# How Resilience Factors Influence Adjustment in Adolescents with Chronic Kidney Disease

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#### **ABSTRACT**

NICOLE M. FENTON: How Resilience Factors Influence Adjustment in Adolescents with Chronic Kidney Disease (Under the direction of Don Baucom Ph.D., Karen M. Gil Ph.D., and Maria Ferris M.D.)

Illness severity may not fully predict an adolescent's adjustment rather; psychosocial factors may be playing a role (Thompson & Gustafson, 1996). The current study utilized the Disability-Distress-Coping Model to conceptualize how resilience factors influence adjustment (Wallander & Varni, 1992). Participants were recruited from the UNC Chapel Hill outpatient clinic and included 50 adolescents age 13-18 with a diagnosis of CKD II or above. Data analysis consisted of a series of regressions, indicating that overall family functioning and specifically family cohesion are significant positive predictor of social functioning. Overall coping efficacy was not a significant predictor of social or psychosocial functioning, however; the efficacies of two specific coping strategies were: emotion regulation and seeking social support. These findings suggest that adolescents with CKD are able to adjust well to having a chronic illness and that family functioning and coping efficacy play an important role in facilitating this positive adjustment.

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To the casual observer, a thesis may appear to be solitary work. However, to complete a project of this magnitude requires a network of support, and I am indebted to many people. I am most especially grateful to my parents, Jean and Dave Fenton, for their guidance and extraordinary support.

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#### Introduction

Pediatric chronic illness is pervasive, affecting an estimated 10-15% of children living in the United States by the time they turn 18 years of age (Davidoff, 2004). One specific illness that has been rising markedly across the world is chronic kidney disease (CKD) (Vupputuri & Jennette, 2007). With the increasing number of diagnosed CKD patients, many societal resources have been devoted to the development of new medical procedures and medications for the treatment of this disease. This focus has led to an increase in the survival rates of children with even the most severe stage of chronic kidney disease (Ettinger, 1990). With the improving survival rates and medical advancement, researchers have begun to shift their focus to examine how psychological variables may influence a child's adjustment, as well as how having a chronic illness may influence a child's overall adjustment.

On the whole, studies have found mixed results regarding the influence of disease status on adolescents' adaptation or adjustment. Some studies have found that disease severity is a significant negative predictor of psychological adjustment and behavioral problems (Daltroy et al., 1992; MacLean, Perrin, Gortmaker, & Pierre, 1992). However, other studies have found illness severity to be a poor predictor of adjustment (Hurtig, Koepke, & Park, 1989; Thompson & Gustafson, 1996). Findings such as these have led many researchers to conclude that illness severity is not the only variable influencing adjustment, but rather that psychosocial factors are also playing a large role (Kazak, 2001; LaGreca, 1988; Valenzuela et al., 2006). Therefore, disease characteristics alone

give an incomplete picture of the factors that may influence an adolescent's adjustment (Schor, Lerner, & Malspeis, 1995).

This incomplete picture has lead researchers to begin examining the wide range of psychosocial variables that may influence adjustment. To date, the majority of this research has focused on identifying the factors that may place an individual at increased risk for poor adjustment (Lindgren, Harper, & Blackman, 1986; MacLean, Perrin, Gortmaker, & Pierre, 1992). Resilience factors that may lead to positive adjustment have been widely overlooked. Resilience factors include both individual characteristics and environmental factors that may influence adjustment (MacLean et al., 1992). Coping is the individual characteristic that has been noted as central to pediatric psychology's theory, research, and clinical practice (Compas et al., 1993). Coping has been described as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as exceeding the resources of a person (Lazarus & Folkman, 1984)." In the developmental literature, family functioning has been identified as a primary environmental influence on children's psychological outcomes (Kazak, Rourke, & Crump, 2003). However, until recently there has been surprisingly little focus on the family when trying to understand the course of adjustment in children and adolescents with chronic illnesses (Drotar, 1997).

#### Coping

Adolescents with a chronic medical illness have ongoing stressors related to their illness that make coping strategies particularly salient. These medical stressors are not a onetime occurrence; rather, they are a frequently occurring event, weather it involves going to doctor's visits, getting epogen shots, or going into surgery. As a result of these

medical demands, this population must utilize their coping strategies more frequently than their healthy peers. Behavioral coping is defined as overt acts that an individual engages in to deal with stress, which may be more easily learned through observation of models in the environment such as parents and peers (Thompson & Gustafon, 1996). In cognitive coping, adolescents must access internal emotions and then regulate them. Studies show that in both healthy adolescents and young adults with a chronic illness, some types of coping strategies change over time while others remain constant (Thompson & Gustafon, 1996). For example, cognitive coping increases with age, whereas behavioral coping develops early and remains consistent across ages. The stability of the coping style is influenced by developmental factors (Compass et al., 1993). Specific coping strategies have been shown to explain significant portions of variance in psychosocial and functional adjustment (Spirito, Stark, & Gil, 1994; Syrjala & Chapko, 1995; Thompson, Gil, Keith, Gustafson, George & Kinney 1994). However, based on children's changing ability to identify and utilize appropriate coping strategies as they move into late adolescence and then young adulthood, it has been suggested that coping efficacy may be an effective way to examine coping across this age group (Siegel, 1992). Coping efficacy is an indication of how effective various coping strategies are in helping the child deal with their problem, regardless of the child's age. Despite the fact that coping efficacy is a useful way to examine coping, it has been largely underutilized.

#### **Family functioning**

The adolescent's individual ability to cope with their illness is important in understanding adjustment to a chronic illness; however, the adolescent is not the only person who must adjust to their illness. Rather, the family as a whole must adapt to an

increase in the number of doctors' appointments, possible financial strain, and an increasing burden on the family's resources. The family serves as an important proximal factor, or current influence, in the child's life (Kazak, Rourke, & Crump, 2003). As an important factor in the child's environment, it has been suggested that the adjustment of children to a stressor may be influenced by the adjustment of the family around them (Broffenbrenner, 1979). This association between family functioning and child adjustment has been demonstrated across many pediatric chronic illness populations. Recent research has shown that families with high flexibility, integration into a social network, clear family boundaries, effective communication, and positive attributions are all predictors of a child's well-being (Kazak, 2001). In a review of the pediatric chronic illness literature, Drotar (1997) concluded that more adaptive family relationships predict better child adjustment. These studies suggest that overall positive family characteristics may exert influence in a consistent manner across illness populations; however, more specific family factors might be differentially important across various illness populations. For example, Varni and colleagues (1996) examined aspects of the family environment related to child adjustment and found that in families where a child was newly diagnosed with cancer, cohesion and expressiveness were especially important when predicting positive adjustment. In pediatric sickle cell patients, family conflict has been shown to be a key predictor of a child's behavior problems (Burke, Kocoshis, Chandra, Whiteway, & Sauer, 1990; Thompson et al., 1999). At present, it is unclear why certain negative or positive aspects of family functioning might be important for specific childhood medical diseases.

Although the roles of individual coping and family functioning have been explored in some chronic illnesses, other illnesses have received less attention. One specific illness subpopulation that is under researched with regard to factors that influence children's and adolescents' adaptation is CKD.

#### Chronic kidney disease

According to the National Kidney Foundation, CKD is defined as having one of the following two characteristics: (a) having kidney damage for greater than or equal to three months due to structural or functional abnormalities, or (b) having a Glomular Filtration Rate (GFR) less than 60 ml/min/1.73 m^2 lasting for 3 months with or without kidney damage (Eknoyan & Levin, 2002). The GFR is an indication of the kidney's ability to filter blood. The typical causes of CKD are congenital or genetic in younger children and acquired in adolescents and young adults (U.S. Renal Data System, Annual data report, 2001). Due to the varying underlying causes of CKD, it occurs across a spectrum from mild to severe (Ferris et al., 2008).

The exact cause of CKD is currently unknown; however, a strong genetic predisposition is suggested by the clustering of CKD found in families (Bergman, Key, Kirk, Warnock, & Rostant, 1996). This genetic predisposition is disproportionately likely to affect ethnic minorities, more specifically African Americans (U.S. Renal Data System, Annual data report, 2001). Another group of individuals at increased risk for a steep decline in renal function are adolescents going through puberty and those in the early post pubertal period (Ardissino et al., 2003). The reason for this increased risk is unknown; however, it is speculated that it may be due to increased sex hormones or an imbalance between the kidney's size and a rapidly growing body size (Warady &

Chadha, 2007). While adolescents are a high risk group for CKD, little research has examined how family functioning and positive coping strategies may serve as a buffer to promote improved adaptation to the disorder for this age group. In fact, the research investigating how psychosocial factors influence pediatric CKD patients is far behind the adult literature (Beidel, 1987; Rodin & Voshart, 1987).

The onset of CKD may be difficult to detect in both adults and children. This is due to the often asymptomatic nature of the disease in its early stages, or because it may masquerade as other common childhood ailments (Ferris et al., 2008). Once detected, there is a complex daily regimen required to manage the illness. This regimen consists of medications once, twice, or even three times a day, food and liquid restrictions, and frequent visits to the doctor (Ferris et al., 2008). The complicated and onerous routine required to manage a chronic illness serves as a possible risk factor for predicting a child's adjustment. Several chronic illness models have been proposed to conceptualize how the psychosocial factors, risk factors, and environment factors may influence adjustment.

### **Conceptual model**

A few of the more highly regarded models are The Transactional Stress and Coping Model, Model of Stress and Coping, and the Disability-Distress-Coping model (Lazarus & Folkman; 1984; Thompson & Gustafson, 1996; Wallander & Varni, 1992). The Disability-Distress-Coping Model has been used across a variety of pediatric populations and is applicable to the current population as well (Burlew, 2002; Malik & Koot, 2009; Wallander & Varni, 1992). A depiction of Wallander and Varni's model as it is applied in the current study is referenced in Appendix A (1992). According to the

model, adjustment is influenced by Risk and Resilience factors. The risk factor for children with a chronic illness is the illness itself. The Resilience factors included in the model are intrapersonal factors, social-ecological factors, and stress processing factors (Wallander & Varni, 1992). Based upon this conceptual model, two resilience concepts emerge as important to the understanding of adjustment in children with chronic kidney disease – family environment and coping. Adaptation or adjustment has been defined in a variety of ways depending on the model, but the current model conceptualizes adjustment as having three components: mental health, social functioning, and physical health (Wallander & Varni, 1992).

The three components of adjustment included in Wallander and Varni's model align closely with the world health organization's broadened definition of health (1992). They define health as "a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmary" (World Health Organization, 1947, p. 26). These three components of health/ adjustment offer a somewhat comprehensive picture of adjustment. By gaining a more complete understanding of how malleable factors such as family functioning and coping strategies may positively influence adjustment, doctors, psychologists, and other healthcare professionals may work to promote these malleable factors and increase the probability of positive adjustment.

#### Family Functioning and Adjustment

As noted by the World Health Organization, all pediatric illnesses have an impact much broader than solely influencing the child's physical development. Rather, social, emotional, and family development are all affected by the illness. The family is intimately linked with both the short and long term course of the child's development

(Kazak, Segal-Andrews, & Johnson, 1995). There are many reasons to consider the adolescent within a family context. Adolescents rarely come unaccompanied to medical appointments and usually rely on their family to provide medical care. Some studies have found that a positive family climate is predictive of positive adjustment in pediatric renal transplant recipients (stage five CKD) (Falger, Landolt, Latal, Rüth, Neuhaus, & Laube, 2008). In another study with pediatric renal failure patients (stage four CKD), the family's expressiveness was found to have a significant negative correlation with the patients' maladaptive behavior (Davis, Tucker, & Fennell, 1996). Family functioning when positive can help facilitate positive adjustment; however, negative family functioning may result in a child's maladjustment. In the next three sub-sections, the relationship between family functioning and the three domains of adjustment will be examined.

#### Family functioning and mental health – depressive symptomology.

Depression is one important, potentially high risk type of maladjustment confronting children with CKD. Some findings indicate that children with CKD may be specifically at greater risk for internalizing problems such as depression, anxiety, and worry (Garralda, Jameson, Reynolds, & Postlethwaite, 1988). Research into the etiology of depression has identified a sense of loss as essential to the development of the disorder. The experience of loss may, in fact, be more influential than genetic factors in the development of depression (Kessler, 1997). Loss can be experienced in multiple ways, including loss of opportunities, loss of self-esteem, loss of freedom, etc. An accumulation of multiple losses may place an individual at increased risk for developing depression (Brown & Harris, 1989). Examining the types of loss in the context of

adolescents with CKD makes apparent that as the disease progresses, adolescents may experience multiple forms of loss. For example, these adolescents may feel a loss of freedom as they are now more carefully monitored and attend doctors' appointments once, twice, or even three times a week. They also may experience a lowered self-esteem as the medication side-effects such as acne and shorter stature occur. Unfortunately, it is not well understood why certain adolescents with CKD develop depression in response to these losses and others do not.

Researchers in the pediatric chronic illness field have suggested that a positive family environment may serve as a buffer against the chronic illness and facilitate lower levels of depression in adolescents (Harbeck-Weber, Fisher, & Dittner, 2003). In adolescents with CKD, only one study to date has examined the relationship between family functioning and depressive symptomology. This investigation found that when children's families are high in cohesion and expressiveness, and low in conflict, the child had significantly lower depressive symptoms (Soliday, Kool, & Lande, 2000). Thus, future research is merited to continue examining this relationship.

### Family functioning and physical health.

Chronic kidney disease has been characterized as a "silent illness" (Ferris et al., 2008). This means that while the disease could be progressing, with increasing levels of protein in the urine and lower filtration rates, a person may not realize it. Unlike other chronic illnesses such as juvenile rheumatoid arthritis in which the patient experiences pain if they do not take their prescribed medications, or irritable bowel disease in which the patient would end up in the bathroom, patients with CKD do not experience an immediate consequence if they do not take their medications. In fact, the individual may

not have any associated pain or discomfort until the disease has progressed to such a severe stage that an organ transplant is necessary (Bergman, Key, Kirk, Warnock, & Rostant, 1996).

Medication non-adherence may be defined as a patient not following their prescribed medical regimen. The implications of non-adherence are serious and include more frequent medical complications and hospitalizations, higher health care costs, increased risk for rejection (in transplant patients), and death (Falkenstein, Flynn, Kirkpatrick, Casa-Melley, & Dunn, 2004). Overall medication non-adherence rate for pediatric populations is approximately 50–55% (Rapoff, 1999). Non-adherence is estimated to be even higher in patients who do not experience the short term consequence of non-adherence, such as pain or a bowl movement (La Greca & Bearman, 2003). Thus, adherence to medication becomes a central factor in determining the physical health of patients with CKD.

Overall the pediatric literature has emphasized the importance of the family in a patient's treatment adherence (LaGreca, 1988). However, the role of the family in treatment adherence has been examined in only a few pediatric nephrology studies. In renal failure patients, positive family behaviors are significantly correlated with measures of medication adherence and diet adherence (Davis et al., 1996). In another investigation, thirty-two renal transplant recipients were assessed for their level of medication adherence. The findings indicated that positive family functioning was related to medication (prednisone and cyclosporine) adherence (Foulkes, Boggs, Fennell, & Skibinski, 1993).

More adaptive family functioning could result in fewer unnecessary emergency room visits and hospitalizations, and medication adherence could mediate this relationship or be the mechanism through which adaptive family functioning contributes to unnecessary hospital visits. To date no studies have examined this relationship in CKD patients. Studies have shown, however, that in patients with kidney disease, higher family cohesion was predictive of fewer hospitalizations (Falger et al., 2008). Reducing the number of unnecessary hospitalizations is especially important in the CKD population because this illness is found more frequently in ethnic minorities such as African Americans (Ferris, Gipson, Kimmel, & Eggers, 2006). National averages show that African Americans have higher rates of Medicaid and lower household incomes (DeNavas-Walt, Proctor, & Lee, 2005). Therefore unnecessary hospitalizations and emergency room visits could be especially taxing on this ethnic group's limited resources. Gaining an increased understanding between family functioning, medication adherence, and medical complications related to hospitalizations has important implied implications for these adolescents and their families.

#### Family functioning and social functioning – peer relationships.

As youth move from late childhood to early adolescence, peer relationships begin to gain increasing significance (Kerns, Contreras, & Neal-Barnett, 2000). At the same time, however, peer comparison and evaluation become particularly salient, a potential source of difficulty for adolescents with CKD (Duncan, 1993). That is, social functioning may be especially difficult for adolescents with CKD because of the many side effects that can occur from taking their prescribed medications. One such side effect is Anemia. Anemia is associated with a reduced ability to exercise; this can be especially

problematic for adolescents when sports and physical activities are often emphasized (Wong, Mylrea, Feber, Drukker, & Filler, 2006). Other side effects include: increased chronic inflammation, difficulties sleeping, neuro-cognitive deficits, cardiovascular disease (CVD), and a risk for slowed growth (Chesney et al., 2006). Slowed growth can result in adolescents looking substantially younger than their chronological age. A decreased ability to participate in sports activities and overall younger appearance suggest possible reasons why these adolescents may experience more difficulty making positive peer relationships. The studies to date that have examined social functioning in adolescents with CKD present a mixed picture. Some studies have found social functioning in children with CKD to be relatively similar to that of demographically matched peers (Brem et al., 1988; Soliday et al., 2000), whereas other studies have shown that adolescents with CKD have lower social functioning (Fukunishi & Honda, 1995; Fukunishi & Kudo, 1995).

The association between an adolescent's positive family functioning and their peer relationships has not been examined in the CKD population; however, it has been explored in healthy adolescent populations (Parke, Cassidy, Burks, Carson, & Boyum, 1992). Among healthy adolescents, families with positive expressiveness have children with higher levels of social functioning (Isley, O'Neil, & Parke, 1996). However, it is unclear whether a positive family environment will be associated with more positive peer relationships for adolescents with CKD. On the one hand, due to the additional challenges facing adolescents with CKD such as medication side effects, positive family functioning may become particularly important in helping adolescents navigate complex peer relationships. On the other hand, concrete and observable side effects such as

slowed growth and physical limitations might be so strong that the family cannot overcome how peers react to the patient.

#### Adolescence and family functioning summary

Adolescence is a time filled with many transitions, and, as a result, it may be a difficult period for even the healthiest individuals. It is typically a time of uncertainty about one's future, higher risk-taking behaviors, and increased peer criticism. Adding the additional stressor of having a chronic illness may place adolescents with CKD at increased risk for poor adjustment. These adolescents may experience a feeling of lossloss of freedom, opportunities, and control, which may increase their risk of depressive symptomology. Furthermore, during adolescence there is typically a sharp increase in risk-taking behaviors. Whereas these risks are often harmless, children with CKD who do not take their medications may experience grave consequences, including hospitalizations, emergency room visits, or even death. Finally, as adolescence is a time of increased peer criticism, the physical consequences that CKD patients experience such as a shorter stature and acne may result in peer rejection or criticism. These characteristics of adolescence may put some individuals at increased risk for poor outcomes; however, some adolescents are able to navigate these challenges successful. It is unclear what factors allow some individuals to maneuver positively through these challenges and others to be less successful.

Some investigators have suggested that the family is intimately linked with both the short and long term course of a child and adolescent's development (Kazak, Segal-Andrews, & Johnson, 1995). The previous section delineated how past research and current theory leads the current investigator to believe that positive aspects of family

functioning can allow an adolescent with CKD to overcome the obstacles they face and experience an overall positive adjustment. Whereas the family's functioning is a key environmental influence linked to adolescent development, coping is a central individual characteristic in healthy adaptation (Compas et al.,1993). Noting the many stressors that adolescents with CKD face, if they are able to utilize positive coping strategies that are effective in helping them deal with their problems, they may be able to overcome these challenges effectively.

#### **Coping and Adjustment**

Coping has traditionally been defined as thoughts and behaviors that are used to manage the internal and external demands of situations that are appraised as stressful (Lazarus & Folkman, 1984). The daily challenges and uncertainties of managing a chronic illness have been characterized by many as stressful (Graue, Wentzel-Larsen, & Bru, 2004). Some studies suggest that adolescents with a chronic illness are able to cope well with these constant challenges and uncertainties (Seiffge-Krenke, 2001); other studies, however, suggest this may not be the case (Paluszny, DeBeukelaer, & Rowane, 1991).

Whereas there is a discrepancy in the literature regarding how well adolescents with a chronic illness are able to cope, there also is a discrepancy about how the coping process itself should be conceptualized. Some suggest that coping efforts should be categorized in a variety of ways: voluntary versus involuntary, engagement versus disengagement, problem-focused versus emotion focused, and behavioral versus cognitive coping (Compas, Connor-Smith, & Saltzman, 2001; Gil, Wilson, & Edens, 1997). A voluntary behavior would be characterized as goal-directed, whereas an

involuntary response would be something that does not involve a specific intention (such as an increased heart rate). An engagement behavior involves actively employing a specific strategy to address the stressor, whereas an avoidance behavior involves not addressing the problem. Emotion focused coping involves actions designed to improve one's emotional reaction to a stressful situation, whereas problem focused coping involves changing the environment to reduce stress. Behavioral coping is generally defined as overt acts the individual engages in to deal with stress, whereas cognitive coping involves mental strategies used to deal with stress (Gil, Wilson, & Edens, 1997). There is considerable overlap between these categories; however, according to these models, no coping strategies are inherently good or bad. Rather, the appropriateness of a coping strategy depends on the match between the coping strategy and the demands of the situation. Each of these approaches to examining coping may offer different strengths and may be useful when examining a specific, prominent stressor in a given population. For example, in adolescents with sickle cell disease, coping strategies used with disease related pain were strongly predictive of emergency room visits (Gil et al., 1991). However, in many instances it is unclear a priori which coping strategies are likely to be of most benefit or how various coping strategies should be grouped into categories for further examination. In this case, some investigators have suggested a competency-based approach which emphasizes coping efficacy (Cadman et al., 1991; Kazak & Marvin, 1984). This competency-based approach does not examine the specific coping strategy used; rather, this approach is designed to focus on how effective the coping strategies are in helping an individual deal with a given problem. Using this approach, researchers are able to present the individual with a variety of coping strategies and ask how much that

given strategy would help them solve their problem. The following three sections address how coping efficacy may be related to how well adolescents manage their mental, physical, and social health in the context of chronic kidney disease.

#### Coping and mental health – depressive symptomology.

As noted earlier, few studies have examined the mental health of children with CKD. The studies that do exist present mixed findings. In one study with 38 CKD stage IV participants, self-reports indicated that they had significantly impaired levels of psychosocial functioning and significantly impaired levels of positive emotions (Falger, Landolt, Latal, Rüth, Neuhaus, & Laube, 2008). In addition, other studies have found significant differences between the level of internalizing symptoms experienced by adolescents with CKD and the level of symptoms experienced by healthy peers (Amr, 2009). However, other investigators have found no difference between the psychosocial functioning of children with CKD V and healthy controls (Qvist et al., 2004). Although the bases for these inconsistent findings are unclear, to some extent, measurement issues can account for mixed findings. More specifically, many of these investigations have employed scales that are not normalized on a chronic illness population; thus, the endorsement of some concerns and symptoms might be the result of the disorder itself rather than being an index of psychological functioning.

To the investigator's knowledge, only one study has examined children's coping and depressive symptoms in pediatric CKD patients; however, that study did not examine the relationship between these two constructs. The psychosocial character traits and coping skills of 12 children with end-stage renal failure were examined. The children with end-stage renal failure had sub-clinical levels of depression and anxiety; however,

they did have very low personal and social adjustment scores. The coping strategies most often utilized by these participants were self-reliance and sharing with a close personal friend (Brem, Brem, McGrath, & Spirito, 1988). This investigation explored the coping strategies used but did not investigate coping efficacy which appears to be an important part of the coping process. It may be that the efficacy of the coping strategy is more influential than the specific strategy used when predicting internalizing symptoms.

#### Coping and physical health.

Medication adherence is important for all chronic illness, however; medication non-adherence is especially prevalent across pediatric illnesses (Drotar, 2000) Rates of pediatric non-adherence have been estimated to be as high as 50-55% (Rapoff, 1999). It may be especially difficult for CKD patients to remember to take their medications as there is not an immediate and noticeable physical side effect to cue them when they forget. If CKD patients maintain appropriate follow up care and take their medications as prescribed, the illness will be stabilized and hospitalizations and emergency room visits typically can be avoided. If the patient is non-adherent to their medications, however, they may experience noticeable disease progression and hospitalization may be required. Despite the fact that there is not an immediate consequence for non-adherence, many CKD patients are successful in remembering to take their medications. This suggests that there are other factors than the disease characteristics themselves that influence medication adherence. In the previous section, it was delineated how family functioning may be an important variable in determining medication adherence. In addition, adolescents' coping may be an important individual factor influencing medication

adherence. If the adolescent is able to cope successfully with having a chronic illness, they may remember to take their medications and, in turn, avoid hospitalizations.

Several investigations have examined the relationship between coping and medication adherence. In one study with hemodialysis patients (CKD stage IV), positive coping strategies predicted better adherence (Christensen, Benotsch, Wiebe, & Lawton, 1995). In another study, helping patients develop coping and problem solving skills resulted in the patients demonstrating higher levels of disease self-management, such as more frequently attending doctor's visits and calling in their prescriptions to be refilled (Creer & Holroyd, 1997). Other studies that have examined the influence of coping on health care utilization found that children high on coping attempts require less frequent health care services (Broome, Maikler, Kelber, Bailey, & Lea, 2001; Gil, Williams, Thompson, & Kinney, 1991). Findings from another investigation suggested that the association between coping and health care utilization may be mediated by medication adherence. The investigators found that coping by avoidance of threat-related information was associated with shorter times to dialysis therapy. A shorter time to dialysis therapy may be an indication of quicker disease progression due to a lack of medication adherence or a lack of routine medical follow up (Devins, Mendelssohn, Barre, & Binik, 2003). No studies to date, however, have specifically examined if medication adherence meditates the relationship between a patient's coping strategies and the number of hospitalizations and ER visits they need.

#### Coping and social functioning – peer relationships.

As noted when adolescents' social functioning was discussed in relation to family functioning, as youth move from late childhood to early adolescence, peer relationships

begin to gain increasing significance (Kerns, Contreras, & Neal-Barnett, 2000). As peer relationships are increasing in significance, peer comparison and evaluation are also increasing (Duncan, 1993). This may present difficulties for adolescents with CKD as the side effects from their medications may result in their looking younger than their chronological age and an inability to participate in physical exercise. Examining social functioning across pediatric populations, such as those with cancer, studies suggest an overall impairment in functioning (Boman & Bodegard, 1995; Mackie et al., 2000; Mulhern et al., 1989). The few studies that have examined social functioning in CKD patients have found conflicting results. In one study, 78 patients with CKD reported to have impaired levels of social functioning (Fadrowski, et al., 2006). In another study, children with CKD had lower social functioning when compared with healthy peers (Brem, Brem, McGrath, & Spirito, 1988). Additionally, after a kidney transplantation (CKD stage V), adolescents reported concern about poor relationships with peers (Manificat, Dazord, Cochat, Morin, Plainguet, & Debray, 2003). Other studies, however, suggest that adolescents' social functioning may be within normal range (Brem et al., 1988; Falger et al., 2008; Soliday et al., 2000). No studies to date have examined if coping may be a predictor of social functioning in adolescents with CKD. Children with high coping efficacy may be able to navigate the challenges associated with having CKD successfully and, therefore, be able to develop positive peer relationships. This may not be the case, however, and those with high coping efficacy may not be able to overcome the potential problems created by their medication side effects and, as a result, still have poor peer relationships.

#### **Current Study and Hypotheses**

Based on the disability-distress-coping model, the current study will examine how family functioning and coping influence depressive symptoms, physical health, and social functioning in adolescents with chronic kidney disease. As noted below, both positive family functioning and higher levels of coping efficacy by the adolescent are predicted to contribute to more positive adjustment to chronic kidney disease.

## **Hypothesis 1**

Consistent with the literature sited above, higher levels of positive family functioning and lower levels of negative family functioning are hypothesized to be associated with lower levels of depressive symptomatology and higher levels of social functioning for adolescents with chronic kidney disease when age and disease severity are controlled for. More specifically:

### Hypothesis 1a.

Higher family conflict ratings will predict higher levels of depressive symptomology and lower levels of social functioning when age, family cohesion, family expressiveness, and disease severity are controlled for.

### Hypothesis 1b.

Higher family cohesion ratings will predict lower levels of depressive symptomology and higher levels of social functioning when age, family conflict, family expressiveness, and disease severity are controlled for.

#### Hypothesis 1c.

Higher family expressiveness ratings will predict higher levels of depressive symptomology and lower levels of social functioning when age, family conflict, family cohesion, and disease severity are controlled for.

#### **Hypothesis 2**

Consistent with the literature sited above, higher levels of coping efficacy among adolescents are hypothesized to be associated with lower levels of depressive symptomatology and higher levels of social functioning when age and disease severity are controlled for.

## Hypothesis 3a

As suggested by the studies presented above, the relationship between coping efficacy and health care utilization will be partially mediated by medication adherence when age and disease severity are controlled for.

#### Hypothesis 3b

Building upon the past research, it is hypothesized that the relationship between global family functioning and health care utilization will be partially mediated by medication adherence when age and disease severity are controlled for.

#### Method

#### **Participants**

Recruitment occurred at the UNC Chapel Hill Pediatric Kidney Center's outpatient clinic. All patients who were 13 to 18 years old and had a diagnosis of chronic kidney disease stage two or above were approached to participate. Medical eligibility was determined through consultation with the patient's nephrologist and a chart review. Those with CKD stage 2 or higher were eligible to participate regardless of when the original diagnosis was made or how long they have received treatment at UNC. If an individual (or their parent if they were less than 18 years old) did not speak English fluently, they were excluded from the study. Also, patients with significant cognitive or developmental

delays were excluded. Furthermore, only individuals who were living with their parents or legal guardian were eligible to participate.

The study sample consisted of 50 individuals (35 males, 15 females), and 10 people approached that declined to participate; therefore, study participation was 83.33%. The mean age of the participants was 15.52 years (SD= 1.80). The majority of the sample was African American (54%), followed by Caucasian individuals (28%), and Hispanic individuals (12%). The prevalence of African Americans in the sample is reflective of both the prevalence of African Americans at the UNC Kidney Center and the larger population of individuals who are diagnosed with CKD. The majority of the participants were living in a one parent home (58%; parents were single, separated or divorced); however, a large number of adolescents were also living in nuclear families (38%). The sample had approximately 10% of the participants on Medicaid, 72% with private insurance, 10% with no insurance, and 8% with medicare (as determined by chart review).

With regard to disease characteristics, the average age at diagnosis was 9.06 years old (SD= 5.62), and on average, the adolescents in this population took approximately 7.24 (SD=5.34) medications per day. The majority of the participants were in CKD stage 2 (48%), closely followed by stage 4 (34%).

#### Procedure

After full approval from the institutional review board was obtained, recruitment at the UNC Chapel Hill Pediatric Kidney Center's outpatient clinic proceeded as follows. Once the potential participant and their parent were brought out of the clinic waiting area and into a private room, the primary investigator (PI) approached the family. Waiting until the patient entered a private room allowed confidentiality and privacy to be more

easily maintained. The PI briefly described the study to the potential participant and their parent if they are less than 18 years old, or to the young adult alone if they are 18. The PI explained that the study was being conducted to better understand the thoughts and feelings of individuals with CKD and to better understand how the disease has impacted various parts of their life such as school, their family, and their friends. Next, it was explained that there are not any direct benefits for participating in the study but, hopefully, the results of the study will allow doctors and psychologists who work with CKD patients to better understand their experience. Subsequently, the patients were told that approximately 15-30 minutes are needed for them to complete all of the questionnaires on a computer which was in each of the patient's rooms. Finally, the primary investigator silently waited in the room for a minute to allow the potential participant (and their parent if applicable) to decide if they would like to participate.

If a desire to participate was expressed, informed assent and consent was obtained from the participant and guardian, as appropriate. The scales as well as the consent forms were completed on computers through the web survey tool 'Qualtrics.' Every effort was used to ensure the confidentiality and privacy of all participants. When logging onto the program, participants entered their study ID number into the computer. Only the study's PI had access to the master list that paired the participant's name to their study id number. There are no known personal risks or discomforts associated with participating in the study. Once enrolled in the study, the participant was administered the scales. The patients completed five scales that gathered information about their family functioning, coping strategies, quality of life, depressive symptoms, disease burden, demographics, and health care utilization.

After study completion, a chart review and nephrology consultation was conducted for all participants. The chart review and consultation aimed to establish the patient's stage of CKD. The severity ranged from CKD stage 2 to CKD stage 5. This was important to determine because disease severity was entered as a co-variate in the data analysis model.

#### Measures

#### Family environment.

Family Relationship Index; FRI (Holahan & Moos, 1983; Moos & Moos, 1994). This self-administered questionnaire is a shorter version of the Family Environment Scale (FES) with 27 items in three of the 10 FES domains: conflict, cohesion, and expressiveness. Cohesion in this scale is defined as the degree of commitment, help, and support family members provide for one another. Expressiveness in this scale is defined as the extent to which family members are encouraged to express their feelings directly, and conflict is defined as the amount of openly expressed anger and conflict among family members (Moos & Moos, 2009). The questions are true or false statements about families. An example of a question from the conflict subscale is "we fight a lot in our family." An example of an expressiveness question is: "we tell each other about our personal problems." A score on the overall family environment can be calculated as well as the three subscale scores: conflict, cohesion, and expressiveness.

In the *Journal of Pediatric Psychology's* article on evidence based assessment of family functioning, the FRI received a rating of well-established, the highest rating (Alderfer et al., 2008). This subset of scales from the FES and their composite score have been used with families of children who have asthma, diabetes, juvenile rheumatoid

arthritis, recurrent abdominal pain, sickle cell disease, and those undergoing bone marrow transplant (Alderfer et al., 2008).

#### Coping strategies and efficacy.

KidCope (Spirito, Stark, & Williams, 1988). The KidCope is a self-report questionnaire with two versions, one for younger children 7-12 years old (15 items), and one for older children ages 13-18 (10 items) which was used in the current investigation. The questionnaire first asks the individual to describe a difficult problem related to their illness. Then, the participant is asked about their emotional reaction to the problem and the coping strategies used to resolve the problem. The coping styles consists of cognitive restructuring, problem solving, social support, and positive emotional regulation, distraction, blaming others, wishful thinking, resignation, and negative emotion regulation. The coping strategies that the individuals endorse are used to create a frequency score (how often did you do this?) and an efficacy score (how much did this help?). The frequency responses are given on a 4-point Likert-type scale ranging from "not at all" to "almost all the time" and the efficacy responses are given on a 5-point Likert-type scale ranging from "not at all" to "very much" for the efficacy question.

Several studies using a number of different samples, including children with medical illnesses, have been conducted to establish the reliability and validity of this measure. Reliability scores have ranged from moderate (0.41) to fairly high (0.83) in (Spirito et al., 1988). The construct validity of this measure was assessed by comparing the measure to two previously validated measures, the Coping Strategies Inventory (CSI; Tobin, 1991) and the Adolescent-Coping Orientation for Problem Experiences Inventory (ACOPE; Patterson & McCubbin, 1987). The correlations between the coping strategies

in the CSI and the Kidcope were moderate to high (range: .33-.77). This high association was expected as the two are conceptually very similar. The Kidcope and the ACOPE were somewhat less correlated (range: .08 to .62), with higher associations existing between coping strategies that were conceptually similar (Spirito et al., 1988).

#### Childhood depressive symptoms.

Child Depression Inventory: short-form (CDI; Kovacs, 1982). This self-administered questionnaire consists of 10 questions. There is only one version of the CDI given to children ranging in age from 7 to 17 years; however the conversion scores are standardized by age and gender. The questions ask the child how they have been feeling in the past two weeks with three answers to choose from. An example of the answers are "a) I do not feel alone, b) I feel alone many times, c) I feel alone all the time." In the *Journal of Pediatric Psychology's* evidence based assessment article on adjustment, the CDI received a rating of well-established which was the highest rating (Holmbeck et al., 2008).

#### Social functioning and overall health related quality of life (HR-QOL).

Pediatric Quality of Life Inventory; version 4.0 (PedsQL; Varni, Seid, & Rode, 1999). This self-administered, 23 question measure was designed to assess the impact of disease and treatment on an individual's physical functioning, emotional functioning, social functioning, and school functioning (Varni, Seid, & Kurtin, 2001). It has two versions—one for children age 8-12 and one for adolescents age 13-18. With the different cognitive abilities of the children, the two versions of the questionnaire parallel each other, but the younger version is worded more simply (Varni et al., 1999). The

questionnaire includes a list of difficulties that the child may have encountered over the past month, and they are asked to respond how much of a problem that item has been for them. The responses range on a 5-point Likert-type scale from "never" to "almost always." An example of a question from the emotional functioning section is, "I feel afraid or scared" and "I worry about what will happen to me." An example of a question from the social functioning section is "I have trouble getting along with other people my age" and, "I cannot do things that other people my age can do."

The PedsQL has been used in a wide range of pediatric populations (Berrin et. al., 2007; Hommel, Davis & Baldassano, 2008; McClellan, Schatz, Sanchez & Roberts, 2008). This questionnaire received a rating of well-established in the *Journal of Pediatric Psychology*'s review of evidence based assessments of HR-QOL (Palermo et al., 2008).

#### Health outcomes and demographic information.

Family information form (Thompson, Varni, & Hanson, 1987) from the PedsQL. This self-report questionnaire asks the patient to indicate demographic information such as their age, gender, and race. It also asks about their parents' marital status, occupation, and highest level of education. Further, the patient is asked to indicate the number of overnight hospital and emergency room visits they have had in the past 12 months. Finally, the questionnaire asks in the past thirty days how many times the child has missed school, the number of days they were too sick to play, and the number of days that they needed someone to care for them. This measure has been used with a variety of pediatric populations (Varni et al., 2001).

The supplemental demographic form asks about the family's yearly household income, the number of residents in the home (income and number of residents will be

used to calculate the family's socioeconomic status), the number of medications they take on a typical day, and who is in charge of their child's medications. Also, to get an indication of medication adherence, the participant is asked the number of medications they miss on a typical day and the number of medications they are late taking on a typical day.

#### Results

#### **Descriptive Statistics**

Initial descriptive statistics were run to examine the mean level of conflict, cohesion, expressiveness, and overall family functioning as measured by the Family Relationship Index (Moos & Moos, 1994). The possible range for each of these subscales is 0-9. The mean, standard deviation and observed range for cohesion, expressiveness and conflict are as follows; 7.28(1.53, 2-9), 5.02(1.7, 2-8), and 2.84(2.14, 0-8). The mean for overall family functioning (a composite of the above 3 subscales) is 18.46 (SD=4.19). The correlation matrix among the three subscales is displayed in table 1. Table 2 displays the subscale means obtained in this sample when compared to 17,730 healthy individuals and 5,435 distressed individuals. This table depicts that the average level of cohesion and expressiveness was higher in the current sample of individuals than in comparison sample of 5,435 distressed individuals. Also, the level of conflict is lower in the current sample than in the sample of distressed individuals. In comparison to the healthy individuals, the current sample obtained higher levels of cohesion, the same level of expressiveness, and lower levels of conflict (Moos & Moos, 2009).

Initial descriptive statistics also were conducted to examine the mean level of depressive symptoms and overall level of social functioning. Depressive symptoms were

measured by the Child Depression Inventory: short-form (CDI; Kovacs, 1982). The raw score obtained by using this inventory is converted into a *T*-score, based on the participant's age and gender. In the current study, the adolescents reported below average levels of depressive symptoms; the mean was a *T*-score of 44.82 and a standard deviation of 5.57. Scores below 55 are unlikely to be associated with depressive disorder; scores 55–64 indicate possible risk, and scores above 65 are likely to be associated with depressive disorder (Kovacs, 1982). The range of obtained scores was 39-63. The large majority of the sample received a score that is unlikely to be associated with depressive disorder (92%), and a small portion of the sample had scores that indicate possible risk of depression (18%). No participants in the sample reported enough depressive symptoms to indicate that they were likely to be suffering from depression.

The PedsQL (PedsQL; Varni, Seid, & Rode, 1999) was used to obtain a score of psychosocial functioning (composite of emotional, social, and school functioning), physiological functioning and social functioning. The current sample obtained a mean of 89.3 (*SD*=11.07, *Observed Range* =60-100) for the social functioning subscale; a mean of 78.0 (*SD* =12.15, *Observed Range* =50-100) on overall psychosocial functioning, and a mean of 81.9 on the physical functioning subscale (*SD* =17.76, *Observed Range*= 34-100). The possible range for each of these domains was 0-100. As the PedsQl does not have any published normative data, a table comparing the current sample to a variety of pediatric chronic illness populations was created (Table 3).

Coping strategies were measured by the KidCope (Spirito, Stark, & Williams, 1988). The manual states that if someone cannot think of a medical stressor initially to prompt them. Sixty-seven percent of the sample needed prompting to think of a problem

or stressor related to their illness. Initial descriptive statistics also reveal that the coping strategy of seeking social support (M = 2.96, Range 1-4) was the most frequent coping strategy, followed by wishful thinking (M = 2.78), and positive emotional regulation (M = 2.68). The participants rated the efficacy of these coping strategies on average as 3.01 (SD= .81, Range 1-5). As past studies have shown that in both healthy adolescents and young adults with a chronic illness, coping attempts change over time, an ANOVA was conducted to examine if in the current sample, coping strategies were utilized a significantly different amount across age groups (Band & Weisz, 1988; Brown, O'Keeffe, Sanders, & Baker, 1986). Consistent with past studies, the current sample utilizes wishful thinking and self criticism to a significantly different degree across age groups (Table 4). However, overall coping efficacy and the coping efficacy of the specific coping strategies did not vary significantly across age groups. The results are presented in Table 5.

Health care utilization was measured by combining the patient's number of hospitalizations and number of emergency room visits in the past year. The average amount of healthcare utilization was less than one hospitalization or ER visit per person in the last year (M = 0.76, SD = 1.35, Range = 0-7). Hospitalizations that directly followed from an emergency room visit were only counted once, as it was important to capture such healthcare utilization as representing one medical emergency.

Medication non-adherence was calculated by dividing the number of medications that a child reported not taking each day by the number of medications that a child was prescribed to take each day. The adolescents were considered non-adherent if 20% or more of their medications were missed on average (Rapoff, 1999). Only 28% (14)

participants) of the sample reported missing any medications on a given day. On average, the sample reported missing 8.7% (SD= 18.6%) of their medications; however, the 14 non-adherent participants reported not taking on average 34.8% (SD = 26%) of their medications.

### Family Functioning as a Predictor of Depressive Symptoms and Social Functioning

Hypotheses 1a, 1b, 1c were analyzed using general linear regression. To test these hypotheses, two linear regression models were fit, one with depression as the outcome, and the other with social functioning as the outcome. Both models included the subdomains of family functioning (conflict, cohesion, expressiveness), age, and disease severity. The two models that were fit are:

- 1) Depressive\_Symptoms =  $B_{0D} + B_{1D}$ Family\_Conflict +  $B_{2D}$  Family\_Cohesion +  $B_{3D}$  Family\_Expressiveness +  $B_{4D}$  Age +  $B_{5D}$  Disease\_Severity + Error<sub>D</sub>
- 2) Social\_Functioning =  $B_{0S} + B_{1S}$  Family\_Conflict +  $B_{2S}$  Family\_Cohesion +  $B_{3S}$  Family\_Expressiveness +  $B_{4S}$  Age +  $B_{5S}$  Disease\_Severity + Error<sub>S</sub>

Hypothesis 1a, that higher family conflict ratings would predict higher levels of depressive symptomology and lower levels of social functioning when age, family cohesion, family expressiveness, and disease severity are controlled for was not supported. In equation 1 shown above, conflict did not have a significant beta weight and, therefore, was not a significant predictor of an individual's depressive symptoms. The results are presented in Table 6. Next equation 2, shown above, was used to examine if conflict was a significant predictor of social functioning. In this inclusive model, none of the variables had significant beta weights. Therefore in the inclusive model, none of the

functioning. The results are presented in Table 7. If age alone is entered into the model as a single covariate, however, a significant amount of variance is accounted for ( $R^2 = 11.1\%$ , p < .05). This is due to the fact that age and the other variables share a large portion of the variance, so the inclusive model is not significant; however, independently age is a significant positive predictor of social functioning.

Hypothesis 1b, that higher family cohesion ratings will predict lower levels of depressive symptomology and higher levels of social functioning when age, family conflict, family expressiveness, and disease severity are controlled for was also analyzed using the above stated linear regression equations. Using equation, 1 cohesion did not have a significant beta weight and therefore was not a significant predictor of an individual's depressive symptoms. The results are displayed in Table 8. Using equation 2, cohesion did have a significant beta weight and, therefore, was a significant predictor of an individual's social functioning as predicted. The results are presented in Table 9. Using a hierarchical regression (table 10), the amount of variance that cohesion accounts for above and beyond the variance accounted for by the other variables can be examined. Covariates to control for age and disease severity were entered at Step 1. Conflict and expressiveness were entered into the model at Step 2 and resulted in a significant full model ( $R^2 = .18$ , p < .05), indicating that the model overall is still significant; however, adding conflict and expressiveness to the model does not account for a significant amount of variance above and beyond that accounted for by age and disease severity. Cohesion was added at Step 3; this resulted in a significant model ( $R^2 = .34$ , p < .05) and a significant amount of variance accounted for above and beyond the variance accounted for by age, disease severity, conflict, and expressiveness ( $\Delta R^2 = .16$ , p < .05).

Hypothesis 1c, that higher family expressiveness ratings will predict higher levels of depressive symptomology and lower levels of social functioning when age, family conflict, family cohesion, and disease severity are controlled for was also analyzed using linear regression. Using equation 1, expressiveness did not have a significant beta weight and, therefore, was not a significant predictor of an individual's depressive symptoms (Table 11). Likewise, expressiveness was not a significant predictor of social functioning (Table 12).

### Post-hoc analyses

Given that cohesion was a significant predictor of social functioning in the current sample, post hoc analyses were conducted to examine whether cohesion would also be a significant predictor of overall psychosocial functioning and physiological functioning. Cohesion was a significant predictor of overall psychosocial functioning (as measured by the PedsQL) when age and disease severity were held constant ( $R^2 = .29$ , P<.001). Holding age and disease severity constant, cohesion was not a significant predictor of physiological functioning. Additionally, it is of interest to note that cohesion was not a significant predictor of coping efficacy or positive coping strategies.

### Coping Efficacy as a Predictor of Depressive Symptoms and Social Functioning

Hypothesis 2, that higher levels of coping efficacy among adolescents would be associated with lower levels of depressive symptoms and higher levels of social functioning when age and disease severity are controlled for was also tested using a linear regression. To test this hypothesis, two linear regression models were fit-- one with depressive symptomatology as the outcome, and the other with social functioning as the

outcome. Both models included coping efficacy, age, and disease severity. The two models were:

- 3) Depressive\_Symptoms =  $B_{0CD} + B_{1CD}$  Coping\_Efficacy +  $B_{2CD}$  Age +  $B_{3CD}$ Disease\_Severity + Error<sub>CD</sub>
- 4) Social\_Functioning =  $B_{0CS} + B_{1CS}$  Coping\_Efficacy +  $B_{2CS}$  Age +  $B_{3CS}$ Disease\_Severity + Error<sub>CS</sub>

Using equation 3, coping efficacy did not have a significant beta weight and, therefore, was not a significant predictor of an individual's depressive symptoms (Table 13). Likewise, coping efficacy was not a significant predictor of an individual's social functioning (Table 14). Interestingly, overall coping efficacy also was not a significant predictor of overall psychosocial or physiological functioning. However, the efficacy of two specific coping strategies were significant predictors of social functioning and overall psychosocial functioning when holding age and disease severity constant; emotion regulation ( $R^2 = .18$ , p < .05;  $R^2 = .32$ , p < .05), respectively; and seeking social support ( $R^2 = .22$ , p < .05;  $R^2 = .23$ , p < .05), respectively. These two coping strategies are also two of the three most frequently used coping strategies in the given sample.

#### Post-hoc analyses

Given that the efficacy of emotion regulation and seeking social support were both significant predictors of social and psychosocial functioning, it was important to examine if these same factors would be significant predictors of physiological well being. Specifically it was examined whether the rated efficacy of seeking social support would be a significant negative predictor of hospitalizations and emergency room visits. It was found that while holding age and disease severity constant, the efficacy of seeking social

support was a significant negative predictor of hospitalizations and emergency room visits.

## Medication Non-Adherence as a Mediator of Coping Efficacy and Health Care Utilization

Hypothesis 3a, that coping efficacy and health care utilization will be partially mediated by medication non-adherence when age and disease severity are controlled for, was analyzed using the Baron and Kenney (1997) approach. The Baron and Kenny procedure was applied via a series of regression analyses, with each analysis designed to examine specific relationships within the mediation model. Determination of mediation or not was then based on the pattern of results. A figure depicting the Baron and Kenney approach as utilized by the current study is shown in Figure 2. In the figure, each of the coefficients a, b, c, and c represents the linear influences of one variable on the other. The coefficient c is defined as the total effect of coping efficacy (X) on healthcare utilization(Y). The coefficient c is the direct effect of coping efficacy (X) on healthcare utilization(Y). Additionally, ab is the indirect effect of coping efficacy (X) on healthcare utilization(Y).

To use the Baron and Kenney approach, a series of regressions were employed:

- 5) Health\_Care =  $k_1 + c$  Coping Efficacy +  $B_5$  Age +  $B_6$  Disease Severity
- 6) Med\_Non-Adherence = k<sub>2</sub> + a Coping Efficacy + B<sub>7</sub> Age + B<sub>8</sub> Disease Severity
- 7) Health\_Care =  $k_3 + c$ ' Coping Efficacy + b Med\_Non-Adhernece +  $B_9$  Age +  $B_{10}$  Disease Severity

Using regression equation 5, the results indicated that the overall coping efficacy variable (c) was not a statistically significant predictor of healthcare utilization (Table 15). Without a statistically significant result, there cannot be a mediation effect; thus, no further analyses were conducted.

### **Post Hoc Analyses**

Because overall coping efficacy was not a predictor of social functioning or overall psychosocial functioning but the coping efficacy of specific strategies was predictive, particular coping strategies were also examined within a mediational framework. More specifically, does medication non-adherence mediate the relationship between the coping efficacy of resignation and healthcare utilization? All of the steps used to examine 3a remained the same except, instead of X being coping (which was used in the previous model); X was now the efficacy of resignation (Figure 4). The specific equations are written below.

- a) Health\_Care =  $k_1 + c$  Resignation Efficacy +  $B_5$  Age +  $B_6$  Disease Severity
- b) Med\_Non-Adherence =  $k_2 + a$  Resignation Efficacy +  $B_7$  Age +  $B_8$  Disease Severity
- c) Health\_Care =  $k_3 + c$ ' Resignation Efficacy + b Med\_Non-Adhernece +  $B_9$ Age +  $B_{10}$  Disease Severity

Using equation a, it was found that the efficacy of resignation was a significant positive predictor of healthcare utilization ( $R^2$ = .339, p < .05) above and beyond the control variables. These results are presented in Table 16 and are represented by letter c in figure 4. This implies a significant total effect which is a necessary condition for mediation to occur. As this association was significant, the analyses moved to equation b.

Using this equation, the efficacy of resignation was a significant positive predictor of medication non-adherence ( $R^2$ = .178, p < .05) when controlling for age and disease severity (Table 17). This implies a significant effect of the coping efficacy of resignation on medication non-adherence which is also a necessary condition for mediation to occur. As step b was significant, the analyses continued to step c. Using equation c, it was determined that medication non-adherence and resignation efficacy are both significant predictors of healthcare utilization ( $R^2$ = .281, p < .05) when controlling for age and disease severity (Table 18). The analysis completed in step c is represented by letter c' in Figure 4. These results indicate that the coping efficacy of resignation has an effect on healthcare use beyond that of medication non-adherence. This is consistent with partial mediation which exists when X has an effect on Y beyond that of the mediator. Referring to Figure 4 it can be seen that c>>c' and c' are significant.

# Medication Adherence as a Mediator of Global Family Functioning and Health Care Use

Hypothesis 3b, that that the relationship between global family functioning and health care utilization would be partially mediated by medication non-adherence when age and disease severity are controlled for, was also analyzed using the Baron and Kenney (1997) approach. The Baron and Kenny procedure was applied via a series of regression analyses:

- d) Healthcare  $= k_1 + c$  Global Family Functioning  $+ B_5$  Age  $+ B_6$  Disease Severity
- e) Med Non-Adherence =  $k_2 + a$  Global Family Functioning +  $B_7$  Age +  $B_8$  Disease Severity

f) Healthcare = k<sub>3</sub> + c' Global Family Functioning + b Med\_Non-Adhernece +
 B<sub>9</sub> Age + B<sub>10</sub> Disease Severity

Using regression equation 8, the results indicated that the global family functioning variable (c) was not a statistically significant predictor of healthcare utilization (Table 19). Without a statistically significant result there cannot be a mediation effect; thus, no further analyses were conducted.

### **Post Hoc Analyses**

As specific family characteristics such as cohesion were significant predictors of psychosocial functioning and social functioning, but overall family functioning was not, post hoc analyses were conducted to examine if specific family characteristics were significant moderators of healthcare utilization and medication non-adherence. However, neither conflict, cohesion, nor expressiveness was a significant predictor of healthcare utilization. Without a statistically significant association, there cannot be a mediation effect; thus, no further analyses were conducted.

#### Discussion

Worldwide the prevalence of Chronic Kidney Disease has been rising markedly (Vupputuri & Jennette, 2007) and while the occurrence of CKD is increasing across all ages, adolescents are specifically at increased risk for steep renal decline once diagnosed (Ardissino et al., 2003). Despite this increased risk, the picture regarding the adjustment of adolescents with CKD is mixed, and our understanding of their adjustment lags behind the adult literature (Beidel, 1987; Rodin & Voshart, 1987). Only a handful of studies have examined the adjustment of these adolescents. Some studies indicate that this population may be at increased risk for depression (Garralda, Jameson, Reynolds, &

Postlethwaite, 1988), low social functioning (Fukunishi & Honda, 1995; Fukunishi & Kudo, 1995), and medication non-adherence (Creer & Holroyd, 1997) whereas others have found more positive adjustment (Brem et al., 1988; Falger, Landolt, Latal, Ruth, Neuhaus, 7 Laube, 2008). These mixed findings suggest that illness severity alone is not the only factor influencing adjustment; rather, environmental and individual factors may be key to understanding why some adolescents are able to adjust positively to their illness and others are not. It has been suggested that the family is the most significant environmental influence in a child's life (Kazak, Rourke, & Crump, 2003). Coping or managing the environmental and internal demands through various thoughts and behaviors (Lazarus & Folkman, 1984) is frequently necessary due to the daily challenges and uncertainties that adolescents with a chronic illness face (Graue, Wentzel-Larsen, Bru, 2004).

The current study sought to further characterize the adjustment of the adolescent CKD population and examine what coping strategies and family factors play key roles in predicting adjustment. The results indicate that, overall, the current sample is relatively well-adjusted in the domains of mental health, social functioning, and physical health. Furthermore, findings suggest that both family functioning, specifically cohesion levels, and the efficacy of different coping strategies such as emotion regulation and seeking social support are helpful in understanding an adolescent's adjustment to CKD.

Past research has shown that the family is intimately linked with both the short and long term course of an adolescent's development (Kazak, Segal-Andrews, Johnson, 1995). Specifically, an adolescent's social development appears to be significantly affected by influences such as parental socialization and the family environment

(Eisenberg, Fabes, & Spinrad, 2006). Therefore, it was hypothesized that better family functioning would be associated with higher levels of social functioning. Whereas this (and other hypotheses) are predicated upon a causal process in which family functioning influences the adolescent's social functioning, the cross sectional nature of the current investigation precludes such conclusions. This hypothesis was partially supported by the finding that a family's level of cohesion did predict higher social functioning. Cohesion is defined as the degree of commitment, help, and support family members provide for one another. This association had not previously been examined in a CKD population; however, the current result is consistent with research in healthy adolescent populations (Parke, Cassidy, Burks, Carson, & Boyum, 1992). This finding suggests that while adolescents with CKD will experience certain concrete and observable side effects such as slowed growth and physical limitations due to their illness, a positive family environment might help the adolescent overcome these barriers and develop positive peer relationships. Whereas some may expect the families in the current sample to have lower levels of functioning due to the stress and burden of a chronic illness, this is not the case. In fact, when compared to 17,730 healthy individuals, the current sample obtained higher levels of cohesion, the same level of expressiveness, and lower levels of conflict (Moos & Moos, 2009). The association between a healthy family system and the development of an adolescent's positive peer relationships speaks to the importance of the family as the primary socialization agent. The adolescent's experience in a healthy family environment may affect their prosocial development through a variety of mechanisms and processes, including modeling, teaching, and emphasizing prosocial behaviors and values (McLellan & Youniss, 2003).

Positive family functioning may allow adolescents the opportunity to model prosocial behaviors in their peer relationships that they have observed in their families, behaviors such as helping and supporting friends, expressing their feelings directly, and minimizing the amount of conflict. The influence of modeling may not be limited to social functioning; in fact, it may play a large role in predicting an adolescent's overall psychosocial functioning (Eley & Gregory, 2004). In the domain of school functioning, positive parental involvement has been shown to be associated with adolescent's learning and in turn school outcomes (Coleman, 1993). Additionally, family studies indicate that children of parents with psychological disorders display higher rates of psychopathology than do relatives of family members without psychological disorders (Burstein & Ginsburg, 2010). Consistent with past literature, the current study found that family functioning, specifically higher levels of cohesion, predicted higher levels of psychosocial functioning. The positive family environment may serve as a buffer against the chronic illness and facilitate lower levels of psychosocial distress in adolescents (Harbeck-Weber, Fisher, & Dittner, 2003). This buffer appears to be dependent upon high levels of family cohesion; however, contrary to study hypotheses neither expressiveness nor conflict was a significant predictor of social or psychosocial functioning. Expressiveness is the extent to which family members are encouraged to express feelings directly, and conflict is the amount of openly expressed anger (Moos & Moos, 1994). Past research examining the significance of expressiveness and conflict in predicting adjustment is mixed (Davis, Tucker, & Fennell, 1996; Isley, O'Neil, & Parke, 1996). The current findings suggest that the specific amount of expressed emotions in a family may be less important than an overall feeling of unity among family members. Thus, there is not one specific way to obtain this positive family structure; instead, high or low levels of conflict and expressiveness may exist as long as a general positive family atmosphere exists.

Whereas the current results are consistent with the notion that positive family functioning might help buffer the adolescent against broad domains of poor psychosocial adjustment, depression is a potentially high-risk type of maladjustment confronting children with CKD. Some studies suggest that children with CKD may be at greater risk for internalizing problems; however, it is unclear if a positive family environment could safeguard against such a harmful outcome (Garralda, Jameson, Reynolds, & Postlethwaite, 1988). Results indicate that family functioning was not a significant predictor of depressive symptoms in the current sample. However, overall low levels and a restricted range of depressive symptoms were displayed in the current sample, making it difficult to examine associations between depression and the other variables of interest. Thus, the significance of the family in a more distressed population cannot be evaluated in the current sample. In fact, in the current sample the large majority of adolescents received a depression score that is unlikely to be associated with depressive disorder (92%), and no participants in the sample reported enough depressive symptoms to indicate that they were likely to be suffering from depression. These results are surprising as research into the etiology of depression has identified *loss* as essential to the development of the disorder (Kessler, 1997). Adolescents with CDK would appear to experience loss in multiple ways: the loss of freedom, lower self-esteem, and loss of opportunities. However, in the current sample when asked to identify something related to their illness that has been difficult in the past month, the majority of participants (67%) needed prompting to think of recent difficult situations. This could suggest that while this sample is likely experiencing many difficult events and possible losses (e.g., doctors visits, medication, shots, missing school, inability to play sports), they are not processing these circumstances as onerous and difficult. Instead, as suggested by Paluszny, DeBeukelaer, and Rowane (1991), adolescents who live with a chronic illness may learn to cope effectively with the stressors and, thus, accept the changes in their lifestyle as their new norm.

While the coping efforts of an adolescent with CKD are likely employed significantly more frequently than their healthy peers, there is much discrepancy in the literature regarding how well adolescents with a chronic illness are able to adjust (Amr, 2009; Qvist et al., 2004) and how the coping process itself should be conceptualized (Compas, Connor-Smith, & Saltzman, 2001). As the ability to identify and utilize coping strategies changes as children move from adolescence into young adulthood (Band & Weisz, 1988; Brown, O'Keeffe, Sanders, & Baker, 1986; Gil, Wilson, & Edens, 1997), and coping strategies are employed differently depending on the situational demands, coping efficacy has been suggested as an effective way to examine coping across age groups and across a range of stressors (Siegel, 1992). In accordance with this literature, it was hypothesized that higher levels of coping efficacy would predict higher levels of social functioning.

The discrepant conceptualizations of coping have resulted in mixed perspectives concerning the most appropriate way to analyze the coping efficacy section of the KidCope. The manual states that the items were not categorized into any higher order structure because the efficacy of a particular coping strategy is believed to vary by

situation (Spirito, 1996). However, over the years, a burgeoning interest in using the KidCope to develop a higher order factor structure has developed (i.e., positive/negative, approach/avoidance). Spirito and colleagues gathered a sample of 3,000 children and adolescents with the aim of examining the factor structure using the entire sample and with several well-defined sub-samples. One such sub-sample was children with a chronic illness. While the stressors selected by the children all centered on their illness, it was found that depending on the problem selected by the patient, different factor structures emerged. For example, a two-factor structure (i.e., approach/avoidance efficacy) emerged when the problem selected involved aversive medical procedures, but a single-factor structure resulted when the stressor was an extended period of hospitalization (1996). Furthermore, other studies examining coping in hurricane victims have yielded only one factor (Vigna, Hernandez, Kelley, & Gresham, 2010) or as many as three in other chronic illness populations (Spirito, Stark, & Tyc, 1994). These findings suggest that the categorization of a coping efficacy strategy, whether it be derived empirically or conceptually, cannot be separated from the situation in which it is employed. That is, the function or classification of a coping efficacy strategy (e.g., adaptive/non-adaptive) does not remain identical across situations but, rather, as initially suggested by Spirito and colleagues, it varies depending on the situation. Therefore, while a higher order factor (i.e., overall coping efficacy) was employed in the current investigation, the findings of Spirito and colleagues (1996) suggest that grouping the strategies into factors may be inappropriate and instead examining specific coping efficacy strategies may be more appropriate.

Consistent with Spirito and colleagues' assertion, the results of the current study found that overall coping efficacy was not a significant predictor of social functioning. This finding is contrary to the initial hypothesis and provides support for the idea that coping does not remain identical across situations but rather varies depending on the situation. Therefore, it may be important to examine the individual strategies independently. In the current sample, two coping efficacy strategies emerged as particularly salient: emotion regulation and seeking social support. While both of these strategies are significant predictors of social functioning, the two may operate in different ways. The ability to regulate emotions is an important aspect of adaptive functioning in society. Within the CKD population, no studies to date have examined the relationship between emotion regulation and social functioning; however, within bi-polar patients, studies have found that the lack of emotion regulation is a key predictor of relapse (Butzlaff & Hooley, 1998). Further, friends and family members of these individuals report feeling like they are 'walking on egg shells,' uncertain how the bi-polar individual will react in any given situation. Over time this uncertainty may result in negatively affected social relationships (Thomas, 1980). Conversely, the high level of positive emotion regulation within the current sample was a significant predictor of positive social functioning and psychosocial functioning, suggesting that being able to positively regulate emotion may increase one's social functioning and overall psychosocial functioning.

The internal coping strategy of emotion regulation was not the only significant coping efficacy strategy to predict social functioning. Many studies have provided evidence for the positive effects of perceived social support on emotional and physical

functioning (Cohen, Underwood, & Gottlieb, 2000). Consistent with this research, the current investigation found that the efficacy of seeking social support was a significant predictor of overall psychosocial functioning. The proactive approach of engaging others when faced with a stressful situation may facilitate a feeling of closeness within peer relationships (Rudolph, 2010) and, thus, better overall social functioning.

While the efficacy of both internal and interpersonal coping strategies were significant predictors of social functioning and overall psychosocial functioning, it was unclear if these coping strategies would play a similarly important role when trying to understand the development of depressive symptoms. Only one study to date has examined coping and depressive symptoms in pediatric CKD patients (Brem, Brem, McGrath, & Spirito, 1988); however, that investigation did not examine the relationship between these two constructs. Similar to the current study, Brem et al. found seeking social support to be the most frequently used coping efficacy strategy (Brem, Brem, McGrath, & Spirito, 1988). Other investigations regarding the level of depressive symptoms in pediatric CKD patients have been mixed (Amr, 2009; Qvist et al., 2004). Given this literature, it was hypothesized that higher coping efficacy would predict lower levels of depressive symptoms. This hypothesis was not supported; neither overall coping efficacy nor any of the specific coping efficacy strategies were significant predictors of depression. However, as mentioned above, overall low levels and a restricted range of depressive symptoms were displayed in the current sample, making it difficult to examine associations between depression and the other variables of interest. Thus, the significance of coping efficacy in a more distressed population cannot be evaluated in the current sample.

Specific coping efficacy strategies were found to be significant predictors of positive adjustment outcomes such as social functioning and overall psychosocial functioning; however, these strategies may also be important when trying to understand indicators of maladjustment. One type of maladjustment with serious repercussions is medication non-adherence. When patients do not follow their prescribed medical regimen, the implications may include more frequent medical complications and hospitalizations (Falkenstein, Flynn, Kirkpatrick, Casa-Melley, & Dunn, 2004). While appropriate treatment of CKD cannot undo damage that the kidney has previously incurred, correct medication use and follow-up care should stabilize the illness making hospitalizations and emergency room visits uncommon (Ferris et al., 2008). Several studies have found a relationship between positive coping strategies and better medication adherence (Christensen, Benotsch, Wiebe, & Lawton, 1995), and higher coping attempts and less frequent health care use (Broome, Mailkler, Kelber, Bailye, & Lea, 2001).

Based on these prior studies, it was hypothesized that the relationship between coping efficacy and health care utilization would be partially mediated by medication adherence. No studies to date however have specifically examined this relationship. This hypothesis, however, was not supported. Consistent with the prior hypotheses in the current study, overall coping efficacy appears to be a poor construct and was not a significant predictor of healthcare use. Rather, it may be important to examine the individual strategies independently. One such strategy is resignation. Resignation may be associated with a sense of hopelessness and helplessness. Patients with high levels of resignation coping efficacy may think that that they have no control over their health

outcomes and may, therefore, not take appropriate healthcare steps to ensure their optimum health. Consistent with this possible explanation, it was found that higher levels of coping resignation predicted more healthcare use, and this association was partially mediated by poor medication adherence. The fact that there is partial mediation suggests that the coping efficacy of resignation directly influences healthcare use. This may initially seem counterintuitive due to the patient's likely indifference to maintain consistent medical care. However, healthcare use in the current study was defined as the number of ER visits and hospitalizations. Thus healthcare use is not an indication of health maintenance; rather, it is suggestive of a medical emergency. This relationship partially operates by a patient being non-adherent to their medications. While medication will help to stabilize CKD making hospitalizations and ER visits fairly uncommon, if patients do not take their medications as prescribed, their illness will continue to progress and more intensive medical care may be required. Therefore, a patient who feels resigned and uses this coping strategy when dealing with stressors related to their chronic illness may decide to be non-adherent to their medication and, as a result, have more hospitalizations and ER visits.

Partial mediation allows one to begin to understand how coping efficacy strategy of resignation influences healthcare use; however, the fact that mediation was only partial suggests that there are other unidentified factors operating. There are many other healthcare behaviors that one should follow when diagnosed with CKD, such as following a diet low in sodium and phosphorus, being consistently followed by a doctor, and playing low impact sports (Smith, 2009). In addition to these possible healthcare behaviors, it may be that having resignation as a prime coping strategy causes a

metabolic change or other physiological changes in the body that makes one more susceptible to needing intensive medical care. These factors may be interesting to examine in the future when trying to further understand how coping resignation influences healthcare use.

Whereas future research may facilitate a deeper understanding of how resignation influences healthcare use, the findings from hypothesis 3b suggest that family functioning may not be a significant factor when predicting medication adherence. Although these results are contrary to past studies, it suggests that in the current sample instead of the family unit facilitating medication taking, the patients themselves may be in charge of their medications (Foulkes, Boggs, Fennell, & Skibinski, 1993). In past studies, positive family functioning may have facilitated an environment where parents reminded their children to take their medications. However, at the UNC clinic doctors emphasize medical activation. This includes encouraging adolescents to be responsible for their own medications; thus, family factors may become less important.

A few limitations for the current study merit discussion. First, this study is a cross-sectional examination of the relationship between coping, family functioning, and adjustment in adolescents with CKD. Whereas the hypotheses are predicated upon a causal process in which family functioning and coping efficacy influence the adolescent's adjustment, the cross sectional nature of the current investigation precludes such conclusions. The directionality of the hypotheses is logical given past research and the current study model; however, it could be that the adjustment of the child is, in fact, influencing their family functioning or coping. Thus, future longitudinal studies will provide opportunities to examine the direction of association, which is important given

possible bi-directionality. A second limitation of the current investigation is that recruitment occurred from one hospital in one location. This suggests that the results of the study may not be generalizable to the remainder of the country. However, the findings are representative of the state of NC, as patients must drive from such long distances to reach the hospital, and the sample includes a range of economic statuses, races, and ages. In addition, the results should not be generalized to adolescents with other chronic illnesses as studies suggest that the role of coping and family functioning may operate differently in different illness populations (Lewis & Klieweser, 1996; Miller et al., 2009). Additionally, the results of this study do not generalize to a more severely depressed population. Future studies should include multi-site investigations, and if more depressed CKD patients are present in that sample, inferences about the role of these resilience factors can be drawn. The last limitation of this study is that only self-reported measures of medication adherence and healthcare utilization were obtained. As researchers have shown that bio-markers, labs, and prescription refill records may be good objective measures of adherence, this may be an important next step for researchers to take.

Some strengths of this study should also be noted. This study examines an understudied age group and understudied illness population, adolescents with Chronic Kidney Disease. Previous literature examining CKD has focused on adults and while this is the same illness, it does little to inform adjustment in the pediatric population. As adolescents with CKD are at increased risk for steep renal decline, understanding factors that may facilitate better physical and psychosocial adjustment becomes especially critical (Ardissino et al., 2003). The current study is also one of the first to focus on resilience factors within this population. Prior research has predominantly focused on

either internal or environmental risk factors that may place youth at jeopardy of maladjustment. In addition to furthering an understanding of resilience factors that may facilitate a positive adjustment, these results may be used by pediatric psychologists at hospitals to facilitate positive adjustment. The clinical implications are important to note as illness severity factors cannot be changed, but the resilience factors examined in this study can be modified.

Families with an adolescent who is given a diagnosis of Chronic Kidney Disease should understand that the illness itself is not the only factor important when determining adjustment. While psychologists may facilitate factors that encourage positive adjustment, families and healthcare providers may also serve a crucial role. Having a positive family environment that is cohesive can be critical when predicting a child's psychosocial adjustment. By having a cohesive environment and modeling positive coping strategies such as seeking social support and emotion regulation, adolescents may learn adaptive coping strategies to deal effectively with the stressors they experience. Healthcare providers also can facilitate positive adjustment by encouraging their patients to recognize that that the course of the illness is very much under the patient's control. By preventing feelings of resignation, helplessness, and hopelessness, patients may become more motivated to follow the suggested medical regimen. Future research is needed to replicate and further validate these results; however, this study gives an initial look into the importance of individual and interpersonal factors when understanding adjustment to CKD.

Table 1

Correlation Matrix between the Three Sub-Scales of the Family Relationship Index

			1.	2.	3.
1.	Cohesion				
		Pearson	1	.439**	442**
	Correlation			.001	.001
		Significance		50	50
		N			
2.	Expressiveness				
		Pearson		1	359*
	Correlation				.011
		Significance			50
		N			
3.	Conflict				
		Pearson			1
	Correlation				
		Significance			
		N			

<sup>\*</sup>p <.05, \*\*p <.01

Table 2

Means and Standard Deviations of the Three Subscales of the Family Relationship Index:
Comparison of the Current Sample to a Healthy and Distressed Sample (Moos & Moos, 2009)

	Current Study (n=46)	Healthy Sample (n=17,730)	<b>Distressed Sample</b> (n=5,435)
	Mean (SD)	Mean (SD)	Mean (SD)
Cohesion	7.3 (1.5)	6.7 (2.2)	5.3 (2.6)
Expressiveness	5.1 (1.7)	5.1 (2.0)	4.6 (2.0)
Conflict	2.8 (2.1)	3.6 (2.2)	4.4 (2.5)

Table 3

Comparison of the Current Sample's Score on the PedsQL to Various Pediatric Populations

Pediatric Population	Reference	Social Functioning	Emotional Functioning	School Functioning	Physical Functioning	Psychosocial Functioning
		Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
CKD N=50	Current Study	89.3 (11.1)	75.9 (17.5)	68.8 (18.6)	81.89 (17.8)	78.0 (12.2)
Oncology N=389	Varni, Limbers, & Burwinkle, 2007	75.4 (21.1)	72.0 (20.9)	68.2 (81.1)	72.0 (21.4)	72.0 (16.3)
Sickle Cell N=68	McClellan, Schatz, Sanchez, & Roberts, 2008	71.2 (23.8)	65.5 (22.1)	57.2 (18.1)	69.3 (19.8)	64.5 (18.1)
Obesity N=107	Ingerski, Janicke, & Silverstein, 2007	75.3 (22.8)	70.1 (22.7)	67.6 (21.0)	79.1 (18.2)	71.05 (16.7)
Glycogen Storage Disease N=31	Storch et al., 2008	71.4 (15.8)	68.2 (16.3)	71.4 (12.5)	75.6 (14.2)	70.3 (10.7)
Irritable Bowel Disease N=36	Hommel, Davis, & Baldassano, 2008	84.3 (16.7)	76.3 (19.3)	73.2 (21.4)	82.8 (13.1)	77.9 (17.02)
Spinal Cord Injury N=197	Garma, Kelly, Daharsh, & Vogel, 2010	74.4 (19.0)	68.6 (19.6)	66.0 (19.6)	69.8 (14.8)	69.7 (19.4)
Healthy N=5840	Varni, Limbers, & Burwinkle, 2007	85.2 (16.8)	79.3 (18.2)	81.1 (16.5)	87.5 (13.5)	81.9 (14.1)

Table 4

ANOVA Table:
Frequency of Use for Various Coping Strategies across Age groups:
Group 1: 13-14 years, Group 2: 15-16, Group 3: 17-18

Coping Strategy	Sum of Squares	df	Mean Square	F	
Distraction					
Between Group	4.404	2	2.202	2.037	
Within Group	50.816	47	1.081		
Total	55,220	49			
Social Withdrawal					
Between Group	2.911	2	1.456	1.095	
Within Group	62.469	47	1.329		
Total	65.380	49			
Cognitive Restructuring					
Between Group	1.796	2	.898	.914	
Within Group	46.204	47	.983		
Total	48.000	49			
Self Criticism					
Between Group	.974	2	.487	.517	
Within Group	44.246	47	.941		
Total	45.220	49			
Blame Others					
Between Group	1.532	2	.766	.772	
Within Group	46.648	47	.993		
Total	48.180	49			
Problem Solve					
Between Group	.367	2	.183	.134	
Within Group	64.113	47	1.364		
Total	64.480	49			
Negative Emotion Regulation					
Between Group	9.725	2	4.862	1.562	
Within Group	146.295	47	3.113		
Total	156.020	49			
Positive Emotion Regulation					
Between Group	5.534	2	2.767	3.482**	
Within Group	37.346	47	.795		
Total	42.880	49			
Wishful Thinking					
Between Group	14.106	2	7.053	6.839**	
Within Group	48.474	47	1.031		
Total	62.580	49			
Social Support		<u>-</u>			
Between Group	1.083	2	.542	.544	
Within Group	46.837	47	.997	· <del>-</del> · ·	
Total	47.920	49	•221		
Resignation	.,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	.,			
Between Group	.251	2	.126	.092	
				.072	
Within Group	64.069	47	1.363		

<sup>\*</sup>p<.10, \*\*p<.05, \*\*\*p<.001

Table 5

ANOVA Table:

Efficacy of Use for Various Coping Strategies across Age groups:

Group 1: 13-14 years, Group 2: 15-16, Group 3: 17-18

Coping Strategy	Sum of Squares	df	Mean Square	F
Distraction				
Between Group	6.438	2	3.219	1.751
Within Group	86.382	47	1.838	
Total	92.820	49		
Social Withdrawal				
Between Group	.461	2	.231	.112
Within Group	96.819	47	2.060	
Total	97.280	49		
Cognitive Restructuring				
Between Group	1.520	2	.760	.513
Within Group	69.600	47	1.481	
Total	71.120	49		
Self Criticism				
Between Group	5.160	2	2.580	1.082
Within Group	112.060	47	2.384	
Total	117.220	49		
Blame Others				
Between Group	2.244	2	1.122	.518
Within Group	101.776	47	2.165	
Total	104.020	49		
Problem Solve				
Between Group	7.645	2	3.823	1.888
Within Group	95.175	47	2.025	
Total	102.820	49		
Negative Emotion Regulation				
Between Group	1.554	2	.777	.335
Within Group	108.946	47	2.318	
Total	110.500	49		
Positive Emotion Regulation				
Between Group	2.557	2	1.279	1.006
Within Group	59.763	47	1.272	
Total	62.320	49		
Wishful Thinking				
Between Group	10.176	2	5.088	2.820
Within Group	77.904	47	1.658	
Total	88.080	49		
Social Support				
Between Group	5.706	2	2.853	1.628
Within Group	82.374	47	1.753	-
Total	88.080	49		
Resignation				
Between Group	7.805	2	3.903	1.778
Within Group	103.175	47	2.195	
Total	110.980	49	2.170	

<sup>\*</sup>p<.10, \*\*p < .05, \*\*\*p < .001

Table 6

Analysis of Hypothesis 1a:

That Higher Levels of Conflict will Predict Higher Levels of Depressive
Symptoms when Age, Disease Severity, Cohesion and Expressiveness are
Controlled For.

Variable	В	SE	β	
Conflict	169	.426	065	
Cohesion	365	.647	100**	
Expressiveness	392	.563	119	
Age	196	.497	063	
Disease Severity	911	.671	200	

<sup>\*</sup>p<.10, \*\*p<.05, \*\*\*p<.001

Table 7

Analysis of Hypothesis 1a:

That Higher Levels of Conflict will Predict Lower Levels of Social Functioning when Age, Disease Severity, Cohesion, and Expressiveness are Controlled For.

Variable	В	SE	β	
Conflict	459	.722	089	
Cohesion	3.567	1.096	.492*	
Expressiveness	285	.953	044	
Age	.981	.841	.160	
Disease Severity	173	1.136	019	

<sup>\*</sup>p<.10, \*\*p<.05, \*\*\*p<.001

Table 8

Analysis of Hypothesis 1b:

That Higher Levels of Cohesion will Predict Lower Levels of Depressive Symptoms when Age, Disease Severity, Conflict, and Expressiveness are Controlled For.

Variable	В	SE	β	
Cohesion	365	.647	100	
Conflict	169	.426	065	
Expressiveness	392	.563	119	
Age	196	.497	063	
Disease Severity	911	.671	200	

<sup>\*</sup>p<.10, \*\*p<.05, \*\*\*p<.001

Table 9

Analysis of Hypothesis 1b:

That Higher Levels of Cohesion will Predict Higher Levels of Social Functioning when Age, Disease Severity, Conflict, and Expressiveness are Controlled For.

Variable	В	SE	β	
Cohesion	3.567	1.096	.492**	
Conflict	459	.722	089	
Expressiveness	285	.953	044	
Age	.981	.841	.160	
Disease Severity	173	1.136	019	

<sup>\*</sup>p<.10, \*\*p<.05, \*\*\*p<.001

Table 10

Hypothesis 1b:

Summary of Hierarchical Regression Analysis: Does Cohesion Account for a Significant Amount of Variance in Social Functioning Above and Beyond the Variance Accounted for by the Other Variables

Step	Variable	β	F	$\Delta \mathbf{R^2}$	$\mathbb{R}^2$
1	Age, Disease Severity	.31, .08	2.88	.11*	.11*
2	Family Conflict, Expresiveness	25, .07	2.53	.07	.18**
4	Family Cohesion	.49	4.57	.16**	.34**

<sup>\*</sup>p<.10, \*\*p < .05, \*\*\*p < .001

Table 11

Analysis of Hypothesis 1c:

That Higher Levels of Expressiveness will Predict Lower Levels of Depressive Symptoms when Age, Disease Severity, Cohesion, and Conflict are Controlled For.

Variable	В	SE	β	
Expressiveness	392	.563	119	
Cohesion	365	.647	100	
Conflict	169	.426	065	
Age	196	.497	063	
Disease Severity	911	.671	200	

<sup>\*</sup>p<.10, \*\*p<.05, \*\*\*p<.001

Table 12

Analysis of Hypothesis 1c:

That Higher Levels of Expressiveness will Predict Higher Levels of Social

Functioning when Age, Disease Severity, Cohesion, and Conflict are Controlled

For.

Variable	В	SE	β	
Expressiveness	285	.953	044	
Cohesion	3.567	1.096	.492**	
Conflict	459	.722	089	
Age	.981	.841	.160	
Disease Severity	173	1.136	019	

<sup>\*</sup>p<.10, \*\*p < .05, \*\*\*p < .001

Table 13

Analysis of Hypothesis 2:

That Higher Levels of Coping Efficacy will Predict Lower Levels of Depressive Symptoms when Age and Disease Severity are Controlled For.

Variable	В	SE	β	
Coping Efficacy	.727	.990	.105	
Age	461	.445	149	
Disease Severity	-1.045	.646	230	

<sup>\*</sup>p<.10, \*\*p<.05, \*\*\*p<.001

Table 14

Analysis of Hypothesis 2 (Continued):

That Higher Levels of Coping Efficacy will Predict Higher Levels of Social Functioning when Age and Disease Severity are Controlled For.

Variable	В	SE	В	
Coping Efficacy	.978	1.933	.071	
Age	1.861	.868	.302**	
Disease Severity	.662	1.261	.073	

<sup>\*</sup>p<.10, \*\*p < .05, \*\*\*p < .001

Table 15

Analysis of Hypothesis 3a: Step 1 (using equation 5) of the Baron and Kenny Procedure
That Coping Efficacy will be a Significant Predictor of Healthcare Utilization
when Age and Disease Severity are Controlled for.

Variable	В	SE	β	
Coping Efficacy	137	.234	083	
Age	194	.105	263*	
Disease Severity	.153	.153	.141	

<sup>\*</sup>p<.10, \*\*p < .05, \*\*\*p < .001

Table 16

Post Hoc Analysis of Hypothesis 3a: Step 1 (equation a) of the Baron and Kenny Procedure

That the Coping Efficacy of Resignation will be a Significant Predictor of Healthcare Utilization when Age and Disease Severity are Controlled for.

Variable	В	SE	β
Coping Efficacy of Resignation	.394	.112	.439***
Age	173	.094	230*
Disease Severity	.243	.138	.221*

<sup>\*</sup>p<.10, \*\*p<.05, \*\*\*p<.001

Table 17

Post Hoc Analysis of Hypothesis 3a: Step 2 (equation b) of the Baron and Kenny Procedure

That the Coping Efficacy of Resignation will be a Significant Predictor of Medication Non-Adherence when Age and Disease Severity are Controlled for.

Variable	В	SE	β	
Coping Efficacy of Resignation	.052	.019	.371**	
Age	024	.016	203	
Disease Severity	004	.023	025	

<sup>\*</sup>p<.10, \*\*p<.05, \*\*\*p<.001

Table 18

Post Hoc Analysis of Hypothesis 3a: Step 3 (equation c) of the Baron and Kenny Procedure

That the Coping Efficacy of Resignation and Medication Non-Adherence will be a Significant Predictor of Healthcare Utilization when Age and Disease Severity are Controlled for.

Variable	В	SE	β	
Coping Efficacy of Resignation	.305	.117	.340**	
Medication Non- Adherence	1.723	.862	.267**	
Age	132	.094	176	
Disease Severity	.250	.134	.227*	

<sup>\*</sup>p<.10, \*\*p < .05, \*\*\*p < .001

Table 19

Analysis of Hypothesis 3b: Step 1 (using equation 8) of the Baron and Kenny Procedure
That Global Family Functioning will be a Significant Predictor of Healthcare
Utilization when Age and Disease Severity are controlled for.

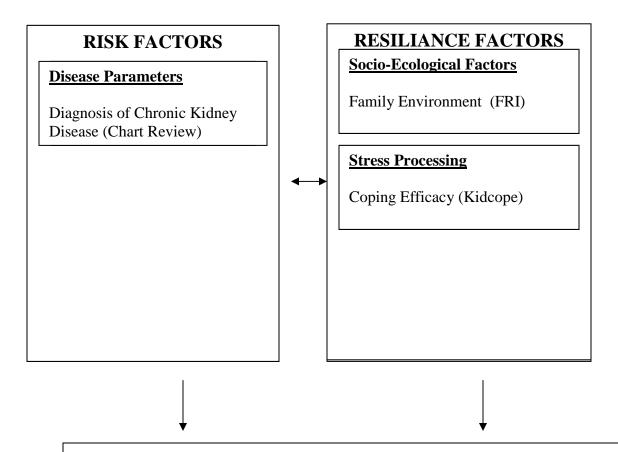
Variable	В	SE	β	
Coping Efficacy	.475	.715	.091	
Age	.801	.321	.344**	
Disease Severity	.348	.466	.102	

<sup>\*</sup>p<.10, \*\*p < .05, \*\*\*p < .001

Figure 1

Wallander & Varni's Disability-Stress-Coping Model: Adapted to Reflect the Current

Study



# ADAPTATION / ADJUSTMENT

## **Mental Health**

About My Feelings (Ped-QL Subscale)

Depressive Symptomology (CDI)

### **Physical Health**

About My Health and Activities (Peds-QL Sub-Scale)

Hospitalizations and Emergency Room Visits (Chart Review)

Medication Adherence (Self-Report)

## **Social Functioning**

How I Get Along With Others (Peds-QL Sub-Scale)

Figure 2

Model depicting the use of the Barron and Kenney Procedure for Hypothesis 3a

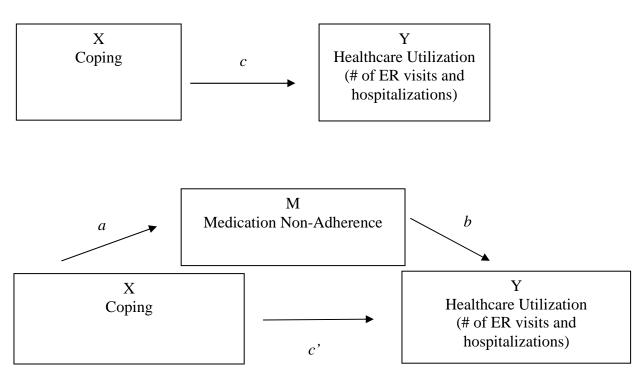


Figure 3

Model depicting the use of the Barron and Kenney Procedure for Hypothesis 3b

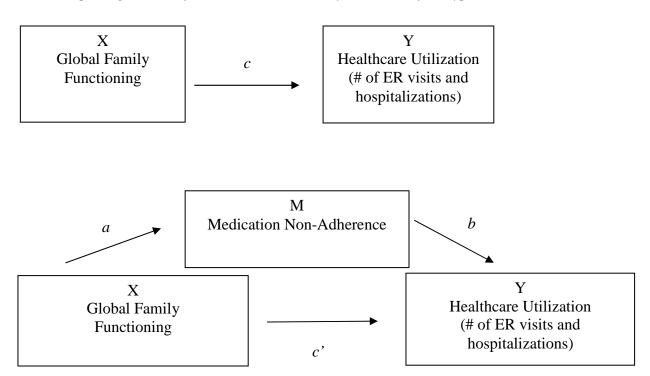
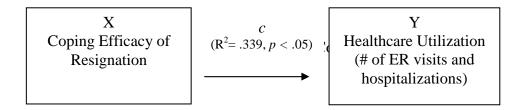
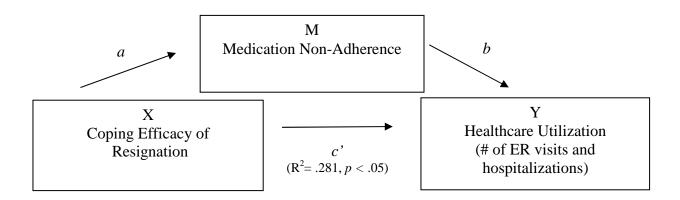


Figure 4

Does medication adherence mediate the relationship between the coping efficacy of resignation and healthcare utilization? Using the Barron and Kenney Procedure-





#### References

- Alderfer, M. A., Fiese, B. H., Gold, J. I., Cutuli, J. J., Holmbeck, G. N., & Goldbeck, L.(2008). Evidence-based assessment in pediatric psychology: Family measures. *Journal of Pediatric Psychology*, *33*(9), 1046–1061.
- Amr, M., Bakr, A., Gilany, A., Hammad, A., El-Refaey, A., & El-Mougy, A. (2009). Multi-method assessment of behavior adjustment in children with chronic kidney disease. *Pediatric Nephrology*, 24, 341–347.
- Ardissino, G., Dacco, V., Testa, S., Bonaudo, R., Claris-Appiani, A., & Taioli, E. (2003). Epidemiology of chronic renal failure in children: data from the ItalKid project. *Pediatrics*, 111, 382-387.
- Band, E., & Weisz, J. (1988). How to feel better when it feels bad: Children's perspective of coping with everyday stress. *Developmental Psychology*, 24, 247-253.
- Baron, R. M., & Kenny, D. A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, *51*, 1173-1182.
- Beidel, D.C. (1987). Psychological factors in organ transplantation. *Clinical Psychology Review*, 7, 677-694.
- Berrin, S. J., Malcarne, V. L., Varni, J. W., Burwinkle, T. M., Sherman, S. A., & Artavia, K. (2007). Pain, fatigue, and school functioning in children with cerebral palsy: A path-analytic model. *Journal of Pediatric Psychology*, 32(3), 330–337.
- Bergman, S., Key, B., Kirk, K., Warnock, D., & Rostant, S. (1996). Kidney disease in the first-degree relatives of African-Americans with hypertensive end-stage renal disease. *American Journal of Kidney Disease*, 27, 341-346.
- Blotcky, A. D., Raczynski, J. M., Gunvitch, R., & Smith, K. (1985). Family influences on hopelessness among children early in the cancer experience. *Journal of Pediatric Psychology*, 10(4), 479-493.
- Brem, A. S., Brem, F. S., McGrath, M., & Spirito, A. (1988). Psychosocial characteristics and coping skills in children maintained on chronic dialysis. *Pediatric Nephrology*, *2*(*4*), 460-465.
- Boman, K., & Bodegard, G. (1995). Psychological long-term coping with experiences of disease and treatment in childhood cancer survivors. *Paediatrica*, 84, 1395–1402.
- Broffenbrenner, U. (1979). The ecology of human development. Cambridge, MA: Harvard University Press.

- Broome, M., Maikler, V., Kelber, S., Bailey, P., & Lea, G. (2001). An intervention to increase coping and reduce health care utilization for school-age children and adolescents with sickle cell disease. *Journal of National Black Nurses'*Association, 12(2), 6-14.
- Brown, G., & Harris, T. (1989). Life events and illness. New York: Guilford.
- Brown, J., O'Keeffe, J., Sanders, S., & Baker, B. (1986). Developmental change in children's cognition to stressful and painful situations. *Journal of Pediatric Psychology*, 11, 343-357.
- Burke, P., Kocoshis, S. A., Chandra, R., Whiteway, M., & Sauer, J. (1990). Determinants of depression in recent onset pediatric inflammatory bowel disease. *Journal of the American Academy of Child and Adolescent Psychiatry*, 29, 608–610.
- Burlew, A. K. (2002). Empirically derived guidelines for assessing the psychosocial needs of children and adolescents with sickle cell. *Social Work in Health Care*, *36*(1), 29-44.
- Burstein, M., & Ginsburg, G.S. (2010). The effect of parental modeling of anxious behaviors and cognitions in school-aged children: An experimental pilot study. Behavioral Research and Therapy, 48, 506-515.
- Butzlaff, R.L., & Hooley, J.M. (1998). Expressed emotion and psychiatric relapse. *Archives of General Psychiatry*, *55*, 547–552.
- Cheng & Chan (2003). Factorial structure of the KidCope in Hong Kong adolescents. *Journal of Genetic Psychology, 164(3),* 261-266.
- Chesney, R. W., Brewer, E., Moxey-Mims, M., Watkins, S., Furth, S. L., & Harmon, S. (2006). Report of an NIH task force on research priorities in chronic kidney disease in children. *Pediatric nephrology*, 21, 14-25.
- Christensen, A., Benotsch, E., Wiebe, J., & Lawton W. (1995). Coping with treatment-related stress: Effects on patient adherence in hemodialysis. *Journal of Consulting and Clinical Psychology*, 63(3), 454-459.
- Clercq, B. D., Fruyt, F. D., Koot, H. M., & Benoit, Y. (2004). Quality of life in children surviving cancer: A personality and multi-informant perspective. *Journal of Pediatric Psychology*, 29(8), 579-590.
- Cohen, S. (2004). Social relationships and health. *American Psychologist*, 59, 676–684.
- Cohen, S., Underwood, L. G., & Gottlieb, B. H. (2000). Social support measurement and intervention: A guide for health and social scientists. New York: Oxford University Press.

- Coleman, J. S. (1993). The rational reconstruction of society. *American Sociological Review*, 58,1–15.
- Compass, B. E., Orosan, P. G., & Grant, K. E. (1993). Adolescent stress and coping: Implications for psychopathology during adolescence. *Journal of Adolescence*, *16*, 331–349.
- Daltroy, L. H., Larson, M. G., Eaton, H. M., Partridge, A. J., Pless, B., & Rogers M. P. (1992). Psychosocial adjustment in juvenile arthritis. *Journal of Pediatric Psychology*, 17, 277-289.
- Davis, M. C., Tucker, C. M., & Fennell, R. S. (1996). Family behavior, adaptation, and treatment adherence of pediatric nephrology patients. *Pediatric Nephrology*, 10(2), 160-166.
- Davidoff, A.J. (2004). Identifying children with special health care needs in the National Health Interview Survey: a new resource for policy analysis. *Health Services Research*, 39(1), 53-71.
- DeNavas-Walt, C., Proctor, B. D., & Lee, C. H. (2005). Income, poverty, and health insurance coverage in the United States, *U.S. Census Bureau; Current Population Reports*, 60-231.
- Devins, G. M., Mendelssohn, D. C., Barre, P. E., & Binik, Y. M. (2003). Predialysis psycho-educational intervention and coping styles influence time to dialysis in chronic kidney disease. *American Journal of Kidney Diseases*, 42(4), 693-703.
- Drotar, D. (1997). Relating parent and family functioning to the psychological adjustment of children with chronic health conditions: What have we learned? What do we need to know? *Journal of Pediatric Psychology*, 22, 149-165.
- Drotar, D. (2000). Promoting adherence to medical treatment in childhood chronic illness: Concepts, methods, and interventions. Mahwah, NJ: Lawrence Erlbaum Associates.
- Duncan, S. C. (1993). The role of cognitive appraisal and friendship provisions in adolescent's affect and motivation toward activity in physical education. *Research Quarterly for Exercise and Sport*, 64, 314-323.
- Eknoyan, G., & Levin, N. W. (2002). K/DOQI Clinical practice guidelines for chronic kidney disease: evaluation, classification, and stratification. *American Journal of Kidney Disease*, 39, 1-226.
- Eley, T. C., & Gregory, A. M. (2004). Behavioral genetics. In T. L. Morris, & J. S. March (Eds.), Anxiety disorders in children and adolescents (2nd ed.). (pp. 71e96) NewYork City, NY: The Guilford Press.

- Ettinger, R. B. (1990). Renal Transplantation. Renal Disease in Children, 4, 371-383.
- Falkenstein, K., Flynn, L., Kirkpatrick, B., Casa-Melley, A., & Dunn, S. (2004). Noncompliance in children post-liver transplant. Who are the culprits? *Pediatric Transplantation*, 8, 233–236.
- Falger, J., Landolt, M. A., Latal, B., Rüth, E. M., Neuhaus, T. J., & Laube, G. F. (2008). Outcome after renal transplantation. Part II: Quality of life and psychosocial adjustment. *Pediatric Nephrology*, 23, 1347–1354.
- Fadrowski, J., Cole, S. R., Hwang, W., Fiorenza, J., Weiss, R. A., & Gerson, A. (2006). Changes in physical and psychosocial functioning among adolescents with chronic kidney disease. *Pediatric Nephrology*, *21*, 394–399.
- Ferris, M., Gipson, D., Kimmel, P., & Eggers, P. (2006). Trends in treatment and outcomes of survival of adolescents initiating end-stage renal disease care in the United States of America. *Pediatric Nephrology*, 21, 1020-1026.
- Ferris, M., Patel, U. D., Massengill, S., Gipson, D., Conley, W., & Layton, B. (2008). Pediatric chronic kidney disease in North Carolina. *North Carolina Medical Journal*, 69, 208-214.
- Foulkes, L., Boggs, S. R., Fennell, R. S., & Skibinski, K. (1993). Social support, family variables, and compliance in renal transplant children. *Pediatric Nephrology*, 7, 185-188. Fukunishi, I. & Honda, M. (1995) School adjustment of children with end-stage renal disease. *Pediatric Nephrology*, 9, 553–557.
- Fukunishi, I. & Kudo, H. (1995) Psychiatric problems of pediatric end-stage renal failure. *General Hospital Psychiatry*, 17, 32–36.
- Garralda, M. E., Jameson, R. A., Reynolds, J. M., & Postlethwaite, R. J. (1988). Psychiatric adjustment in children with chronic renal failure. *Journal of child psychology and psychiatry*, 29(1), 79-90.
- Garma, S. I., Kelly, E. H., Daharsh, E. Z., & Vogel, L. C. (2010). Health related quality of life after pediatric spinal cord injury. *Journal of Pediatric Psychology*, 1, 1-11.
- Gil, K., Williams, D., Thompson, R., & Kinney, T. (1991). Sickle cell disease in children and adolescents: The relation of child and parent pain coping strategies to adjustment. *Journal of Pediatric Psychology*, *16*(5), 643-663.
- Gil, K., Wilson, J., & Ednes, J. (1997). The stability of pain coping strategies in young children, adolescents, and adults with sickle cell disease over an 18-month period. *The Clinical Journal of Pain*, 13(2), 110-115.

- Graue M, Wentzel-Larsen T, & Bru E. (2004). The coping styles of adolescents with type 1 diabetes are associated with degree of metabolic control. *Diabetes Care*, 27, 1313–1317.
- Group. Kessler, R. (1997). The effects of stressful life events on depression. In J. Spence, J. Darley, & D. Foss (Eds.), Annual review of psychology (pp. 191-214). Palo Alto, CA: Annual Reviews.
- Harbeck-Weber, C., Fisher, J. L., Dittner, C. A. Promoting Coping and Enhancing Adaptation to Illness. Handbook of pediatric psychology (3rd ed.). Roberts, Michael C. (Ed); pp. 99-118. New York, NY, US: Guilford Press, 2003. xxiv, 772.
- Holahan, C. J., & Moos, R. H. (1983). The quality of social support: Measures of family and work relationships. *British journal of clinical psychology*, 22(3), 157-168.
- Holmbeck, G., Thill, A., Bachanas, P., Garber, J., Bearman, K., & Abad, M. (2008). Evidence-based assessment in pediatric psychology: Measures of psychosocial adjustment and psychopathology. *Journal of Pediatric Psychology*, *33*(9), 958–980.
- Hommel, K. A., Davis, C. M. & Baldassano, R. N. (2008). Medication adherence and quality of life in pediatric inflammatory bowel disease. *Journal of Pediatric Psychology*, *33*(8), 867–874.
- Hurtig, A. L., Koepke, D., & Park K. B. (1989). Relation between severity of chronic illness and adjustment in children and adolescents with sickle cell disease. *Journal of Pediatric Psychology*, 14, 117-132.
- Ingerski, L. M., Janicke, D. M., & Silverstein, J. H. (2007). Brief report: Quality of life in overweight youth The role of multiple informants and perceived social support. Journal of Pediatric Psychology, 32(7), 869-874.
- Isley, S., O'Neil, R., & Parke, R. D. (1996). The relations of parental affect and control behaviors to children's classroom acceptance: A concurrent and predictive analysis. *Early Education and Development*, 7, 7-23.
- Kazak, A. (2001). Comprehensive care for children with cancer and their families. A socio-ecological framework guiding research, practice and policy. *Children's Services: Social Policy; Research and Practice*, *4*, 217-233.
- Kazak, A. E., Rourke, M. T., & Crump, T. A. (2003). Families and other systems in pediatric psychology. In M. C. Roberts (Ed.), Handbook of pediatric psychology (pp. 159–175). New York, NY: The Guilford Press.

- Kellerman, J., & Katz, E. (1977). Adolescents with cancer: Theoretical, clinical and research issues. *Journal of Pediatric Psychology*, *2*, 127-131.
- Kerns, K. Contreras, J. M., & Neal-Barnett, A. M. (2000). Linking two social worlds. Family and peers (pp. 195-225). Westport, CT, US: Praeger Publishers/Greenwood Publishing
- Kovascs, M., Brent, D., Steinberg, T. F., Paulauskas, S., & Reid, J. (1986). Children's self-report of psychological adjustment and coping strategies during the first year of insulin dependent diabetes mellitus. *Diabetes Care*, *9*, 472-479.
- LaGreca, A. M. (1988). Adherence to prescribed medical regimens. In: Routh DK (ed), Handbook of pediatric psychology. TheGuilford Press, New York, pp299-320.
- La Greca, A. M., & Bearman, K. J. (2003). Adherence to pediatric treatment regimens. In M. C. Roberts (Ed.), Handbook of pediatric psychology (pp. 119–140). New York: The Guilford Press.
- Lazarus, R., & Folkman, S. (1984). Stress, appraisal, and coping. New York: Springer.
- Lewis, H. A., & Kliewer, W. (1996). Hope, coping, and adjustment among children with sickle cell disease: Tests of mediator and moderator models. *Journal of Pediatric Psychology*, 21(1), 25-41.
- Lindgren, S. D., Harper, D. C., & Blackman J. A. (1986). Environmental influences and perinatal risk factors in high-risk children. *Journal of Pediatric Psychology*, 11(4), 531-547.
- Mackie, E., Hill, J., Kiomdryn, H., & McNally, R. (2000). Adult psychosocial outcomes in long-term survivors of acute lymphoblastic leukemia and Wilms' tumor: A controlled study. *Lancet*, *355*, 1310–1314.
- MacLean, W. E., Perrin, J. M., Gortmaker, S., & Pierre, C. B. (1992). Psychological adjustment of children with asthma: Effects of illness severity and recent stressful life events. *Journal of Pediatric Psychology*, *17*, 159-171.
- Malik, J. A., & Koot, H. M. (2009). Explaining the adjustment of adolescents with type 1 diabetes. *Diabetes Care*, *5*, 774-780.
- Manificat, S., Dazord, A., Cochat, P., Morin, D., Plainguet, F., & Debray, D. (2003). Quality of life of children and adolescents after kidney or liver transplantation: child, parents and caregiver's point of view. *Pediatric Transplant*, 7, 228–235.
- McClellan, C. B., Schatz, J., Sanchez, C., & Roberts C. W. (2008). Validity of the Pediatric Quality of Life Inventory for Youth with Sickle Cell Disease. *Journal of Pediatric Psychology*, 33(10), 1153–1162.

- McLellan, J. A., & Youniss, J. (2003). Two systems of youth service: Determinants of voluntary and required youth community service. *Journal of Youth and Adolescence*, 32, 47–58.
- Miller, K. S., Vannatta, K., Compas, B. E., Vasey, M., McGoron, K., Salley, G., & Gerhardt, D. (2009). The role of coping and temperament in the adjustment of children with cancer. *Journal of Pediatric Psychology*, *34*(10), 1135–1143.
- Moos, R. H., & Moos, B. S. (1994). The family environment Scale manual (3rd ed.), Palo Alto, CA: Consulting Psychologists Press; Mind Garden.
- Moos, R. H., & Moos, B. S. (2009). The family environment Scale manual (4th ed.), Palo Alto, CA: Consulting Psychologists Press; Mind Garden.
- Mulhern, R. K., Wasserman, A. L., Friedman, A. G., & Fairclough, D. (1989). Social competence and behavioral adjustment of children who are long-term survivors of cancer. *Pediatrics*, 83, 18–25.
- Palermo, T. M., Long, A. C., Lewandowski, A. S., Drotar, D. Quittner, A. L., & Walker, L. S. (2008). Evidence-based Assessment of Health-related Quality of Life and Functional Impairment in Pediatric Psychology. *Journal of Pediatric Psychology*, 33(9), 983–996.
- Paluszny, M. J., DeBeukelaer, M. M., & Rowane, William A. (1991). Families coping with the multiple crises of a chronic illness. *Loss, Grief & Care*, 5, 15-26.
- Parke, R. D., Cassidy, J., Burks, V. M., Carson, J. L., & Boyum, L. (1992). Familial contributions to peer competence among young children: The role of interactive and affective processes. In R. D. Parke & G. W. Ladd (Eds.), *Family-peer relationships: Modes of linkage* (pp. 107-134). Hillsdale, NJ: Erlbaum.
- Patterson, J. M., & McCubbin, H. J. (1987). Adolescent coping style and behaviors: Conceptualization and measurement. *Journal of Adolescence*, *10*, 163–186.
- Qvist, E., Narhi, V., Apajasalo, M., Ronnholm, K., Jalanko, H., Almqvist, F., & Holmberg, C. (2004). Psychosocial adjustment and quality of life after renal transplantation in early childhood. *Pediatric Transplant*, 8, 120–125.
- Rapoff, M. A. (1999). Adherence to pediatric medical regimens. New York: Kluwer Press.
- Rodin, G., & Voshart, K. (1987). Depressive symptoms and functional impairment in the medically ill. *General Hospital Psychiatry*, *9*, 251-258.
- Rudolph, K. D. (2010), Implicit Theories of Peer Relationships. *Social Development*, 19: 113–129.

- Schor, E. L., Lerner, D. J. & Malspeis, S. (1995). Physician's assessment of functional status and well-being. *Archives of Internal Medicine*, *155*, 309-314.
- Seiffge-Krenke I. Diabetic Adolescents and Their Families: Stress, Coping, and Adaptation. Cambridge, UK: Cambridge University Press; 2001.
- Smith, R. (2009). Modification of lifestyle and diet. *Clinical and Experimental Nephrology*, *13*, 228-230.
- Spirito, A., (1996). Commentary: Pitfalls in the use of brief screening measures of coping. Journal of Pediatric Psychology, 21(4), 573-575.
- Spirito, A., Stark, L. J., & Tyc, V. L. (1994). Stressors and coping strategies described during hospitalization by chronically ill children. *Journal of Clinical Child Psychology*, 23,314–322.
- Spirito, A., Stark, L. J. & Williams, C. (1988) Development of a brief coping checklist for use with pediatric populations. *Journal of Pediatric Psychology*, *13*, 555–574.
- Storch, E., Keeley, M., Merlo, L., Jacob, M., Correia, C., & Weinstein, D. (2008). Psychosocial functioning in youth with glycogen storage disease type I. *Journal of Pediatric Psychology*, *33*(7), 728-738.
- Thomas, J. W. (1980). Basic beliefs and assumptions of the bi-polar system. *Perkins Journal*, 1, 1-26.
- Thompson, R. J., Armstrong, F. D., Kronenberger, W. G., Scott, D., McCabe, M. A., & Smith, B. (1999). Family functioning, neurocognitive functioning, and behavior problems in children with sickle cell disease. *Journal of Pediatric Psychiatry*, 24, 491-498.
- Thompson, R. J., & Gustafson, K. E. (1996). Adaptation to chronic childhood illness. Washington, DC: American Psychological Association.
- Thompson, K. L., Varni, J. W., & Hanson, V. (1987). Comprehensive assessment of pain in juvenile rheumatoid arthritis: An empirical model. *Journal of Pediatric Psychology*, 12, 1987.
- Tobin, D. L. (1991). User's manual for the Coping Strategies Inventory. Ohio University, Athens. Unpublished manuscript.
- U.S. Renal Data System, USRDA 2001 Annual data report (2001). Atlas of end-stage renal disease in the United States, national institutes of diabetes and kidney disease. Bethesda, MD, USA.

- Valenzuela, J. M., Patino, A. M., McCullough, J., Ring, C., Sanchez, J., & Eidson, M. (2006). Insulin pump therapy and health-related quality of life in children and adolescents with type 1 diabetes. *Journal of Pediatric Psychology*, 31(6), 650-666.
- Varni, J. W., Katz, E. R., Colegrove, R., & Dolgin, M. (1996). Family functioning predictors of adjustment in children with newly diagnosed cancer: A prospective analysis. *Journal of Child Psychology and Psychiatry*, *37*, 321–328.
- Varni, J. W., Limbers, C., & Burwinkle, T. M. (2007). Literature review: Health-related quality of life measurement in pediatric oncology: Hearing the voices of children. *Journal of Pediatric Psychology*, 32(9), 1151-1163.
- Varni, J.W., Seid, M., & Rode, C. A. (1999). The PedsQL™: Measurement Model for the Pediatric Quality of Life Inventory. *Medical Care*, *37*(2), 126-139.
- Varni, J. W. Seid, M., & Kurtin, P. S. (2001). The PedsQL<sup>TM</sup> 4.0: Reliability and validity of the Pediatric Quality of Life Inventory<sup>TM</sup> Version 4.0 Generic Core Scales in healthy and patient populations. *Medical Care*, 39(8), 800-812.
- Vigna, J. F., Hernandez, B. C., Kelley, L. M., & Gresham, M. F. (2010). Coping behavior in hurricane-affected african american youth: Psychometric properties of the Kidcope. *Journal of Black Psychology*, *36*, 98-109.
- Vupputuri, S., & Jennette, C. E. (2007). The Burden of Kidney Disease in North Carolina, 2007. Chapel Hill, NC: University of North Carolina Kidney Center; 2007.
- Wallander, J. L., & Varni, J. W. (1992). Adjustment in children with chronic physical disorders: Programmatic research on a disability-stress-coping model. In A. M. La Greca, L. Siegel, J. L. Wallander, & C. E. Walker (Eds.), Stress and coping in child health (pp. 279-298). New York: Guilford Press.
- Warady, B. A., & Chadha, V. (2007). Chronic kidney disease in children: the global perspective. *Pediatric Nephrology*, 22, 1999–2009.
- Wong, H., Mylrea, K., Feber, J., Drukker, A., & Filler, G. (2006). Prevalence of complications in children with chronic kidney disease according to KDOQI. *Kidney International*, 70, 585-590.
- World Health Organization. (1947). The constitution of the World Health Organization