	55%
Moisturizers	71.4%
Topical Creams	74%
Wet Wraps	53%
Allergen Removal	65%
Topical Medications	90%

Reasons for non-adherence behaviors in each of the six types of adherence were broken down into three categories: Internal Reasons, External Reasons, and Parent-Child Interactional Reasons. The percentage of Parent-Child Interactional Reasons were equal or greater than the reasons for either Internal or External reasons in each of the categories except Allergen Removal. The Bleach Bath reasons consisted of 40.7% percent of respondents reporting Parent-Child Interactional Reasons, while 18.6% reported External reasons and 15.1% reported Internal reasons. Moisturizers consisted of an equal percentage of External and Parent-Child interactional reasons at 17.4%, while Internal reasons comprised 10.5%. Topical Medications, once again, had a higher rate of parent-child interactional reasons for non-adherence behaviors at 23.3% with External reasons at 12.8% and Internal reasons at 11.6%. Wet wraps again had the highest respondents of Parent-Child Interactional reasons at 12.8% compared to External reasons at 9.3% and Internal reasons at 5.8%. Topical Creams included 5.8% Parent-Child Interactional Reasons, 5.7% External reasons and 2.5% internal reasons. Allergen Removal was the only category in which Parent-Child Interactional factors was not the highest percentage, with 3.5% of respondents reporting Parent-Child Interactional reasons, 23.3% reporting External reasons, and 1.2% reporting Internal Reasons (See Table 8).

Table 8: Percentage of Factor Type by Medical Adherence Type

<u>Medical Adherence Type</u>	<u>External</u>	<u>Internal</u>	<u>Parent-Child</u>
Bleach Bath	18.6%	15.1%	40.7%
Moisturizers	17.4%	10.5%	17.4%
Topical Medications	12.8%	11.6%	23.3%
Wet Wraps	9.3%	5.8%	12.8%
Topical Creams	5.7%	2.5%	5.8%
Allergen Removal	23.3%	1.2%	3.5%

Statistical Analysis of Hypotheses

The statistical analysis of the eleven hypotheses in this study produced five statistically significant findings. Two of the significant findings include the Parenting Stress Index (PSI) which is broken down into the subscales of Difficult Child (PSIDC), Parent-Child Dysfunctional Interaction (PSIPCDI) Parental Distress (PSIPD), Total Score (PSITS) and Defensive Responding (PSIDR). An additional variable was added to each subscale to discern between scores that fell in the clinically significant range vs. those that did not (PSIDCSIG), PSIPCDISIG) (PSIPDSIG), (PSITSSIG) and (PSIDRSIG). First, a statistically significant negative correlation was found between a clinically significant score on the Difficult Child subscale on the PSI (PSIDCSIG) and the rate of adherence in the subscale of Topical Medications. Second, a statistically significant negative correlation was found between a clinically significant score on the Total Score of the PSI (PSITSSIG) and the rate of adherence in the subscale of Bleach Bath.

There were two additional statistically significant findings under Hypothesis 9. First, the parental report of the child's level of disease severity as compared to other children with eczema (COMPARESEV) was positively correlated with Parent Child Interactional Factors (PCIF) as a reason for non-adherence in the area of Bleach Baths and Wet Wraps.

Hypothesis 1

H1: Higher levels of parent-perceived child distress as measured by the Difficult Child scale of the PSI will positively correlate with rates of medical adherence on each of the six scales.

Table 9: Spearman's Correlations for Hypothesis 1

<u>Measure</u>	<u>PSIDC</u>		
	<u>Rho</u>	<u>p</u>	<u>df</u>
Bleach Bath	-.199	.083	77
Moisturizers	-.012	.914	83
Topical Medications	-.173	.123	81
Wet Wraps	-.021	.891	45
Topical Creams	-.084	.533	57
Allergen Removal	.155	.308	45

Spearman Correlations were conducted to investigate any possible relationship between the Difficult Child Scale of the PSI (PSIDC) and the rate of medical adherence on each of the six categories. No statistically significant correlations were found between PSIDC and medical adherence on any of the six categories of adherence. In fact, most relationships, though not statistically significant, showed a slightly negative correlation between parental reports of the child distress and the rates of medical adherence in all categories of adherence except for Allergen Removal.

Hypothesis 2

H2: Higher levels of Parental Distress as measured by the Parental Distress scale of the PSI will negatively correlate with rates of medical adherence on each of the six scales.

Spearman's Correlations for Hypothesis 2

<u>Measure</u>	<u>Rho</u>	<u>PSIPD</u>	<u>N</u>
Bleach Bath	-1.35	.243	77
Moisturizers	-0.66	.554	83
Topical Medications	.019	.869	81
Wet Wraps	.019	.900	45
Topical Creams	.033	.810	57
Allergen Removal	-.043	.779	45

A series of Spearman's correlations were conducted to test the hypothesis that there would be a negative correlation between Parental Distress (PSIPD) and rates of medical adherence in each of the six categories. Although there appeared to be a negative correlation between Parental Distress and Bleach Bath adherence, none of the correlations were statistically significant. This hypothesis was therefore not supported.

Table 10: Spearman's Correlations for Hypothesis 2

Measure	Rho	p	df
<i>PSIPDSIG</i>			
Bleach Baths	-.122	.290	77
Moisturizers	.122	.274	83
Topical Medications	.040	.723	81
Wet Wraps	-.072	.639	45
Topical Creams	.224	.094	57
Allergen Removal	-.124	.417	45
<i>PSIPCDISIG</i>			
Bleach Baths	-.170	.139	77
Moisturizers	.047	.673	83
Topical Medications	-.092	.416	81
Wet Wraps	-.003	.984	45
Topical Creams	-.048	.721	57
Allergen Removal	-.012	.936	45
<i>PSIDCSIG</i>			
Bleach Baths	-.216	.059	77
Moisturizers	.007	.947	83
Topical Medications	-.244*	.028	81
Wet Wraps	-.103	.499	45
Topical Creams	-.075	.578	57
Allergen Removal	.140	.360	45
<i>PSITSSIG</i>			
Bleach Baths	-.128	.268	77
Moisturizers	.115	.300	83
Topical Medications	-.064	.572	81
Wet Wraps	-.136	.373	45
Topical Creams	.012	.932	57
Allergen Removal	-.019	.902	45

Note. * $p < .05$.

A series of Spearman's correlations were conducted to test this hypothesis. The results indicated minimal support for a possible relationship between parental distress (PSIPDSIG) and medical adherence in each of the six categories. The only statistically significant result (See Table 9) of each of these analyses was a negative correlation between a clinically significant score on the Difficult Child Scale with the results of these analyses being included in Table 4. Overall, these

results indicated only minimal support for this second hypothesis as one of the analyses conducted was found to achieve statistical significance. A significant, negative correlation was found between a clinically significant positive score on the PSI Difficult Child Scale and the Adherence subscale of Topical Moisturizers. There were no statistically significant findings within the clinically significant scores on any of the other scales of the PSI (PD, PCID, DC or TS) and any of the six types of medical adherence.

Hypothesis 3

H3: Higher levels of parent-perceived parent-child interactional stress as measured by the Dysfunctional Interaction scale of the PSI will negatively correlate with rates of medical adherence on each of the six scales.

Table 11: Spearman's Correlations for Hypothesis 2

Measure	PSIPD		
	Rho	p	N
Bleach Bath	-.215	.060	77
Moisturizers	-.108	.329	83
Topical Medications	-.061	.590	81
Wet Wraps	.076	.621	45
Topical Creams	.040	.770	57
Allergen Removal	.106	.489	45

A series of Spearman correlations were conducted in order to test this study's third hypothesis. Each scale of the PSI (DC, PD, and PCIF) were compared to the rates of medical adherence rates on each of the six categories (Bleach Baths, Moisturizers, Topical Medications, Wet Wraps, Topical Creams, and Allergen Removal). No statistically significant correlation was found between the level of parent-perceived Parent-Child Dysfunctional Interaction (PCDI) as measured by the PSI and each of the six scales of medical adherence. Therefore, this third hypothesis is not supported.

Hypothesis 4

H4: Higher levels of the total score of Parental Stress Index will negatively correlate with rates of medical adherence on each of the six scales

Table 12: Spearman's Correlations for Hypothesis 4

Measure	PSITS		
	<u>Rho</u>	<u>p</u>	<u>df</u>
Bleach Baths	-.237*	.038	77
Moisturizers	-.039	.728	83
Topical Medications	-.116	.302	81
Wet Wraps	-.021	.893	45
Topical Creams	-.014	.915	57
Allergens	.064	.676	45

*Note. *p<.05.*

These results were found to partially support the fourth hypothesis that higher levels of Parental Stress Total Score (PSITS) would negative correlate with medical adherence in each of the six categories. One significant correlation was found from the six correlational analyses conducted. This statistically significant negative correlation was found between PSI Total Score and Bleach Bath Adherence. Though not statistically significant, four of the other categories (Moisturizers, Topical Medications, Wet Wraps and Topical Medications) all showed a negative correlation.

Hypothesis 5

H5: Parents who report high levels of parent-perceived child distress as measured by the Difficult Child scale of the PSI will have higher rate of responses of internal reasons for non-adherence behaviors.

Table 13: Pearson's Correlations for Hypothesis 5

Measure	PSIDC		
	<i>r</i>	<i>p</i>	<i>df</i>
Bleach Baths	-.216	.059	77
Moisturizers	-.048	.670	83
Topical Medications	-.092	.414	81
Wet Wraps	-.034	.826	45
Topical Creams	-.082	.543	57
Allergen Removal	.091	.550	45

In order to test this hypothesis, a series of Pearson's correlations were conducted. As presented in Table 7, no statistically significant correlations were found among the six correlations conducted here. These results fail to support this study's fifth hypothesis that parents who reported higher levels of Child Distress on the PSI (PSICD) scale would have higher rates of internal reasons for non-adherent behaviors.

Hypothesis 6

H6: Parents who report high levels of parent distress as measured by the Parent Distress scale of the PSI will have higher rate of responses of external reasons for non-adherence behaviors.

Table 14: Spearman's Correlations for Hypothesis 6

<u>Measure</u>	<u>Rho</u>	<u>PSIPD</u>	<u>df</u>
Bleach Baths EXT	.013	.903	86
Moisturizers EXT	.124	.256	86
Topical Medications EXT	-.053	.625	86
Wet Wraps EXT	.132	.227	86
Topical Creams EXT	.088	.419	86
Allergen Removal EXT	.093	.395	86

A series of Spearman correlations were conducted in order to test the hypothesis that higher levels of Parental Distress (PSIPD) would positively correlate with higher rates of external reasons for non-adherent behaviors. As shown in the following table, none of the correlations conducted were found to achieve statistical significance. All of the six categories with the exception of Topical Medications showed a positive correlation, but none of the relationships were statistically significant. Therefore, there is no evidence to support that high scores of the Parent Distress Scale of the PSI (PSIPD) would correlate with higher rates of external reasons for non-adherence behaviors.

Hypothesis 7

H7: Parents who report high levels of parent-child interactional distress as measured by the Dysfunctional Interaction scale of the PSI will have higher rate of responses of interpersonal reasons for non-adherence behaviors.

Table 15: Spearman's Correlations for Hypothesis 7

Measure	PSIPCDI		
	Rho	p	df
Bleach Bath PCIF	.168	.121	86
Moisturizers PCIF	.057	.604	86
Topical Medications PCIF	.157	.150	86
Wet Wraps PCIF	-.092	.401	86
Topical Creams PCIF	-.027	.804	86
Allergen Removal PCIF	.149	.171	86

Spearman's correlations were conducted in order to test the hypothesis that higher rates of the Parent-Child Dysfunctional Interaction subscale would positively correlate with higher levels of Parent-Child Interactional factors as reasons for non-adherent behaviors. The analysis resulted in no statistically significant findings and two of the correlations (Wet Wraps and Topical Creams) showed possible negative correlations. Therefore, the hypothesis that high rates of Parent-Child Dysfunctional Interaction on the PSI Scale would correlate with higher rates of interpersonal reasons for non-adherence behaviors was not confirmed.

Hypothesis 8

H8: Parental rating of disease severity will positively correlate with physician rating of disease severity.

Table 16: Spearman's Correlations for Hypothesis 8

<u>Measure</u>	<u>Rho</u>	<u>p</u>	<u>df</u>
<i>Compare SEV</i>			
PHYDS	.011	.923	85
PHYADH	-.187	.087	85
PHYRTT	-.009	.934	85
<i>Current SEV</i>			
PHYDS	-.103	.346	85
PHYADH	-.153	.162	85
PHYRTT	-.122	.265	85

Two separate sets of Spearman's correlations were conducted in this hypothesis: First, Spearman correlations sought to examine the relationship between the parental rating of current disease severity (CurrentSev) to the Physician Rating of Disease Severity (PHYDS), Physician Rating of Adherence (PHYADH) and Physician Rating of Response to Treatment (PHYRTT). Second, Spearman correlations examined the relationship between the parental rating of disease severity compared to other children with AD (CompareSev) to the Physician Rating of Disease Severity (PHYDS), Physician Rating of Adherence (PHYADH) and Physician Rating of Response to Treatment (PHYRTT). There were no significant correlations found between any of the three physician's ratings (PHYDS, PHYADH or PHYRTT) and either parental rating of disease severity (CurrentSev or CompareSev). These results fail to support the hypothesis that the parental rating of disease severity would positively correlate with physician rating of disease severity.

Hypothesis 9

H9: Parents of children who report lower levels of disease severity will differ from parents of children with high levels of severity on categories of reasons for medical non-adherence.

Table 17: Spearman's Correlations for Hypothesis 9

<u>Measure</u>	<u>Chi²</u>	<u>p</u>	<u>df</u>
<i>Compare SEV</i>			
Bleach Bath EXT	-	-	-
Bleach Bath ADH	2.481	.648	4
Bleach Bath INT	1.330	.856	4
Bleach Bath PCIF	9.527*	.049	4
Moisturizers EXT	8.059	.089	4
Moisturizers INT	.674	.954	4
Moisturizers PCIF	11.587	.171	8
Topical Medications EXT	1.923	.750	4
Topical Medications INT	1.385	.847	4
Topical Medications PCIF	4.878	.300	4
Wet Wraps EXT	4.390	.356	4
Wet Wraps INT	1.129	.890	4
Wet Wraps PCIF	15.402*	.004	4
Topical Creams EXT	4.156	.385	4
Topical Creams INT	5.245	.263	4
Topical Creams PCIF	4.156	.385	4
Allergen Removal EXT	8.945	.062	4
Allergen Removal INT	3.132	.536	4
Allergen Removal PCIF	1.705	.790	4
<i>Current SEV</i>			
Bleach Bath EXT	4.578	.333	4
Bleach Bath ADH	-	-	-
Bleach Bath INT	4.654	.325	4
Bleach Bath PCIF	.744	.946	4
Moisturizers EXT	5.250	.263	4
Moisturizers INT	.974	.914	4
Moisturizers PCIF	10.652	.222	8
Topical Medications EXT	12.014*	.017	4
Topical Medications INT	6.461	.167	4
Topical Medications PCIF	3.405	.492	4
Wet Wraps EXT	.689	.953	4
Wet Wraps INT	8.526	.074	4
Wet Wraps PCIF	6.199	.185	4
Topical Creams EXT	.321	.988	4

Table 17 Continued: Spearman's Correlations for Hypothesis 9

Measure	Chi ²	<i>p</i>	<i>df</i>
Topical Creams INT	2.777	.596	4
Topical Creams PCIF	1.298	.862	4
Allergen Removal EXT	4.190	.381	4
Allergen Removal INT	2.771	.597	4
Allergen Removal PCIF	1.063	.900	4

Note. **p*<.05.

A series of Pearson's chi-square analyses were conducted in order to test the hypothesis that low levels of reported disease severity (both CurrentSev and CompareSev) would differ in the reasons for non-adherence behaviors (ie. Internal, external or Parent-Child) from high levels of reported disease severity. A significant association was found between Compare SEV and Bleach Bath/Parent-Child Interactional Factors. Therefore, parents who reported higher levels of comparative severity reported more parent-child interactional factors as a reason for non-compliance with Bleach Baths than parents who reported lower levels of comparative disease severity. A significant association was also found between Current SEV and Topical Medications External Factors. Parents who reported higher levels of current disease severity reported higher rates of external reasons for non-adherence behaviors with Topical Medications. These results provide limited support to the hypothesis that level of disease severity may have an influence on reasons for non-adherence behaviors.

Hypothesis 10

H10: Rates of physician-reported disease improvement will positively correlate with parental-reported rates of medical adherence on each of the six scales.

Table 18: Spearman's Correlations for Hypothesis 10

<u>Measure</u>	<u>Rho</u>	<u>p</u>	<u>df</u>
<i>PHYADH</i>			
Bleach Bath ADH	-.202	.081	76
Moisturizers ADH	-.147	.188	82
Topical Medications ADH	-.139	.218	80
Wet Wraps ADH	.028	.853	45
Topical Creams ADH	.157	.242	57
Allergen Removal ADH	.112	.463	45
<i>PHYADH</i>			
Bleach Bath ADH	.189	.102	76
Moisturizer ADH	-.094	.403	82
Topical Medications ADH	-.139	.218	80
Wet Wrap ADH	.291	.053	45
Topical Creams ADH	.092	.494	57
Allergen Removal ADH	.061	.692	45
<i>PHYRTT</i>			
Bleach Bath ADH	.051	.661	76
Moisturizers ADH	.108	.334	82
Topical Medications ADH	.060	.595	80
Wet Wraps ADH	.102	.504	45
Topical Creams ADH	.040	.767	57
Allergen Removal ADH	.054	.722	45

Spearman correlations were performed to test a possible relationship between physician-reported rates of medical adherence and parent-reported rates of medical adherence. Although there was a consistent positive correlation between the two variables in each of the six categories of medical adherence, none of the correlations were found to be statistically significant. Therefore, the hypothesis that there is a relationship between parental-reported rates of medical adherence and physician rates of disease improvement is not supported.

Hypothesis 11

H11: Physician's rating of adherence will positively correlate with parental rating of medical adherence on each of the six medical adherence scales (Bleach baths, moisturizers, topical medications, wet wraps, other medications, and removal of allergens).

Spearman correlations were conducted to assess the relationship between physician rating of adherence and parental rating of medical adherence on each of the six scales. No statistically significant relationship was found between parental rating of medical adherence in any of the six categories and physician's rating of adherence (Table 18).

Conclusion

The current study includes 86 parents of children with Atopic Dermatitis, however one subject was excluded from the study due to not identifying as the child's legal guardian or primary caregiver. Parents made up the majority of primary caregivers at 79.1% , while 2.3% of subjects reported being step-parents, 2.3% of subjects reported being grandparents, and 1.2% of respondents reported being a foster parent. The majority of the primary caregivers participating in the study were female (79.1%) with 16.3% being male and 4.7% missing. Household incomes consisted of 41.9% reporting \$30,000 or less annually with 58.1% reporting yearly incomes at over \$30,000 per year. Married parents made up 58.1% of the study, with single parents at 29.1%, divorced at 5.8%, 2.3% remarried, 1.2% widowed, and 3 cohabitating.

The mean age of the children in the study was 6.542 years. with an average duration of time child had eczema being 5.62 years. Fifty percent of the children were male while 47.7% were female (2.3% missing). Identified race of the children included 50% Caucasian, 36%

African American, 3.5% Asian, 4.7% Hispanic, 3.5% Biracial and 2.3% Other.

There were five statistically significant findings in the study. First, a negative correlation was found between a positive score on the PSI Difficult Child subscale and level of adherence on topical medications. Second, a positive Total Score on the Parenting Stress Index was found to be negatively correlated with the adherence of Bleach Baths. Third, parental reports of comparative severity of child's eczema was found to be positively correlated with parents reporting a Parent-Child Interactional Factor reason for non-adherence with bleach baths. Fourth, parental reports of comparative severity of child's eczema was found to be positively correlated with a Parent-Child Interactional Factor for non-adherence with bleach baths. Finally, parental-rating of current severity of the child's eczema was positively correlated with parents reporting an External Factor reasons for non-adherence to topical moisturizers.

Statistical analysis regarding the other hypotheses were not found to be statistically insignificant. There was no association found between separate scales of the PSI with the level of adherence behaviors. There were no significant correlations found between PSI subscales and reasons for non-adherence behaviors. Finally, there was no statistically significant relationship found between parental ratings of medical adherence and physician reports of either adherence or disease improvement. adherence to physician reports to disease severity and adherence

CHAPTER V: DISCUSSION

The present study had five overall objectives. First, it aimed to add to the existing Chisolm framework of adherence behaviors in children with Atopic Dermatitis (2009). Second, it examined the overall rate of adherence on each of six types of adherence behaviors. Third, it sought to understand the relationship between parent-child interactional factors and each of the six types of adherence behaviors. Fourth, the study explored the relationship between areas of parental stress and each of the six types of adherence behaviors. Finally, the study explored if any correlation exists between parental report and physician report of disease severity and rates of adherence. This chapter will explore the results related to each of these goals. In addition, limitations to this study and areas for future research will be examined.

There were several basic assumptions that provided the framework for the design of this study. . One assumption was that medical adherence leads to better treatment outcomes (Ben-Gashir, Seed & Hay, 2004; Ohya, et al, 2001). A second assumption was that the time consuming, expensive, and stressful nature of managing a child with AD makes medical adherence difficult for parents (Ben-Gashir, Seed & Hay, 2004; Ohya, et al. 2001; Krejci-Manwaring, et al. 2007). Third, it was assumed parental reporting of adherence would be somewhat overreported in rates of adherence based on previous studies but that the reasons for non-adherence would be accurate (Krejci-Manwaring, et al., 2007; Nolan & Feldman, 2003). Fourth, that the existing model of adherence behavior by Chisolm, including external and internal reasons for non-adherence behavior, would be supported by quantitative data (2009). Finally, that the addition of interpersonal factors would seek to explain more of the non-adherent behaviors than previous models (Ohya, et al. 2001; Daud, Garralda & David, 2003; Balkrishnan, Housman, Carroll & Feldman, 2003). These assumptions were based on experiences of the researcher in raising children with AD, and stimulated by stories of other parents who have raised children with AD. Additionally, these assumptions were also based on hearing the experiences of the staff in a dermatological practice that treats children with AD. A final factor influencing this study was the research that currently exists on the topic of

medical adherence, family stress, and AD (Ohya, et al., 2001; Daud, Garralda & David, 2003; Balkrishnan, Housman, Carroll & Feldman, 2003; Ou, Feldman & Balkrishnan, 2010).

Although several of these assumptions were supported by the current study, others were not supported by the data. One assumption that seemed to be supported by the data is that parents reported just as many interactional factors for non-adherence behaviors as internal or external factors. However, several of the afore-mentioned assumptions were questioned in the data. For instance, parents did not report higher levels of stress than national averages of parents without children with chronic illness. Second, parents seemed to report much higher rates of adherence than previous studies involving parental-self report have found. The following discussion will attempt to provide reflections on the results and make meaning of the discrepancies.

Discussion of Findings

Demographic Information

The study was conducted at two different sites in order to increase the demographic diversity of the sample in terms ethnicity and socioeconomic status. One site was located in an urban area of St. Louis City, and the second site was in a more suburban area of the greater metropolitan St. Louis Area. A national survey of the prevalence of children with AD found a high percentage of children with African American race, single mother households, and households with higher socioeconomic status (Shaw, Currie, Koudelka & Simpson, 2010). This data was then compared to this national survey to assess how closely the demographics of this sample match larger samples taken throughout the United States. The next paragraph will compare the results of the national study to the results of the current study.

The racial demographics in this study included 36% African American, 50% Caucasian, 3.5% Asian, 4.7% Hispanic, 3.5% Biracial and 2% who identified as “Other”. African American subjects were more prevalent in the study than in the national study (Shaw, Currie, Koudelka & Simpson, 2010). Single parent households made up 29.1% of the study, with 58.1% reporting being married. This contradicts the national survey which reports a higher percentage of single parent households being represented in children with AD. The large percentage of higher socioeconomic status in the national study also did not seem to be consistent in this study, with 41.9% of households having incomes of less than \$30,000 per year and 43% being about \$60,000. However, some respondents reported receiving financial support from either grandparents, significant others, or friends that may not be accounted for in the household income. The discrepancies between the national survey and the current population may possibly be explained through being limited to the greater metropolitan St. Louis area and only restricting the study to one practice as well as a disproportionate ratio of the surveys being returned in an urban area.

Parental Stress

The impact of having a child with Atopic Dermatitis on the stress of the parents has been well-documented (Warschburger, Buccholz & Petermann, 2004; Ben-Gashir, Seed & Hay, 2002; Chamlin, 2006; Balkrishnan, et al., 2003). There is also a strong correlation between increased disease severity and higher family levels of stress (Balkrishnan, et al., 2003). It would stand to reason, then, that the overall average scores of the PSI Total Scores in the study would be higher than the average level found in the general population. The mean of the PSI Total Score in this study was 65.79. This compares to the normative average of parents (without children with chronic illnesses) mean of 73.44 with a SD of 25.56 (Reitman, Currier & Stickle, 2002). The

averages of the subscale in this study were Parental Distress: 23.08; Difficult Child: 24.1; and Dysfunctional Interaction: 18.66. The percentages of each subscale of the normative study was Parental Distress: 24.67 with a SD of 9.13; Difficult Child: 26.61 with an SD of 9.69 and Dysfunctional Interaction 22.22 with a SD of 8.90 (Reitman, Currier & Stickle, 2002). Therefore, the means of each of the subscales reported in the study, as well as the mean of the Total Score in the study, were lower than the national average of parents without chronic illness. This result would seem to indicate an under-reporting of stress by the parents. The subscale of Defensive Responding in this study, which assesses whether or not a respondent is answering in a truthful way, was 22.1%. The high rate of defensive responding, along with the overall averages being lower than the overall population, lends support to the argument that the participants in this study were under-responding rates of parental stress.

There are several possible reasons for the possible defensive, underreporting of parental stress. One possibility, of course, is that the respondents answered correctly and this population differs significantly on levels of stress with other studies. However, the high rate of defensive responding (22.1%) would appear to discredit this possibility. The underreporting of stress could also be a result of the parent filling out the survey in front of the child in a doctor's office. Parents may have filled out the survey quickly and defensively due to the pressure of time and worry that the clinical staff may see the results. Either way, the apparent underreporting of stress in parents significantly impacted the study's ability to ascertain how that stress affects adherence behaviors.

Adherence Behaviors

The purpose of this study was to look into the rates of adherence of each of the six types of adherence categories and to look for variations in the types of adherence to further tailor interventions to those areas of adherence that have the lowest rates. The rates of adherence reported in this study was as follows: Bleach Baths 55%; Moisturizers 71.4%; Topical Creams: 74%; Wet Wraps 53%; Allergen Removal 65%; and Topical Medications 90.6%. These reported rates of adherence are clearly higher than that assessed in MEMS studies, and are also on the high end of even self-report data (Hodari, Nanton, Carroll, Feldman & Balkrishnan, 2006).

Several studies have sought to assess medication adherence rates in children with AD with reported rates ranging from 11% to 93%, with a median of 58% (Ou, Feldman & Balkrishnan, 2010; Krejci-Manwaring, et al., 2007; Burkhart & Dunbar, 2002; Serup et al., 2006). When compared to “gold standard” adherence measurement techniques such as the MEMS system wherein the use of medication is electronically monitored, parent self-reports have consistently been shown to be over-reported (Hodari, Nanton, Carroll, Feldman & Balkrishnan, 2006). However, MEMS is only able to monitor the adherence in medication use, and not able to assess adherence to bleach bath, wet wrap, other medications, or removal of allergen protocols. In fact, previous studies on adherence have been limited to the use of topical medications and neglected the other areas of treatment. The presumption of this study was that the reported rates of medical adherence would be higher than those reported in the MEMS studies (less than 50% but lower than the 93%) (Hodari, Nanton, Carroll, Feldman & Balkrishnan, 2006).

Some studies neglect the concept of adherence altogether and focus instead on disease improvement, assuming that disease improvement is due to adherence (Bass, Anderson & Feldman, 2015). Therefore, the other areas of adherence have never been quantitatively addressed to date.

The reasons for the high rates of self-reported adherence by parents in this study could be multi-faceted. First, it may be a function of the medical staff handing out the packets and witnessing the consents. This was required by the IRB, however it may have sent the incorrect message to parents that the medical staff would be able to review their answers on the surveys. The parents may have feared that if the clinical staff knew that the parents were not completely adherent that staff would somehow adjust treatment or scold them for not following treatment recommendations. Second, there may have been shame inherent in reporting lack of medical adherence, and it may have been helpful for the survey to normalize non-adherence by putting some disclaimer around how difficult medical adherence is for parents and previous studies' findings on adherence rates. Adding in a semi-structured interview may have been helpful in gaining a relationship with the parents to normalize non-adherence behaviors and allow them to talk openly about the causes. Finally, parents may have been confused about each of the six types of medical adherence due to the complex nature of each type of adherence and it may reflect the parents' overall confusion about what is expected in adherence behaviors. For instance, for each of the six types of adherence behaviors there are different times frames, times per day usage and complicated instructions. A standard medical protocol may include instructions to apply moisturizers 2-3 times per day, 1-2 bleach baths per day using ¼ cup bleach, wet wraps to be applied 3-4 times per day for a period of 15 minutes, application of topical medications 1-2 times per day. Therefore, treatment protocols are complex and time-

consuming (Ohya et al., 2001). Previous studies including “Written Action Plans” have been found to increase adherence rates (Chisolm et al., 2008; Chida et al., 2007; Weber et al., 2008). Parents may not have understood the difference, for instance, between topical medications, moisturizers or topical creams. Therefore, parents may over-report their adherence while only applying one. Bleach baths, allergen removal and wet wraps are types of adherence that are easily discernable, however these measures are typically considered preventative, can be confusing and time consuming, and also showed the lowest rates of adherence.

There are some studies that posit that topical medications have higher rates of adherence than preventative treatments such as bleach baths and allergen removal, however this has never been quantitatively verified (Bass, Anderson & Feldman, 2015). This is especially problematic given that the lack of preventative protocols cause an increased level of disease severity as well as a more frequent use of topical medications which carry greater risk factors. Failure to be adherent to preventative measures such as bleach baths, allergen removal and moisturizer application can leave children with more discomfort, greater sleep disturbances, and higher risk of infections (Bass, Anderson & Feldman, 2015). The rate of adherence for Topical Medications was much higher than any other category in the study at 90.6%, compared to the second highest of Topical Creams at 74% and Bleach Baths at 55%. This would lend support to the prediction that topical medications have higher rates of adherence than preventative treatments.

However, the statistically significant finding in the study of the negative correlation between scores on the PSI-Difficult Child Scale and medical adherence on Topical Medications appears to contradict the hypothesis that higher levels of child distress would predict higher levels of medical adherence to Topical Medications. Although Topical Medication rates were more common than preventative measures, it appears that those rates decline at a statistically

significant rate if the parent views the child as difficult. One possible explanation for this finding is that a parent may have difficulties applying the medications to a child who may become defiant or be sensitive to the burning sensations that the Topical Medications may cause.

The theory that preventative measures will have lower rates of adherence is supported by the low rates of adherence to Bleach Baths (55%), Wet Wraps (53%) and Allergen Removal (65%). Also, the finding of a significant negative correlation between scores on the PSI – Total Score and Bleach Bath Adherence supports the theory that as overall stress rises, the preventative measure of Bleach Baths is less likely to be performed by parents. Again, this is unfortunate since lower adherence rates to preventative measures such as bleach baths can cause more severe disease outbreaks and require the use of stronger medications with higher risk of side effects (Bass, Anderson & Feldman, 2015)

The specific nature of Bleach Baths, (ie. Being time-consuming, sometimes painful for the child, and difficult to manage “forcing a child” to remain in a bleach bath several times a day,) may argue for an increased impact of interactional factors. Bleach baths are inexpensive and simple tasks to perform. However, they can be seen as time consuming and intrusive or painful by both parent and child. There can also be difficulties in parents being able to get children to conform to bleach baths and this may cause power struggles within the parent-child relationship. Understanding and supporting parents through these struggles could result in a lower level of disease severity for the child and a lower risk for the child to require higher risk, systemic medications.

Assessment of Parent-Child Interactional Factors

Chisolm, et al.'s Health Behavior Model for children with Atopic Dermatitis was based on existing adherence frameworks in order to identify new targets aimed at improving adherence (2009). Because effective treatments exist, poor outcomes are typically associated with poor adherence. Conceptual models of adherence behaviors can help to understand the “salient leverage points for intervention” and design empirical studies (Chisolm, et al., 2009, p. 231). Included in this framework are External Factors such as family employment, SES, and access to care, and Internal Factors such as perceived severity of the disease, trust in physician, and self-efficacy of treatment (Chisolm, et al., 2009). Identifying internal and external factors has spurred interventions such as Written Action Plans, educational programs, and support groups (Chida, et al., 2007; Weber, et al., 2008; Chisolm, et al., 2008).

This study explored looking at parent-child interactional factors as a third possible factor to add to Chisolm's Framework of Adherence Behaviors that includes internal and external factors (See Figure 3). The expectation of the study was that if parents were given options of explaining their non-adherent behavior, they would list parent-child interactional factors as well as internal and external factors. Chisolm anecdotally acknowledged that one of the possible reasons for non-adherence is the child refusing that the medication be applied due to not liking how it feels. However, he does not include interactional reasons into his framework (Chisolm, 2009). This is supported by other studies where parents have rated their children with AD as demanding, less adaptive and more fearful as well as feeling helpless and experiencing disciplinary issues with their children with AD (Daud, Garralda & David, 1993; Faight, Bierl, Barton & Kemp, 2007). Finally, some studies have found children to be “downright oppositional” and find the medication to be both messy and painful (Ou, Feldman &

Balkrishnan, 2010). If so, this would open up the potential for additional “points for intervention” for treatment including protocols such as filial therapy to decrease the child’s opposition to the parent or parenting classes specific to parents of children with AD to target the specific strategies to increase the child’s compliance to the medical regimen for treatment (Chisolm, et al., 2009, p. 231).

For these reasons, the study posited that parents would also identify Parent-Child Interactional Factor at similar or greater levels to internal and external factors. Parents who reported lower than perfect adherence were asked the reasons for the non-adherence. These reasons were broken up into three categories... Internal Factors, ie. “I don’t know how to do it”, External Factors, ie. “It costs too much”, or Parent-Child Interactional Factors, ie. “My child won’t allow me to do it”. The presumption of the data would be that internal and external factors would be present for each of the six types of adherence behaviors.

In the current study, with the exception of allergen removal, at least as many or more parents listed parent-child factors as compared to either internal or external factors. For instance, 40.7% of parents who were less than perfectly adherent on bleach baths reported parent-child interactional factors with only 18.6% reporting external factors and 15.1% reporting internal factors. Wet wraps also included a greater number of Parent-Child interactional factors (12.8%) than either External (9.3%) or Internal (5.8%) factors. Topical Medications continued this pattern of having a greater percentage of Parent-Child Interactional factors at 23.3% compared to 12.8% External factors and 11.6% Internal factors. The trend of bleach baths, wet wraps and topical medications having higher parent-child factors for non-adherence may be due to the painful or uncomfortable aspect of each of these adherence behaviors to the child. Moisturizers held a 17.4% parent-child interactional factor as compared to 17.4% for external factors and

10.5% for internal factors. Although moisturizers can also be uncomfortable for the child, they typically aren't quite as painful as the topical medications that children report as stinging and being painful to the sensitive skin (Ou, Feldman & Balkrishnan, 2010). Allergen removal is the only category that does not have a comparatively large parent-child response, which may reflect the non-interactive component for the parent-child around allergen removal (See Table 6 on Page 77).

Correlation Between Parental Report and Physician Report of Disease Severity and Adherence Rates

The study predicted that there will be a strong, positive correlation between parental report of disease severity and physician's report of disease severity. It was also posited that there will be a positive correlation between self-report adherence rates and physician's assessment of adherence. Finally, it was also anticipated in this study that there will be a positive correlation between physician reports of adherence and disease improvement.

The results did not show statistically significant correlations between parental self-report and physician assessment of adherence or disease severity. Second, no significant relationship was found between Physician Adherence and Physician Response to Treatment. Once again, the lack of correlation between parental self-report and physician assessment of adherence conflicts with previous studies that have shown a link to exist (Housman et al. 2002; Balkrishnan et al., 2003). Also, the lack of correlation between physician assessment of adherence and physician response to treatment also contradicts previous research that shows a link between medical adherence and disease improvement (Ou, Feldman & Balkrishnan, 2010). Studies have shown a strong correlation between parent and physician reports of disease severity in the child's AD

(Housman, et al. 2002; Balkrishnan, et al., 2003). However, studies have not been done to compare the self-report adherence rates for parents with that of physician's assessment of adherence.

The reasons for the first failure to support the hypothesis may reflect the low sample size of the study or perhaps over or under-reporting of disease severity by the parents. However, the second discrepancy between the hypothesized results of physician assessment of adherence and physician response to treatment is a bit more puzzling due to the consistency of the same physician/physician assistant filling out each form. One possible explanation is that although the physician may be able to accurately monitor the amount of medication being used by asking the parents to bring in the tubes of medication and checking with the pharmacy, they again need to rely on parental self-report for adherence around moisturizers, bleach baths, wet wraps and allergen removal. Therefore, this under or over-reporting may have caused the inconsistencies between the hypothesized results and the actual results of the study.

Limitations of the Study

Several limitations existed in the study design and implementation. First, the reduction in the sample size served to lower the level of statistical power to analyze the hypotheses. The reduction in sample size was done out of necessity due to rate of data collection and reaching a point of saturation within the dermatological practice. However, this lowered sample size served to lower the statistical power of some of the tests used for analysis and could have reduced the ability of the statistical tests to find significant findings. For instance, it became necessary to lower the number of dependent variables, thereby lowering the statistical power of independently running each of the subscales of the PSI. The first three hypotheses were affected by this

lowering of sample size. However, the trend that did exist in the first hypothesis showed a slightly negative correlation (though not statistically significant), between the score of the Difficult Child subscale of the PSI and medical adherence rates, which directly contradicts the first hypothesis that high levels of child distress would predict higher rates of medical adherence.

Second, although it was explicitly stated in the informed consent document that the information would be de-identified and that information would not be passed on to the medical team, the fact that these surveys were handed out by medical staff may have increased the parents' over-reporting of adherence behaviors due to concerns that the medical staff may have access. Because the surveys were designed so that subjects were only prompted to give reasons for non-adherent behaviors when they reported less than perfect adherence rates, this limited the ability of the study to get information on blocks to adherence from all of the subjects.

Third, the limitation of working with one dermatological practice, even if it did collect data at two locations, possibly limited the ability of the study to extrapolate to the larger population of parents of children with AD. Not only was the study limited to one dermatological practice, but it also failed to account for the large percentage of children with AD who are treated by their primary care physicians rather than receiving specialized treatment by a pediatric dermatologist. However, expanding this type of study to more than one practice may have significant limitations since there may be inconsistencies between the instructions for treatment protocols from practice to practice. For instance, one practice may advise all parents to adhere to bleach baths while others may not. This inconsistency would possibly confuse parents and impact the data collected.

The statistical power of the data was weakened by the low levels of scores that reached clinical significance on each of the subscales as well as the total score on the PSI. As discussed earlier in the chapter, the scores in this study are even below national averages of parents with children without chronic illness. This is inconsistent with a wealth of research that shows that AD in children has a negative impact on family and parental stress (Kelsey, Klinnert & Bender, 2010; Chamlin & Chren, 2010). Given that over 22% of respondents responded in ways that were clinically significant for Defensive Responding, there is reason to believe that at least one-fifth of parents underreported their level of Parental Stress.

Also, the lower sample size was detrimental in the power analysis for other variables that had lower response rates, such as “Reasons for Non-Adherence Behaviors”. The “Reasons for Non-Adherence Behaviors” were only filled out by parents who reported less than perfect rates of adherence. Due to the high rates of parent-reported medical adherence in each of the six categories, the actual sample size of parents filling out the “Reasons for Non-Adherence Behaviors” was relatively small. Although some over-reporting of medical adherence was expected in this study due to other studies that showed that parental self-report resulted in higher rates of reported adherence than MEMS testing, the rates of reported adherence in this study were higher than most other self-report adherence studies (Krejci-Manwaring, et al., 2007; Nolan & Feldman, 2009; Hodari, Nanton, Carroll, Feldman & Balkrishnan, 2006). This high level of adherence rates caused low numbers of completed “Reasons for Non-Adherence Behaviors”. Although imputation of the variables with missing data was discussed, after consultation and extensive reading on the process of imputation, the large number of missing data (on some variables up to 50%) made imputation contra-indicated.

The levels of reported adherence behaviors by parents appears to portray higher rates of adherence behaviors than previous studies (Ou, Feldman & Balkrishnan, 2010; Krejci-Manwaring, et al., 2007; Burkhart & Dunbar, 2002; Serup et al., 2006). One possible reason for this was the process of data collection. Although the informed consent explicitly stated that the medical team would only have access to aggregated, de-identified information from the study, the fact that the clinic nurses witnessed the informed consents may have made parents doubt the confidentiality of the study and increased their self-reports of adherence behaviors. It is difficult to assess the expected level of adherence rates, however, due to the unique characteristic of this study in breaking down adherence behaviors into the six different categories.

The process of data collection may have caused some increase in self-reported adherence behaviors. Due to limitations around the IRB in requiring a member of the research team to witness the informed consent documents, the medical staff (specifically clinical nurses within the practice) became responsible for handing out the surveys and describing the study once the packet was requested by the subject. This not only caused a delay in data collection due to the clinical nurses frequently being too busy or overwhelmed to hand out surveys, but also perhaps caused subjects to feel like the information was not confidential from the medical staff. Therefore, it would stand to reason that some subjects would over-report adherence behaviors out of fear of the doctor being informed of their non-adherence behaviors. This would reflect previous studies showing that parents typically over-report adherence behaviors and even increase their adherence behaviors within the week or two prior to a doctor's visit (Hodari, Nanton, Carroll, Feldman & Balkrishnan, 2006)).

Limiting the study to two sites of one dermatological practice allowed for the assurance that a standard medical protocol was given to each patient including wet wraps, bleach baths,

topical moisturizers, and removal of allergens. The use of one dermatological practice also allowed the study to correlate physician assessment of disease severity, response to treatment, and adherence due to the protocol of the practice to assess for each of these scales for each patient. However, the limitations to one practice had several limitations as well. Although the practice had locations in both urban and suburban areas of Metropolitan St. Louis, it covers no rural areas and is not necessarily representative of the national demographics in regards to race, socioeconomic status, and types of household. This may make it difficult to extrapolate the data to the nation-wide population of AD patients.

There may have been limitations to the scales utilized in the study. Although the PSI has been well-validated in a diverse population of parents and has been used in previous studies involving parents of children with AD, there have been no studies validating its use specifically for parents of children with chronic illness. Its questions, ie. “My child seems to cry or fuss more often than most children” or ”My child makes more demands on me than most children” do not account for the objective differences in raising a child with a chronic illness such as AD and may confuse parents in their reporting and cause them to compensate by reporting lower levels of stress. Similar findings exist with using the PSI with children with autism, reporting some symptoms were not accurately reflected due to being too easy or too difficult to endorse (Rao & Biedel, 2009).

Also, the use of the PSI may not be a valid instrument in assessing the parent’s ability to perform adherence behaviors and elicit the support of the child in a supportive, attuned manner that is consistent with secure attachment. Although the PSI does speak to several attachment-related concepts (ie. “My child reacts very strongly when something happens that my child doesn’t like” or “My child gets upset easily over the smallest thing”, it does not specifically

assess the parent's ability to follow through on expectations inherent in the medical adherence protocol, such as applying topical medications that may irritate or sting the child's skin, or have the child taking bleach baths which the child may experience as painful or boring. A different assessment tool such as the Strange Situation for the child or the Adult Attachment Inventory for the parent may be a more valid means of assessing for the parent-child attachment resilience in the face of unrelenting distress of the child and expectations around medical adherence protocols.

Also, the sensitive and complex issues of medical adherence may be better assessed through qualitative interviewing rather than through quantitative, self-reported measures. Parents who may have been leery to complete a form depicting their non-adherence behaviors may have been more open to someone in a semi-structured interview where the parents felt safe in a non-judgmental environment to openly discuss their struggles with adherence and obstacles that stand in their way. Although it is possible that parents were accurately reporting their adherence behaviors, the level of reported adherence does not reflect either previous studies nor physician/nursing assumptions about the level of medical adherence of parents.

The subject of parental stress may have similar obstacles to correct reporting through quantitative measures. First, parents may experience shame in reporting that their child with chronic illness causes stress in the parent-child relationship. This shame may cause under-reporting in the completion of PSI questions, whereas a semi-structured interview may have allowed for more normalization of the stress inherent in raising a child with AD, thereby opening a door for parents to be more honest about their stress and the ways that they attribute that stress (ie. Parental factors, child factors, or interpersonal factors).

Recommendations for Future Research

Written Action Plans, extra office visits, educational programs, and parent educations have been the latest trends in interventions to treat children with AD (Bass, Anderson & Feldman, 2015; Moore, et al., 2009; Shaw, Morell & Goldsmith, 2008; Rork, et al., 2013; Grillo, et al, 2006). These interventions have had varying success on disease improvement, however only one actually looked at the effect on adherence rather than disease severity (Sagransky, 2010) and this was a pilot study and did not show statistically significant improvement likely due to small sample size (Sagransky, 2010; Bass, Anderson & Feldman, 2015). While it is essential to continue looking into parental internal and external reasons for lower rates of medical adherence, the addition of interventions aimed at the parent-child interactional factors are necessary. One such intervention may be parenting classes specifically geared towards the specific needs of parents of children with AD, such as techniques to aid in sleep, giving bleach baths, and managing clingy and demanding behaviors. Another intervention may be therapy techniques such as filial therapy to aid in the development of the attachment bond between child and parent and to decrease the amount of anxiety and oppositional behaviors in the child (Van Fleet, 1994). The use of Eye-Movement-Desensitization-Reprocessing (EMDR) therapy to diminish the sensory hypersensitivity of children with chronic illness is showing some positive results (Hechler, et al., 2010).

It is also clear from the research that using survey research for parental self-report is not an effective measure (Greenlaw, Yentzer, O'Neill, Balkrishnan, Feldman, 2010). Future research could include semi-structured interviews as well as home visits to monitor whether or not families are following through with adherence protocols around wet wraps, bleach baths and allergen removal. Also, the use of therapeutic techniques could also use additional measures

such as skin conductors and heart rate monitors to assess the functioning of the child's autonomic nervous system, which has shown to function abnormally in children with Atopic Dermatitis (Tran et al., 2010).

Conclusion

This study sought to expand insight into the reasons behind non-adherence behaviors in children with Atopic Dermatitis. It expanded the current research into measurement of adherence behaviors, which has historically only focused on topical medications, and included six areas of adherence that are considered standard protocol for care. This expanded definition allows the dermatological community to get more specific information on what areas of medical adherence parents are following, which ones they are not following, and more specific information on blocks to each type of non-adherence behaviors. The study also sought to assess whether or not parent-child interactional factors needed to be added to the existing adherence framework which only included internal and external factors for non-adherence behaviors. Although the limitations in sample size did not allow for many significant findings (as discussed above), it did show clear differences in the rates of medical adherence for each of the six categories, with wet wraps and bleach baths (more preventative measures) having lower adherence rates than topical medications. This is especially problematic due to the inherent side effects of topical medications that do not exist for more preventative measures such as bleach baths and wet wraps. However, it does logically follow that wet wraps and bleach baths are both more time-consuming and more likely to cause a problem dynamic in the parent-child relationship. Creating interventions that would allow for parents to be more adherent with preventative measures may allow for less use of medications that have potentially harmful side effects as well as lower the risk of overall distress and long term psychological consequences for

the child. Although the lack of statistically significant findings in this study is disappointing, it still appears to make the case for expanding further research to assessing for each of the six types of medical adherence and to add the parent-child interactional factors to the current medical adherence framework.

APPENDIX A

Agreement to Participate in Research Study

Principle Investigator: Christine Schneider

Title of Protocol: Factors of Adherence in Children with Atopic Dermatitis

1. You have been asked to participate in a research study aimed at investigating factors that interfere with medical adherence.
2. Your consent for the study is being given voluntarily. You may refuse to participate. Your decision on whether or not to participate will have no impact on your present or future care with the physicians and/or physician's assistants.
3. If you decide to participate in the study, you are free to withdraw at any time without any negative effect on your relationship with any care providers at Cardinal Glennon.
4. You will be asked to fill out 3 short surveys.
5. These surveys involve no risk to you.
6. Participating in this research will have no direct benefit to you.
7. Although the results of this study may be published, no information that could identify you will be included.
8. Care providers at Cardinal Glennon will not have access to specific participant's information and will only be given aggregate data of all participants in the study.

Thank you for your consideration! If you agree to participate in the study, please request a packet from the front desk.

Sincerely,

Christine Schneider, Doctoral Candidate

Medical Family Therapy

St. Louis University

Phone: 314-489-4810

APPENDIX B

SAINT LOUIS UNIVERSITY

Cardinal Glennon Hospital

Research Study Consent Form

STUDY TITLE:	Parent-Child Interactional Factors that Mediate Adherence Behaviors in Children with Atopic Dermatitis
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This consent form contains important information to help you decide whether to participate in a research study.

The study staff will explain this study to you. Ask questions about anything that is not clear at any time. You may take home an unsigned copy of this consent form to think about and discuss with family or friends.

- **Being in a study is voluntary – your choice.**
- **If you join this study, you can still stop at any time.**
- **No one can promise that a study will help you.**
- **Do not join this study unless all of your questions are answered.**

After reading and discussing the information in this consent form you should know:

- Why this research study is being done;
- What will happen during the study;
- Any possible benefits to you;
- The possible risks to you;
- Other options you could choose instead of being in this study;
- Whether being in this study could involve any cost to you; and

RESEARCH STUDY CONSENT FORM

Participant:		IRB #:	
	<i>First Name / Last Name</i>		
Principal Investigator (PI)	Christine Schneider, LCSW	Contact Phone #	314-489-4810
	<i>First Name / Last Name</i> <i>Credentials</i>		
Title of Project:	Parent-Child Interactional Factors that Mediate Adherence Behaviors in Children with Atopic Dermatitis		

“You” refers to the person who takes part in the research study.

You are being asked to take part in a research study conducted by Christine Schneider, LCSW because you are a primary caregiver of a child with Atopic Dermatitis.

This consent document may contain words that you do not understand. Please ask the researcher to explain anything that you do not understand.

1. WHY IS THIS RESEARCH STUDY BEING DONE?

Atopic Dermatitis (Eczema) is a chronic, remitting skin disease that causes an itchy rash. It is estimated to occur in approximately 17% of children in the United States. Eczema has been found to negatively impact a child’s physical, emotional and social functioning. The burden of eczema on children and their families has been shown to be as great as that of insulin-dependent diabetes. Parents report that children with eczema tend to be more fearful and clingy with

increased behavioral problems. Parents of children with eczema report a loss of sleep and a decreased ability to work outside of the home. Finally, parents report more difficulty in parenting and disciplining children with eczema.

Treatment for eczema can be expensive, complicated and time-consuming for primary caregivers. Parents report intense feelings of helplessness and stress related to the treatment of the disease. They also report worrying about the side effects of medication and the psychological distress caused by applying medications on the child. Parents report that children with eczema are reluctant or defiant to treatment.

No study was found in the literature investigating the impact the parent-child interactions on adherence behaviors. The goal of this study is to explore parent-child interactions that affect adherence behaviors in order to better tailor interventions aimed at improving treatment outcomes in children with eczema.

This study will include a maximum of 200 participants from each of the three Cardinal Glennon Pediatric Dermatology sites.

2. WHAT AM I BEING ASKED TO DO?

You are being asked to fill out three confidential surveys: A Demographic questionnaire, an Adherence Scale, and the Parenting Stress Index – Short Form. Each scale should take 5-10 minutes to complete and can be turned in before leaving the office today. This information WILL NOT be made available to the medical staff. You are also being asked for the researcher to gain access to three scales routinely filled out by the physician regarding disease severity, adherence and response to treatment. Your decision to participate will NOT in any way affect your relationship with your medical provider(s). There will be no follow up participation requested.

3. HOW LONG WILL I BE IN THE RESEARCH STUDY?

The anticipated time commitment for you will be 15-30 minutes at today's visit. The research study plans to collect data for a total of 2-3 months.

4. WHAT ARE THE RISKS?

Some questions on the surveys may make you feel uncomfortable. You do not have to answer any question that causes you discomfort. The researcher is willing to discuss any questions you may have regarding these risks and discomforts.

5. ARE THERE BENEFITS TO BEING IN THIS RESEARCH STUDY?

You will not benefit from this research study. Even though you will not receive any benefit, future primary caregivers of children with Atopic Dermatitis may benefit because of what the researchers learn from this research.

6. WHAT OTHER OPTIONS ARE THERE?

You may choose not to be in this research study.

7. WILL MY INFORMATION BE KEPT PRIVATE?

The results of the research study may be published, but your name or identity will not be revealed and your information will remain private. In order to protect your information, the PI researcher Christine Schneider will assign you a Medical ID number that will be used in the place of any identifying information. This Medical ID number will tie the surveys filled out with the scales filled out by the physician. The physician or medical staff at Cardinal Glennon will not have access to any of your survey answers.

The Saint Louis University Institutional Review Board (the Board that is responsible for protecting the welfare of persons who take part in research studies) or other University officials may review your research study records. State or federal laws or court orders may also require that information from your research study records be released.

8. WHAT ARE THE COSTS AND PAYMENTS?

There will be no cost or payment for participating in this study.

9. WHAT HAPPENS IF I AM INJURED BECAUSE I TOOK PART IN THIS RESEARCH

STUDY?

If you believe that you are injured as a result of your participation in the research study, please contact the Chairperson of the Institutional Review Board as stated in section 10.

10. WHO CAN I CALL IF I HAVE QUESTIONS?

If you have any questions or concerns about this research study, or if you have any problems that occur from taking part in this research study, you may call the researcher Christine Schneider, LCSW at 314-489-4810.

11. WHAT ARE MY RIGHTS AND WHAT ELSE SHOULD I KNOW AS A RESEARCH

STUDY VOLUNTEER?

Your participation in this research study is voluntary. You may choose not to be a part of this research study. There will be no penalty to you if you choose not to take part. You may leave the research study at any time. The researcher will let you know of any new information that may affect whether you want to continue to take part in the research study. Your decision to participate will in no way affect your relationship with your medical providers.

12. AM I SURE THAT I UNDERSTAND?

I have read this consent document and have been able to ask questions and state any concerns. The researcher has responded to my questions and concerns. I believe I understand the research study and the potential benefits and risks that are involved.

Statement of Consent

I give my informed and voluntary consent to take part in this research study. I will be given a copy of this consent document for my records.

Consent Signature of Research Participant (18 and over) Date

Print Name of Participant

Signature of Witness

Date

SAINT LOUIS UNIVERSITY – INSTITUTIONAL REVIEW BOARD – APPROVAL STAMP

This form is valid only if the IRB’s approval stamp is shown below.

I certify that I have explained to the above individual(s) the nature and purpose of the research study and the possible benefit and risks associated with participation. I have answered any questions that have been raised and the participant has received a copy of this signed consent document.

Signature of Consenting Research Team Member	Date
<i>First Name / Last Name</i>	<i>Credentials</i>
Printed Name of Consenting Research Team Member	

APPENDIX C

To Be Filled Out By Physician

Participant No. _____

Physician's Assessment of Response to Treatment

Excellent Moderate Minimal None Worse

Perfect Physician Assessment of Adherence

Perfect (>90%) Excellent (60-90%) Good (30-60%) Fair (10-30%) Poor (<10%)

Physician's Assessment of Severity of Illness

Clear Almost Clear Mild Moderate Severe

APPENDIX D

DEMOGRAPHIC/MEDICAL ADHERENCE SCALE

Demographic Information

Are you the person primarily responsible for the care of your child? ____ yes ____ no

Are you the legal guardian of the child? ____ yes ____ no

Why are you seeing the doctor today? (Please circle the correct answer.)

Scheduled visit

Emergency appointment

How old is your child? ____ years ____ months

What is your gender? ____ male ____ female

What is your child's gender? ____ male ____ female

What is your relationship to the child? (Please circle the correct answer.)

Parent

Step-parent

Grandparent

Foster Parent

Other _____

How long has your child had eczema? ____ years ____ months

Compared to other children with eczema, how would you describe your child's eczema overall?
(Please circle the correct answer.)

None

Low Severity

Moderate Severity

High Severity

Extreme Severity

How would you describe your child's eczema currently? (Please circle the correct answer.)

Clear

Better than normal

Normal

Worse than normal

At its worst

What is your child's race? (Please circle the correct answer.)

African American

Caucasian

Asian

Hispanic

Biracial

Other _____

What is the yearly household income where the child resides? (Please circle the correct answer.)

<\$10,000

\$10,000 to 29,999

\$30,000 to 59,999

\$60,000 to 99,999

>\$100,000

What is the marital status of the parents of the child?

Single

Married

Divorced

Remarried

Widowed

Separated

Cohabiting

Who helps you to support your household?

Spouse

Significant Other

Relative

Friend

Parent/Grandparent

Is your child prescribed bleach baths? ____ yes ____ no

If so,

How many times per day are bleach baths prescribed? _____

How often do you follow this advice?

Always
>90%

Almost Always
60-90%

Most of the Time
30-60%

Rarely
10-30%

Never
<10%

If you answered anything but “always”, what stops you following this advice? (please check all that apply)

1. ____ I don't have time.
2. ____ It upsets my child.
3. ____ It is too painful for my child.
4. ____ My child will not allow me to do it.
5. ____ It costs too much.
6. ____ It doesn't seem to help.
7. ____ I worry about whether or not it is safe.
8. ____ I don't know how to do it. -
9. ____ I don't have enough support to do it consistently.
10. ____ Other _____

Has your doctor advised you to apply moisturizers daily? ____ yes ____ no

If so,

How many times per day are moisturizers application prescribed? _____

How often do you follow this advice?

Always
>90%
<10%

Almost Always
60-90%

Most of the Time
30-60%

Rarely
10-30%

Never

If you answered anything but “always”, what stops you following this advice? (please check all that apply)

1. ____ I don't have time.
2. ____ It upsets my child.
3. ____ It is too painful for my child.
4. ____ My child will not allow me to do it.
5. ____ It costs too much.
6. ____ It doesn't seem to help.
7. ____ I worry about whether or not it is safe.
8. ____ I don't know how to do it. -
9. ____ I don't have enough support to do it consistently.
10. ____ Other _____

Is your child prescribed topical medications? ___ yes ___ no

If so,

How many times per day are topical medications prescribed? _____

How often do you follow this advice?

Always >90% <10%	Almost Always 60-90%	Most of the Time 30-60%	Rarely 10-30%	Never
------------------------	-------------------------	----------------------------	------------------	-------

If you answered anything but “always”, what stops you following this advice? (please check all that apply)

1. ___ I don't have time.
2. ___ It upsets my child.
3. ___ It is too painful for my child.
4. ___ My child will not allow me to do it.
5. ___ It costs too much.
6. ___ It doesn't seem to help.
7. ___ I worry about whether or not it is safe.
8. ___ I don't know how to do it. -
9. ___ I don't have enough support to do it consistently.
10. ___ Other _____

Were you advised to use wet wraps on your child? ___ yes ___ no

If so,

How many times per day are wet wraps prescribed? _____

How often do you follow this advice?

Always >90%	Almost Always 60-90%	Most of the Time 30-60%	Rarely 10-30%	Never <10%
----------------	-------------------------	----------------------------	------------------	---------------

If you answered anything but “always”, what stops you following this advice? (please check all that apply)

1. ___ I don't have time.
2. ___ It upsets my child.
3. ___ It is too painful for my child.
4. ___ My child will not allow me to do it.
5. ___ It costs too much.
6. ___ It doesn't seem to help.
7. ___ I worry about whether or not it is safe.
8. ___ I don't know how to do it. -

9. I don't have enough support to do it consistently.

10. Other _____

Is your child prescribed medication other than topical creams? yes no

If so,

How many times per day are other medications prescribed? _____

How often do you follow this advice?

Always >90%	Almost Always 60-90%	Most of the Time 30-60%	Rarely 10-30%	Never <10%
----------------	-------------------------	----------------------------	------------------	---------------

If you answered anything but "always", what stops you following this advice? (please check all that apply)

- I don't have time.
- It upsets my child.
- It is too painful for my child.
- My child will not allow me to do it.
- It costs too much.
- It doesn't seem to help.
- I worry about whether or not it is safe.
- I don't know how to do it.
- I don't have enough support to do it consistently.
- Other _____

Did your physician prescribe for removal of triggers and allergens including dust mites?

How often do you follow this advice?

Always >90%	Almost Always 60-90%	Most of the Time 30-60%	Rarely 10-30%	Never <10%
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If you answered anything but "always", what stops you following this advice? (please check all that apply)

- I don't have time.
- It upsets my child.
- It is too painful for my child.
- My child will not allow me to do it.
- It costs too much.
- It doesn't seem to help.
- I worry about whether or not it is safe.
- I don't know how to do it.
- I don't have enough support to do it consistently.
- Other _____

APPENDIX E

PARENTING STRESS INDEX- SHORT FORM QUESTIONS

Likert scale: 1. (Strongly Agree); 2. (Agree); 3. (Not Sure); 4. (Disagree) 5. (Strongly Disagree)

1. When my child wants something, my child usually keeps trying to get it.
2. My child is so active that it exhausts me.
3. My child appears disorganized and is easily distracted.
4. Compared to most, my child has more difficulty concentrating and paying attention.
5. My child will often stay occupied with a toy for more than 10 minutes.
6. My child wanders away much more than I expected.
7. My child is much more active than I expected.
8. My child squirms and kicks a great deal when being dressed or bathed.
9. My child can be easily distracted from wanting something.
10. My child rarely does things for me that make me feel good.
11. Most times I feel that my child likes me and wants to be close to me.
12. Sometimes I feel my child doesn't like me and doesn't want to be close to me.
13. My child smiles at me much less than I expected.
14. When I do things for my child I get the feeling that my efforts are not appreciated very much.
15. Which statement best describes your child?
 1. Almost always likes to play with me.
 2. Sometimes likes to play with me.
 3. Usually doesn't like to play with me.
 4. Almost never likes to play with me.
16. My child cries and fusses:
 1. Much less than I had expected.
 2. Less than I expected.
 3. About as much as I expected.
 4. Much more than I expected.
 5. It seems almost constant.
17. My child seems to cry or fuss more often than most children.
18. When playing, my child doesn't often giggle or laugh.
19. My child generally wakes up in a bad mood.
20. I feel that my child is very moody and easily upset.
21. My child looks a little different than I expected and it bothers me at times.
22. In some areas my child seems to have forgotten past learnings and has gone back to doing things characteristic of younger children.
23. My child doesn't seem to learn as quickly as most children.
24. My child doesn't seem to smile as much as most children.
25. My child does a few things which bother me a great deal.
26. My child is not able to do as much as I expected.
27. My child does not like to be cuddled or touched very much.

28. When my child came home from the hospital, I had doubtful feelings about my ability to handle being a parent.
29. Being a parent is harder than I thought it would be.
30. I feel capable and on top of things when I am caring for my child.
31. Compared to the average child, my child has a great deal of difficulty in getting used to changes in schedules or changes around the house.
32. My child reacts very strongly when something happens that my child doesn't like.
33. Leaving my child with a babysitter is usually a problem.
34. My child gets upset easily over the smallest thing.
35. My child easily notices and overreacts to loud sounds and bright lights.
36. My child's sleeping or eating schedule was much harder to establish than I expected.
37. My child usually avoids a new toy for a while before beginning to play with it.
38. It takes a long time and it is very hard for my child to get used to new things.
39. My child doesn't seem comfortable when meeting strangers.
40. When upset, my child is:
 1. Easy to calm down.
 2. Harder to calm down than I expected.
 3. Very difficult to calm down
 4. Nothing I do helps to calm my child.
41. I have found that getting my child to do something or stop doing something is:
 1. Much harder than I expected.
 2. Somewhat harder than I expected.
 3. About as hard as I expected.
 4. Somewhat easier than I expected.
 5. Much easier than I expected.
42. Think carefully and count the number of things which your child does that bothers you. For example dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc. Please fill in the number which includes the number of things you counted.
 1. 1-3
 2. 4-5
 3. 6-7
 4. 8-9
 5. 10+
43. When my child cries it usually lasts:
 1. Less than 2 minutes.
 2. 2-5 minutes.
 3. 5-10 minutes.
 4. 10-15 minutes
 5. More than 15 minutes.
44. There are some things my child does that bother me a lot.
45. My child has had more health problems than I expected.



46. As my child has grown older and become more independent, I find myself more worried that my child will get hurt or into trouble.
47. My child turned out to be more of a problem than I had expected.
48. My child seems to be much harder to care for than most.
49. My child is always hanging on me.
50. My child makes more demands on me than most children.
51. I can't make decisions without help.
52. I have had many more problems raising children than I expected.
53. I enjoy being a parent.
54. I feel that I am successful most of the time when I try to get my child to do or not do something.
55. Since I brought my last child home from the hospital, I find that I am not able to take care of this child as well as I thought I could. I need help.
56. I often have the feeling that I cannot handle things very well.
57. When I think about myself as a parent I believe:
1. I can handle anything that happens.
 2. I can handle most things pretty well.
 3. Sometimes I have doubts, but find that I handle most things without any problems.
 4. I have some doubts about being able to handle things.
 5. I don't think I handle things very well at all.
58. I feel that I am:
1. A very good parent.
 2. A better than average parent.
 3. An average parent.
 4. A person who has some trouble being a parent.
 5. Not very good at being a parent.
59. What were the highest levels in school or college you and the child's father/mother have completed?
- Mother:
1. 1-8th grade
 2. 9-12th grade
 3. Vocational or some college
 4. College graduate
 5. Graduate or professional school
60. Father:
1. 1-8th grade
 2. 9-12th grade
 3. Vocational or some college
 4. College graduate
 5. Graduate or professional school
61. How easy is it for you to understand what your child wants or needs?
1. Very easy.
 2. Easy

3. Somewhat difficult
4. It is very hard
5. I usually can't figure out what the problem is.
62. It takes a long time for parents to develop close, warm feelings for their children.
63. I expected to have closer and warmer feelings for my child than I do and this bothers me.
64. Sometimes my child does things that bother me just to be mean.
65. When I was young, I never felt comfortable holding or taking care of children.
66. My child knows that I am his or her parent and wants me more than other people.
67. The number of children that I have now is too many.
68. Most of my life is spent doing things for my child.
69. I find myself giving up more of my life to meet my children's needs than I ever expected.
70. I feel trapped by my responsibilities as a parent.
71. I often feel that my child's needs control my life.
72. Since having this child I have been unable to do new and different things.
73. Since having this child I feel that I am almost never able to do things that I like to do.
74. It is hard to find a place in our home where I can go to be by myself.
75. When I think about the kind of parent I am, I often feel guilty or bad about myself.
76. I am unhappy with the last purchase of clothing I made for myself.
77. When my child misbehaves or fusses too much I feel responsible, as if I didn't do something right.
78. I feel every time my child does something wrong it is really my fault.
79. I often feel guilty about the way I feel towards my child.
80. There are quite a few things that bother me about my life.
81. I felt sadder and more depressed than I expected after leaving the hospital with my baby.
82. I wind up feeling guilty when I get angry at my child and this bothers me.
83. After my child had been home from the hospital for about a month, I noticed that I was feeling more sad and depressed than I had expected.
84. Since having my child, my spouse (male/female friend) has not given me as much help and support as I expected.
85. Having a child has caused more problems than I expected in my relationship with my spouse (male/female friend).
86. Since having a child my spouse (or male/female friend) and I don't do as many things together.
87. Since having a child my spouse (or male/female friend) and I don't spend as much time together as a family as I had expected.
88. Since having my last child, I have had less interest in sex.
89. Having a child seems to have increased the number of problems we have with in-laws and relatives.
90. Having children has been much more expensive than I had expected.
91. I feel alone and without friends.
92. When I go to a party I usually expect not to enjoy myself.
93. I am not as interested in people as I used to be.
94. I often have the feeling that other people my own age don't particularly like my company.

95. When I run into a problem taking care of my children I have a lot of people to whom I can talk to, get help or advice.
96. Since having children I have a lot fewer chances to see my friends and make new friends.
97. During the past six months I have been sicker than usual or have had more aches and pains than I normally do.
98. Physically, I feel good most of the time.
99. Having a child has caused changes in the way I sleep.
100. I don't enjoy things as I used to.
101. Since I've had my child:
1. I have been sick a great deal
 2. I haven't felt as good
 3. I haven't noticed any change in my health
 4. I have been healthier

APPENDIX F

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REFERENCES

- Abidin, R.R. (1990). *Parenting Stress Index-Short Form: Test manual*, Charlottesville, VA: Pediatric Psychological Press.
- Abidin, R.R., (1995). *Parenting Stress Index (PSI) manual*. Lutz, Florida: Psychological Assessment Resources.
- Aday, L.A. & Andersen, R.A. (1974). A framework for the study of access to medical care. *Health Services Research, 9*. 208-220.
- Arndt, J., Smith, N., & Tausk, F. (2008). Stress and atopic dermatitis. *Current Allergy and Asthma Reports, 8*(4), 312-317.
- Asher, M. I., Montefort, S., Björkstén, B., Lai, C. K., Strachan, D. P., Weiland, S. K., & Williams, H. (2006). Worldwide time trends in the prevalence of symptoms of asthma, allergic rhinoconjunctivitis, and eczema in childhood: ISAAC Phases One and Three repeat multicountry cross-sectional surveys. *The Lancet, 368*(9537), 733-743.
- Balkrishnan, R., Housman, T. S., Carroll, C., Feldman, S. R., & Fleischer, A. B. (2003). Disease severity and associated family impact in childhood atopic dermatitis. *Archives of Disease in Childhood, 88*(5), 423-427.
- Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. New Jersey: Prentice Hall.

- Bass, A., Anderson, K. & Feldman, S. (2015). Interventions to increase treatment adherence in pediatric atopic dermatitis: A systematic review. *Journal of Clinical Medicine*, 4(2), 231-242.
- Bauer, P. J. (1996). What do infants recall of their lives? Memory for specific events by one-to two-year-olds. *American Psychologist*, 51(1), 29.
- Beattie, P.B. & Lewis-Jones, M.S.. (2003). Impairment of quality of life in children with skin disease: further validation of the CDLQI and the CLQI. *British Journal of Dermatology*, 148, 77.
- Becker, M.H. (1974). The Health Belief Model and Personal Health Behavior. *Health Education Monographs*, 2, 324-473.
- Beebe, B. & Lachmann, F.M. (1998). Co-constructng inner and relational processes: Self and mutual regulation of infant research and adult treatment. *Psychoanalytical Psychology*, 4, 480-516.
- Ben-Gashir, M.A., Seed, P.T., & Hay, R.J. (2002). Are quality of life and disease severity related in childhood atopic dermatitis? *Journal of the European Academy of Dermatology and Venereology*, 16(5), 455-462.
- Ben-Gashir, M. A., Seed, P. T., & Hay, R. J. (2004). Quality of life and disease severity are correlated in children with atopic dermatitis. *British Journal of Dermatology*, 150(2), 284-290.

- Bender, B.G., Ballard, R., Canono, B.S., Murphy, J.R. & Leung, D.Y.M. (2008). Disease severity, scratching, and sleep quality in patients with atopic dermatitis. *Journal of American Academy of Dermatology*, 58, 415-420.
- Bewley, A. (2008). Expert consensus: time for a change in the way we advise our patients to use topical corticosteroids. *British Journal of Dermatology*, 158(5), 917-920.
- Blessmann Weber, M., Neto, P., Prati, C., Soirefman, M., Mazzotti, N. G., Barzenski, B., & Cestari, T. F. (2008). Improvement of pruritus and quality of life of children with atopic dermatitis and their families after joining support groups. *Journal of the European Academy of Dermatology and Venereology*, 22(8), 992-997.
- Boettger, M. K., Bär, K. J., Dohrmann, A., Müller, H., Mertins, L., Brockmeyer, N. H., & Agelink, M. W. (2009). Increased vagal modulation in atopic dermatitis. *Journal of Dermatological Science*, 53(1), 55-59.
- Boguniewicz, M. (2005). Atopic dermatitis: beyond the itch that rashes. *Immunology and Allergy Clinics of North America*. 25, 33-351.
- Boguniewicz, M., Eichenfield, L. F., & Hultsch, T. (2003). Current management of atopic dermatitis and interruption of the atopic march. *Journal of Allergy and Clinical Immunology*, 112(6), S140-S150.

- Boguniewicz, M., Nicol, N., Kelsay, K., & Leung, D. Y. (2008). A multidisciplinary approach to evaluation and treatment of atopic dermatitis. In *Seminars in Cutaneous Medicine and Surgery* (Vol. 27, No. 2, pp. 115-127). WB Saunders.
- Bowlby, J. (1969). *Attachment and loss v. 3* (Vol. 1). Random House.
- Bowlby, J. (1982). *Attachment and loss: Attachment (Vol. 1)*. Basic Books (AZ).
- Bowlby, J. (1988). *A secure base: Parent-child attachment and healthy human development*. Basic Books.
- Brazelton, T. (1989). *The earliest relationship*. Reading, MA: Addison-Wesley.
- Brenninkmeijer, E. E., Legierse, C. M., Sillevs Smitt, J. H., Last, B. F., Grootenhuis, M. A., & Bos, J. D. (2009). The course of life of patients with childhood atopic dermatitis. *Pediatric Dermatology*, 26(1), 14-22.
- Brown, K. L., Krejci-Manwaring, J., Tusa, M. G., Camacho, F., Alan Jr, B. F., Balkrishnan, R., & Feldman, S. R. (2008). Poor compliance with topical corticosteroids for atopic dermatitis despite severe disease. *Dermatology Online Journal*, 14(9), 13.
- Burkhart, PV., Dunbar-Jacob, J. (2002). Adherence research in the pediatric and adolescent populations: A decade in review. In L. Hayman, M.M. Mahon & J. Turner (eds). *Chronic Illness in Children: An Evidence-Based Approach*. New York: Springer.

Burnham, M.M., Goodlin-Jones, B.L., Gaylor, E.E. & Anders, T.F. (2002). Night-time sleep-wake patterns and self-soothing from birth to one year of age: A longitudinal intervention. *Journal of Child Psychiatry*, 43, 713-725.

Buske-Kirschbaum, A., Geiben, A., Höllig, H., Morschhäuser, E., & Hellhammer, D. (2002). Altered responsiveness of the hypothalamus-pituitary-adrenal axis and the sympathetic adrenomedullary system to stress in patients with atopic dermatitis. *Journal of Clinical Endocrinology & Metabolism*, 87(9), 4245-4251.

Callen, J., Chamlin, S., Eichenfield, L. F., Ellis, C., Girardi, M., Goldfarb, M., Hanifin, J., Lee, P., Margolis, D., Paller, A.S., Piacquadio, D., Peterson, W., Kaulback, K., Fennerty M. & Wintroub, B. U. (2007). A systematic review of the safety of topical therapies for atopic dermatitis. *British Journal of Dermatology*, 156(2), 203-221.

Capristo C, Romei I, Boner AL. (2004). Environmental prevention in atopic eczema dermatitis syndrome (AEDS) and asthma: avoidance of indoor allergens. *Allergy*, 59 (Suppl. 78), 53-60.

Carroll, C., Balkrishnan, R., Feldman, S., Fleischer, A., & Manuel, J. (2005) The burden of atopic dermatitis: Impact on the patient, family and society. *Pediatric Dermatology*, 22(3), 192-199.

- Carroll, C., Feldman, S., Manuel, J. & Balkrishnan, R. (2004). Adherence to topical therapy decreases during the course of an 8-week psoriasis clinical trial: commonly used methods of measuring adherence to topical therapy overestimate actual use. *Journal of the American Academy of Dermatology*, 51, 212-216.
- Cassidy, J., & Shaver, P. R. (Eds.). (2008). *Handbook of attachment: Theory, research, and clinical applications*. Guilford Press.
- Chamlin, S. L. (2006). The psychosocial burden of childhood atopic dermatitis. *Dermatologic Therapy*, 19(2), 104-107.
- Chamlin, S. L., Frieden, I. J., Williams, M. L., & Chren, M. M. (2004). Effects of atopic dermatitis on young American children and their families. *Pediatrics*, 114(3), 607-611.
- Champion, V.L. (1984). Instrument development for health belief model constructs. *Advances in Nursing Science*, 6(3), 73-85.
- Champion, V.L. & Menon, U. (1997). Predicting mammography and breast self-examination in African American women. *Cancer Nursing*, 20(5), 315-522.
- Champion, V.L., Ray, D.W., Heilman, D.K. & Springston, J.K. (2000). A tailored intervention for mammography among low-income African-American women. *Journal of Psychosocial Oncology*, 18(4), 1-13.
- Champion, V.L. & Skinner, C.S. (2008). The Health Belief Model. In K. Glanz, B. Rimer & K. Viswanath (Eds.). *Health Behavior and Health Education: Theory, Research and Practice*, 4th Edition (pp. 45-62). San Francisco: John Wiley & Sons, Inc.

Champion, V.L., Skinner, C.S. and Manon, U. (2005). Development of a self-efficacy scale for mammography. *Research in Nursing and Health*, 28(4), 329-336.

Charman, C. R., Morris, A. D., & Williams, H. C. (2002). Topical corticosteroid phobia in patients with atopic eczema. *British Journal of Dermatology*, 142 (5), 931-936.

Chisolm, S. S., Taylor, S. L., Gryzwacz, J. G., O'Neill, J. L., Balkrishnan, R. R., & Feldman, S. R. (2009). Health behaviour models: a framework for studying adherence in children with atopic dermatitis. *Clinical and Experimental Dermatology*, 35 (3), 228-232.

Chren, M.M., Lasek, R.J., Flocke, S.A., Zyzanski, S.J. (1997). Improved discriminative and evaluative capability of a refined version of Skindex, a quality-of-life instrument for patients with skin diseases. *Archives of Dermatology*, 133, 1433-1440.

Claar, R. L., Simons, L. E., & Logan, D. E. (2008). Parental response to children's pain: the moderating impact of children's emotional distress on symptoms and disability. *Pain*, 138(1), 172-179.

Cork, M.J., Britton, J., Butler, L., Young, S., Murphy, R. & Keohane, S.G. (2003). Comparison of parenting knowledge, therapy utilization and severity of atopic eczema before and after explanation and demonstration of topical therapies by a specialist dermatology nurse. *British Journal of Dermatology*, 149, 582-589.

Crittenden, P. M. (2008). *Raising parents*. Devon, Willan Pub.

Dahl, R. E., Bernhisel-Broadbent, J., Scanlon-Holdford, S., Sampson, H. A., & Lupo, M. (1995).

Sleep disturbances in children with atopic dermatitis. *Archives of Pediatrics & Adolescent Medicine*, 149(8), 856.

Daud, L. R., Garralda, M. E., & David, T. J. (1993). Psychosocial adjustment in preschool

children with atopic eczema. *Archives of Disease in Childhood*, 69(6), 670-676.

De Benedetto, A., Agnihothri, R., McGirt, L.Y., Bankova, L.G., & Beck, L.A. (2009). Atopic

dermatitis: a disease caused by innate immune defects? *Journal of Investigative Dermatology*, 129(1), 14-30.

Dohill, M.A. & Eichenfield, L.F. (2005). A treatment approach for atopic dermatitis. *Pediatric*

Annals, 34(3), 201.

Dozier, M., Cue, K.L., Barnett, L. (1994). Clinicians as caregivers: role of attachment

organization in treatment. *Journal of Consulting and Clinical Psychology*, 62, 793-800.

Ellis, C., Luger, T., Abeck, D., Allen, R., Graham-Brown, R. A. C., De Prost, Y., Eichenfield,

L.F., Ferrandiz, C., Giannetti, A., Hanifin, J., Koo, J., Leung, D., Lynde, C., Ring, J.,

Ruiz-Maldonado, R. & Saurat, J. H. (2003). International Consensus Conference on

Atopic Dermatitis II (ICCAD II*): clinical update and current treatment strategies. *British*

Journal of Dermatology, 148(s63), 3-10.

- Engel-Yeger, B., Habib-Mazawi, S., Parush, S., Rozenman, D., Kessel, A., & Shani-Adir, A. (2007). The sensory profile of children with atopic dermatitis as determined by the sensory profile questionnaire. *Journal of the American Academy of Dermatology*, 57(4), 610-615.
- Faught, J., Bierl, C., Barton, B., & Kemp, A. (2007). Stress in mothers of young children with eczema. *Archives of Disease in Childhood*, 92(8), 683-686.
- Feldman, S. R., Camacho, F. T., Krejci-Manwaring, J., Carroll, C. L., & Balkrishnan, R. (2007). Adherence to topical therapy increases around the time of office visits. *Journal of the American Academy of Dermatology*, 57(1), 81-83.
- Feldman, R., Greenbaum, C. W., & Yirmiya, N. (1999). Mother–infant affect synchrony as an antecedent of the emergence of self-control. *Developmental Psychology*, 35(1), 223.
- Fenerty, S. D., O'Neill, J. L., Gustafson, C. J., & Feldman, S. R. (2013). Maternal Adherence Factors in the Treatment of Pediatric Atopic Dermatitis. *JAMA Dermatology*, 149(2), 229-231.
- Field, A. (2009). *Discovering Statistics Using SPSS, 3rd Ed.* Thousand Oaks, CA: Sage.
- Fischer, G. (1996). Compliance problems in paediatric atopic eczema. *Australian Journal of Dermatology*, 37, s10-s13.

- Fosha, D. (2003). Dyadic regulation and experiential work with emotion and relatedness in trauma and disorganized attachment. *Healing trauma: Attachment, Mind, Body, and Brain*, 221-281.
- Friedman, L.C., Neff, N.E., Webb, J.A. & Latham, C.K. (1998). Age-related differences in mammography use and in breast cancer knowledge, attitudes, and behaviors. *Journal of Cancer Education*, 13, 26-30.
- George, J., Mackinnon, A., Kong, D.C., Stewart, K. (2006). Development and validation of the Beliefs and Behaviors Questionnaire (BBQ). *Patient Education Counseling*, 64, 50-60.
- Gil, K.M., Keefe, F.J., Sampson, H.A., McCaskill, C.C., Rodin, J. & Crisson, J.E. (1987). The relation of stress and family environment to atopic dermatitis symptoms in children. *Journal of Psychosomatic Research*, 31, 673-684.
- Gottman, J.M. (2011). *The Science of Trust: Emotional Attunement for Couples*. W.W. Norton & Company.
- Greenlaw, S.M., Yentzer, B.A., O'Neill, J.L., Balkrishnan, R. & Feldman, S.R. (2010). Assessing adherence to dermatology treatments: a review of self-report and electronic measures. *Skin Research and Technology*, 16, 253-258.
- Grillo, M., Gassner, L., Marshman, G., Dunn, S., Hudson, P. (2006). Pediatric atopic eczema: The impact of an educational intervention. *Pediatric Dermatology*, 23, 428-436.

- Gustafsson, D., Sjöberg, O., & Foucard, T. (2008). Development of allergies and asthma in infants and young children with atopic dermatitis—a prospective follow-up to 7 years of age. *Allergy*, 55(3), 240-245.
- Habib, S. & Morrissey, S., (1999). Stress management for atopic dermatitis. *Behaviour Change*, 6(4), 226-236.
- Hanifin, J. M., Cooper, K. D., Ho, V. C., Kang, S., Krafchik, B. R., Margolis, D. J., Schachner, L.A., Sidbury, R., Whitmore, S., Sieck, C., & Van Voorhees, A. S. (2004). Guidelines of care for atopic dermatitis. *Journal of the American Academy of Dermatology*, 50(3), 391-404.
- Haskett, M.E., Ahern, L.S., Ward, C.S., Allaire, J.C. (2006). Factor structure and validity of the parenting stress-index short form. *Journal of Clinical Child and Adolescent Psychology*, 35(2), 302-312.
- Hauser, C., Wuethrich, B., Matter, L., Wilhelm, J. A., Sonnabend, W., & Schopfer, K. (1985). Staphylococcus aureus skin colonization in atopic dermatitis patients. *Dermatology*, 170(1), 35-39.
- Hechler, T., Blankenburg, M., Dobe, M., Kosfelder, J., Hubner, B. & Zernikow, B. (2010). Effectiveness of a multimodal inpatient treatment for pediatric chronic pain: A comparison between children and adolescents. *European Journal of Pain* (14), 1.

- Heim, C., Newport, D. J., Heit, S., Graham, Y. P., Wilcox, M., Bonsall, R., Miller, A.H. & Nemeroff, C. B. (2000). Pituitary-adrenal and autonomic responses to stress in women after sexual and physical abuse in childhood. *JAMA: The Journal of the American Medical Association*, 284(5), 592-597.
- Hodari, K., Nanton, J., Carroll, C., Feldman, S.R. & Balkrishnan, R. (2006). Adherence in dermatology: A review of the last 20 years. *Journal of Dermatological Treatment*, 17, 136-142.
- Holme, S.A., Man, I., Sharpe, J.L., Dykes, P.J., Lewis-Jones, M.S. & Finlay, A.Y. (2003). The Children's Dermatology Life Quality Index: validation of the cartoon version. *British Journal of Dermatology*, 148, 285-290.
- Homey, B., Steinhoff, M., Ruzicka, T. & Leung, D.Y. (2006). Cytokines and chemokines orchestrate atopic skin inflammation. *Journal of Allergy and Clinical Immunology*, 118(1), 178-189.
- Housman, T.S., Patel, M., Camacho, F., Feldman, S. R., Fleischer, A. B., & Balkrishnan, R. (2002). Use of the Self-Administered Eczema Area and Severity Index by parent caregivers: results of a validation study. *British Journal of Dermatology*, 147(6), 1192-1198.
- Howlett, S. (1999). Emotional dysfunction, child-family relationships and childhood atopic dermatitis. *British Journal of Dermatology*, 140, 381-384.

Hunter, J.J. & Maunder, R.G. (2001). Using attachment theory to understand illness behavior.

General Hospital Psychiatry, 23, 177-182.

Jafferany, M. (2007). Psychodermatology: A guide to understanding common psychocutaneous

disorders. *Primary Care Companion Journal of Clinical Psychiatry, 9(3), 203-213.*

Janz, N.K. & Becker, M.H. (1984). The Health Belief Model: A Decade Later. *Health Education*

Quarterly, 11(1), 1-47.

Kapoor, R., Menon, C., Hoffstad, O., Bilker, W., Leclerc, P., & Margolis, D. J. (2008). The

prevalence of atopic triad in children with physician-confirmed atopic dermatitis. *Journal of the American Academy of Dermatology, 58(1), 68-73.*

Kaugars, A.S., Klinnert, M.D., Price, M., Polintan, M.L. Atkins, F.M., Bratton, D.L. (2003).

Physical and psychosocial functioning of children with atopic dermatitis. *Journal of Allergy and Clinical Immunology, 111, A347.*

Kelsay, K., Klinnert, M., & Bender, B. (2010). Addressing psychosocial aspects of atopic

dermatitis. *Immunology and allergy clinics of North America, 30(3), 385.*

Kemp, A.S. (2003). Cost of illness of atopic dermatitis in children: A societal perspective.

Pharmoeconomics, 21, 105-113.

- Kircik, L. H. (2011). Efficacy and onset of action of hydrocortisone acetate 2.5% and pramoxine hydrochloride 1% lotion for the management of pruritus: results of a pilot study. *The Journal of Clinical and Aesthetic Dermatology*, 4(2), 48.
- Kleinbaum, D.G., Kupper, L.L., Nizam, A. & Muller, K. (2008). *Applied Regression Analysis and Other Multivariable Methods*. Belmont, CA: Thomas Brooks/Cole.
- Koblenzer, C. S., & Koblenzer, P. J. (1988). Chronic intractable atopic eczema: its occurrence as a physical sign of impaired parent-child relationships and psychologic developmental arrest: improvement through parent insight and education. *Archives of Dermatology*, 124(11), 1673.
- Krakowski, A., Eichenfield, L., Dohil, M. (2008). Management of atopic dermatitis in the pediatric population. *Pediatrics*, 122, 812. doi. 10.1542/peds.2007-2232.
- Krejci-Manwaring, J., Tusa, M. G., Carroll, C., Camacho, F., Kaur, M., Carr, D, Fleischer, AB Jr., Balkrishnan, R. & Feldman, S. R. (2007). Stealth monitoring of adherence to topical medication: adherence is very poor in children with atopic dermatitis. *Journal of the American Academy of Dermatology*, 56 (2), 211.
- Latremoliere, A. & Woolf, C.J. (2009). Central sensitization: a generator of pain hypersensitivity by central neural plasticity. *Journal of Pain*, 10, 895-926.

- Laughter, D., Istvan, J.A., Tofte, S.J. & Hanifin, J.M. (2000). The prevalence of atopic dermatitis in Oregon schoolchildren. *Journal of the American Academy of Dermatology*, 43, 649-655.
- Latremoliere, A. & Woolf, C.J. (2009). Central sensitization: a generator of pain hypersensitivity by central neural plasticity. *Journal of Pain*, 10, 895-926.
- Lawson, V., Lewis-Jones, M. S., Finlay, A. Y., Reid, P., & Owens, R. G. (1998). The family impact of childhood atopic dermatitis: the Dermatitis Family Impact Questionnaire. *British Journal of Dermatology*, 138, 107-113.
- Leonard, B.E. (2005). The HPA and immune axes in stress: The involvement of the serotonergic system. *European Psychiatry*, 20(S3), S302-S306.
- Leung, D.Y. & Bieber, T. (2003). Atopic dermatitis. *Lancet*, 361: 151-160.
- Lewis-Jones, M.S. & Finlay, A.Y. (1995). The Children's Dermatology Life Quality Index (CDLQI[®]): initial validation and practical use. *British Journal of Dermatology*, 132, 942-949.
- Lucky, A. W., Leach, A. D., Laskarzewski, P., & Wenck, H. (1997). Use of an Emollient As a Steroid-Sparing Agent in the Treatment of Mild to Moderate Atopic Dermatitis in Children. *Pediatric dermatology*, 14(4), 321-324.

McDonald G. & Kingsbury R. (2006). Does physical pain augment anxious attachment? *Journal of Social and Personal Relationships*, 23(2), 291–304.

McWilliams L.A., Cox B.J., Enns M.W. (2000) Impact of adult attachment styles on pain and disability associated with arthritis in a nationally representative sample. *Clinical Journal of Pain*, 16, 360.

Meredith P.J., Strong J., Feeney J.A. (2006). Adult attachment, anxiety, and pain self-efficacy as predictors of pain intensity and disability. *Pain*, 123, 146–154.

Metry, D., Browning, J., & Rousseau, A. (July, 2007). *Sodium hypochlorite (bleach) baths: a potential measure to reduce the incidence of recurrent, cutaneous Staphylococcus aureus superinfection among susceptible populations*. In Poster Presented at the Society for Pediatric Dermatology Annual Meeting (pp. 12-15).

Mikulincer, M., Shaver, P. R., & Pereg, D. (2003). Attachment theory and affect regulation: The dynamics, development, and cognitive consequences of attachment-related strategies. *Motivation and Emotion*, 27(2), 77-102.

Milner, B., Squire, L. R., & Kandel, E. R. (1998). Cognitive neuroscience and the study of memory. *Neuron*, 20(3), 445-468.

Moore, K., David, T. J., Murray, C. S., Child, F., & Arkwright, P. D. (2006). Effect of childhood eczema and asthma on parental sleep and well-being: a prospective comparative study. *British Journal of Dermatology*, 154(3), 514-518.

Nelson, T. S., & Allred, D. D. (1996). Survey research in marriage and family therapy. *Research Methods in Family Therapy*, 447-468.

Nicholas, D. B., Otley, A., Smith, C., Avolio, J., Munk, M., & Griffiths, A. M. (2007).

Challenges and strategies of children and adolescents with inflammatory bowel disease: a qualitative examination. *Health and Quality of Life Outcomes*, 5(1), 28.

Nolan, B. & Feldman, S. (2009). Dermatologic medication adherence. *Dermatological Clinics*, 27, 113-120.

Novak, N. (2009). New insights into the mechanism and management of allergic diseases: atopic dermatitis. *Allergy*, 64(2), 265-275.

Ogden, P., Minton, K., & Pain, C. (2006). *Trauma and the body: A sensorimotor approach to psychotherapy*. W. W. Norton & Company: New York.

Ohya, Y., Williams, H., Steptoe, A., Saito, H., Iikura, Y., Anderson, R., & Akasawa, A. (2001).

Psychosocial factors and adherence to treatment advice in childhood atopic dermatitis. *Journal of Investigative Dermatology*, 117(4), 852-857.

Osterberg, L. & Blaschke, T. (2005). Adherence to medication. *New England Journal of Medicine*, 353, 487-497.

Ou, H.T., Feldman, S.R. & Balkrishnan, R. (2010). Understanding and improving treatment

adherence in pediatric patients. *Seminars in Cutaneous Medicine and Surgery*, 29, 137-140.

Pauli-Pott, U., Darui, A., & Beckmann, D. (1999). Infants with atopic dermatitis: maternal hopelessness, child-rearing attitudes and perceived infant temperament. *Psychotherapy and Psychosomatics*, 68(1), 39-45.

Porges, S. W., Doussard-Roosevelt, J. A., Portales, A. L., & Greenspan, S. I. (1996). Infant regulation of the vagal “brake” predicts child behavior problems: A psychobiological model of social behavior. *Developmental Psychobiology*, 29(8), 697-712.

Porter, L.S., Davis, D., & Keefe, F.J. (2007). Attachment and pain: Recent findings and future directions. *Pain*, 128(3), 195.

Raimer, S. S. (2000). Managing pediatric atopic dermatitis. *Clinical Pediatrics*, 39(1), 1-14.

Rao, P. A., & Beidel, D. C. (2009). The impact of children with high-functioning autism on parental stress, sibling adjustment, and family functioning. *Behavior Modification*, 33(4), 437-451

Reid, P., Lewis-Jones, M.S. (1995). Sleep disturbance in preschoolers with atopic eczema. *Journal of Clinical and Experimental Dermatology Research*, 20, 38-41.

Reitman, D., Currier, R. & Stickle, T. (2002). A critical evaluation of the Parenting Stress Index-Short Form (PSI-SF) in a head start population. *Journal of Clinical Child & Adolescent Psychology*, 31(3), 384-392.

Renzi, C., Picardi, A., Abeni, D., Agostini, E., Baliva, G., Pasquini, P., Puddu, P. & Braga, M.

(2002). Association of dissatisfaction with care and psychiatric morbidity with poor treatment compliance. *Archives of Dermatology*, 138(3), 337.

Reuveni, H., Chapnick, G., Tal, A., & Tarasiuk, A. (1999). Sleep fragmentation in children with atopic dermatitis. *Archives of Pediatrics & Adolescent Medicine*, 153(3), 249.

Ricci, G., Patrizi, A., Baldi, E., Menna, G., Tabanelli, M. & Masi, M. (2006). Long-term follow-up of atopic dermatitis: retrospective analysis of related risk factors and association with concomitant allergic diseases. *Journal of American Academy of Dermatology*, 55(5), 765-771.

Rork, J.F., Sheehan, W.J., Gaffin, J.M., Timmons, K.G., Sidbury, R., Schneider, L.C.,

Phipatanakul, W. (2012). Parental response to written eczema plans in children with eczema. *Archives of Dermatology*, 148, 391-392.

Rosenblum, L.A., Coplan, J.D., Friedman, S., Basoff, T., Gorman, J.M. & Andrews, M.W.

(1994). Adverse early experiences affect noradrenergic and serotonergic functioning in adult primates. *Biological Psychiatry*, 35, 221-227.

Roth, N., Beyreiss, J., Schlenzka, K., Beyer, H. (1991). Coincidence of attention deficit disorder and atopic disorders in children: empirical findings and hypothetical background. *Journal of Abnormal Child Psychology*, 19, 1-12.

Sack, R., & Hanifin, J. (2010). Scratching below the surface of sleep and itch. *Sleep Medicine Reviews, 14*(6), 349-350.

Sagransky, M.J., Yentzer, B.A., Williams, L.L., Clark, A.R., Taylor, S.L., Feldman, S.R. (2010). A randomized controlled pilot study of the effects of an extra office visit on adherence and outcomes in atopic dermatitis. *Archives of Dermatology, 146*, 1428-1430.

Schachner, L., Field, T., Hernandez-Reif, M., Duarte, A.M. & Krasinger, J. (1998). Atopic dermatitis symptoms decreased in children following massage therapy. *Pediatric Dermatology, 15*, 390-395.

Schacter, D. L., & Buckner, R. L. (1998). Priming and the brain. *Neuron, 20*(2), 185-195.

Schafer, T. (2006). *Epidemiology of atopic eczema*. In J. Ring, B. Przybilla, & T. Ruzicka. Handbook of atopic eczema, second edition, pp. 21-30. New York: Springer-Verlag.

Schore, A. (1994). *Affect regulation and the origin of the self: The neurobiology of emotional development*. Hillsdale, Erlbaum.

Schore, A. (1996). The experience-dependent maturation of a regulatory system in the orbital prefrontal cortex and the origin of developmental psychopathology. *Development and Psychopathology, 8*, 59-88.

Schore, A. (2003). *Affect dysregulation and the disorders of the self*. New York, Norton.

Serup, J., Lindblad, A., Maroti, M., Kjellgren, K. I., Niklasson, E., Ring, L., & Ahlner, J. (2006).

To Follow or Not to Follow Dermatological Treatment A Review of the Literature. *Acta Dermato-Venereologica*, 86(3), 193-197.

Shani-Adir, A., Rozenman, D., Kessel, A., & Engel-Yeger, B. (2009). The relationship between

sensory hypersensitivity and sleep quality of children with atopic dermatitis. *Pediatric Dermatology*, 26(2), 143-149.

Shaw, T. E., Currie, G. P., Koudelka, C. W., & Simpson, E. L. (2010). Eczema prevalence in the

United States: data from the 2003 National Survey of Children's Health. *Journal of Investigative Dermatology*, 131(1), 67-73.

Sherriff, A., & Golding, J. (2002). Hygiene levels in a contemporary population cohort are

associated with wheezing and atopic eczema in preschool infants. *Archives of Disease in Childhood*, 87, 26-29.

Seiffert, K., Hilbert, E., Schaechinger, H., Zouboulis, C. C., & Deter, H. C. (2005).

Psychophysiological reactivity under mental stress in atopic dermatitis. *Dermatology*, 210(4), 286-293.

Shani-Adir, A., Rozenman, D., Kessel, A., & Engel-Yeger, B. (2009). The relationship between

sensory hypersensitivity and sleep quality of children with atopic dermatitis. *Pediatric Dermatology*, 26(2), 143-149.

Siegel, D. (1999). *The Developing Mind*. New York, Guilford Press.

- Siegel, D. (2001). An interpersonal neurobiology of the developing mind: Attachment relationships, “mindsight,” and neural integration. *Infant Mental Health Journal*, 22(1), 67-94.
- Siegel, D. (2013). *Foundations of mindsight and interpersonal neurobiology*. [Audio podcast retrieved from <https://www.mindsightinstitute.com/>].
- Siegel, D. J., & Bryson, T. P. (2011). *The Whole-brain Child: 12 Revolutionary Strategies to Nurture Your Child's Developing Mind*. Random House Digital, Inc.
- Siegel, D., & Hartzell, M. (2003). *Parenting from the inside out*. New York, Penguin.
- Seiffert, K., Hilbert, E., Schaechinger, H., Zouboulis, C. C., & Deter, H. C. (2005). Psychophysiological reactivity under mental stress in atopic dermatitis. *Dermatology*, 210(4), 286-293.
- Spergel, J. M. (2010). From atopic dermatitis to asthma: the atopic march. *Annals of Allergy, Asthma & Immunology*, 105(2), 99-106.
- Sroufe, L.A. & Waters, E. (1977). Heart rate as a convergent measure in clinical and developmental research. *Merrill-Palmer Quarterly*, 23, 3-27.

- Staab, D., Diepgen, T. L., Fartasch, M., Kupfer, J., Lob-Corzilius, T., Ring, J. & Gieler, U. (2006). Age related, structured educational programmes for the management of atopic dermatitis in children and adolescents: multicentre, randomised controlled trial. *British Medical Journal*, 332(7547), 933-938.
- Staab, D., Von Rueden, U., Kehrt, R., Erhart, M., Wenninger, K., Kamtsiuris, P., & Wahn, U. (2002). Evaluation of a parental training program for the management of childhood atopic dermatitis. *Pediatric Allergy and Immunology*, 13(2), 84-90.
- Stein, T., Sonty, N. & Saroyan, J. (2012). “Scratching” beneath the surface: An integrative psychosocial approach to pediatric pruritus and pain. *Clinical Child Psychology and Psychiatry*, 17, 33 – 47.
- Stern, D. (1985). The interpersonal world of the infant. New York: Basic Books.
- Su, J.C., Kemp, A.S., Varigos, G.A., Nolan, T.M. (1997). Atopic eczema: its impact on the family and financial cost. *Archives of Disease in Childhood*, 76, 159-162.
- Tran, B., Papoiu, A., Russoniello, C., Wang, H., Patel, T., Chan, Y., & Yosipovitch, G. (2010). Effect of itch, scratching and mental stress on autonomic nervous system function in atopic dermatitis. *Acta Dermato-Venereologica*, 90(4), 354-361.
- Thompson, D., & Ciechanowski, P. S. (2003). Attaching a new understanding to the patient-physician relationship in family practice. *The Journal of the American Board of Family Practice*, 16(3), 219-226.

Tronick, E., Als, H., Adamson, L., Wise, S., & Brazelton, T. B. (1978). The infant's response to entrapment between contradictory messages in face-to-face interaction. *Journal of the American Academy of Child Psychiatry*, 17, 1-13.

Van der Kolk, B. A. (2006). Clinical implications of neuroscience research in PTSD. *Annals of the New York Academy of Sciences*, 1071(1), 277-293.

VanFleet, R. (1994). *Filial therapy: Strengthening parent-child relationships through play*. Professional Resource Press/Professional Resource Exchange.

von Hertzen, L. & Haahtela, T. (2006). Disconnection of man and the soil: reason for the asthma and atopy epidemic. *Journal of Allergy and Clinical Immunology*, 117, 334-344.

Warschburger, P., Buchholz, H., & Petermann, F. (2004). Psychological adjustment in parents of young children with atopic dermatitis: which factors predict parental quality of life? *British Journal of Dermatology*, 150(2), 304-311.

Weisshaar, E. & Dalgard, F. (2009). Epidemiology of itch: adding to the burden of skin morbidity. *Acta Dermato-Venereologica*. 89(4), 339-350.

Williamson, G., Walters, A. & Shaffer, D. (2002). Caregiver models of self and others, coping, and depression: predictors of depression children with chronic pain. *Health Psychology* 2, (4), 405-410.

Winnicott, D.W. (1990). The theory of the parent-child relationship (1960). In *Maturational Processes and the Facilitating Environment* (pp. 37-55). London: Karnac Books.

Wright, R. J., Cohen, R. T., & Cohen, S. (2005). The impact of stress on the development and expression of atopy. *Current Opinion in Allergy and Clinical Immunology*, 5(1), 23-29.

Zalenko, M., Kraemer, H., Huffman, L., Gschwendt, M., Pageler, N. & Steiner, H. (2005). Heart rate correlates of attachment status in young mothers and their infants. *Journal of the American Academy of Child and Adolescent Psychiatry*, 44, 470-476.

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