THE ADOLESCENT HEALTH BELIEF MODEL: CONCEPTALIZING COGNITIVE FACTORS THAT INFLUENCE MEDICATION NON-ADHERENCE AMONG ADOLESCENTS

Nicole Fenton

A dissertation submitted to the faculty at the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Doctor of Philosophy in The Department of Psychology (Clinical Psychology).

Chapel Hill
2013

Approved by:

Don Baucom

Maria Ferris

Karen M. Gil

Deborah Jones

Sara Algoe

ABSTRACT

Nicole Fenton: The Adolescent Health Belief Model: Conceptualizing Cognitive Factors That
Influence Medication Non-Adherence Among Adolescent
(Under the direction of Don Baucom)

The medication non-adherence literature rarely employs theoretical models, and no
models to date have been modified or created to understand adolescent medication non-
adherence. The first aim of this study was to evaluate whether the six factors in the child health
belief model (CHBM; susceptibility, severity, family support, benefits, barriers, self-efficacy)
could be employed to understand adolescent medication non-adherence. The second aim was to
propose a developmentally appropriate extension of the CHBM and provide an initial empirical
evaluation of this model. This new more complete model is called the adolescent health belief
model, and includes all factors of the CHBM as well as peer support and personal control.
Participants were recruited from the UNC Chapel Hill Pediatric outpatient clinics and included
110 adolescents age 13-21 with a diagnosis of inflammatory bowel disease or chronic kidney
disease. Results indicated that the CHBM as a whole was a significant predictor of medication
non-adherence. Additionally, the factors of perceived benefits, barriers, and self-efficacy were
each significant individual predictors of non-adherence above and beyond the other predictors in
the model. The AHBM as a whole remained a significant predictor of non-adherence. The added
factors of peer support and personal control, however, were not significant. Overall, results
indicate that there is empirical evidence for the use of the CHBM. Further, it may be that
concrete, proximal, cognitive factors such as benefits, barriers, and self-efficacy are of critical
importance when trying to understand an adolescent's medication non-adherence.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

CHBM   Child health belief model

AHBM   Adolescent health belief model

IBD   Inflammatory Bowel Disease

CKD   Chronic Kidney Disease

CHAPTER 1: INTRODUCTION

Chronic illnesses are pervasive, affecting approximately 10-20% of children in the United States (Davidoff, 2004; Judson, 2004). Two frequently understudied chronic illnesses among youth are Inflammatory Bowel Disease (IBD) and Chronic Kidney Disease (CKD). Whereas there are no cures for these chronic illnesses, scientific advances have resulted in an increased survival rate for children with even the most severe stages of these conditions. One key component to successful illness management and increased survival is adherence to medical treatment (Finea et al., 2009). Adherence is defined as taking medication in a way that corresponds with the recommendations from a healthcare provider (Sabate, 2003). When patients do not follow their medication regimen as prescribed or are non-adherent to their medications, many serious complications can occur, such as increased disease activity, frequent hospitalizations, and even death (Dew et al., 2001; Falkenstein, Flynn, Kirkpatrick, Casa-Melley, & Dunn, 2004). Non-adherence and the subsequent complications occur across all ages; however, non-adherence occurs most frequently among adolescents (Dobbels et al., 2005; Rianthavorn & Ettenger, 2005). Consequently, many national consensus reports and conference proceedings have highlighted the need to better understand factors leading to and preventing non-adherence in adolescence (Finea et al., 2009).

Some authors have proposed that the best way to understand non-adherence is to have a conceptual model of the phenomenon (La Greca, 1990). Despite this call for a conceptual model, adolescents have been widely overlooked in the non-adherence literature, and no models to date have been modified or created to understand adolescent medication non-adherence. Thus, the

current investigation will seek to fill this gap in the literature by suggesting a developmentally appropriate model to conceptualize medication non-adherence among adolescents, along with an initial empirical evaluation of this model.

Outline of this Paper and Aims of the Current Study

This paper begins by providing a review of non-adherence and the negative consequences that can result from it. Next, as adolescents are most at risk for non-adherence and physiologically have the poorest outcomes due to non-adherence, a rational for focusing on adolescents is provided. Then, it will be suggested that since adolescents are primarily in charge of their medications, cognitive factors or ways in which adolescents think about medication adherence are key components to understanding adolescent non-adherence. One health model that focuses on cognitions and is frequently used in the pediatric literature is the Child Health Belief Model (CHBM). The CHBM has six components: perceived severity, susceptibility, benefits, barriers, self-efficacy, and family support. Whereas no investigators to date have examined the entire CHBM in adolescents, some studies have addressed specific components of the CHBM. The current investigation was the first to review the empirical support for using the CHBM in adolescents. This review demonstrates that while there are mixed findings regarding whether there is a positive or negative relationship between some of the factors and non-adherence, there is clear evidence for the use of the CHBM in adolescents. Examining each factor independently does not allow for the examination of the relative contribution of each factor in predicting non-adherence. Thus the current study was the first to evaluate the full model and examine the relative contribution of each factor.

Additionally, as the CHBM was developed for pre-adolescents, it does not take into account some of the developmental factors unique to adolescents. Thus, I propose that by adding

two factors to the CHBM (peer support and perceived control), the adolescent health belief model (AHBM) will explain significantly more variance in adolescent non-adherence than the CHBM alone. The AHBM will be evaluated in two different illness populations, chronic kidney disease (CKD) and inflammatory bowel disease (IBD). This section will finish by proposing a conceptual framework to understand how different components of the AHBM may be differentially important depending on the characteristics of the illness.

Medication Non-Adherence

The concept of "compliance" was first introduced by *The World Health Organization* and is defined as patients acting in accordance with their doctors' recommendations (Haynes, Taylor, & Sackett, 1979). In recent years, the term 'compliance' was criticized as too simplistic because it implies a clear hierarchy between the patient and the physician and ignores the patient's thoughts, feelings, and decisions in the process. The term has since been replaced with "adherence" (Feinstein, 1990), which is defined as, "The extent to which a person's behavior corresponds with agreed recommendations from a healthcare provider" (Sabate, 2003, pp. 3–4). A patient's treatment adherence can refer to a range of behaviors such as exercise, dietary modifications, appointment attendance, fluid intake, and taking medications. While all these different components can play a role in a patient's treatment, approximately 65% percent of doctors state that medication adherence is the most important factor in the care of their patient's illness (Ferris et al., 2011). Thus this investigation will focus on medication non-adherence. The exact rate of medication non-adherence among pediatric populations is not known; however, there is a consensus across studies that rates of non-adherence are above 50% (Dunbar-Jacob & Mortimer-Stephens, 2001; La Greca & Bearman, 2003; Rapoff, 1999). One limitation of all non-adherence research is that participants are often involved in medical care, recruited from a

physician's office, and include only those willing to participate. This may result in even the highest estimates of non-adherence being too low (LaGrecca, 1988). Despite these uncertainties, it is clear that across chronic illnesses, rates of pediatric non-adherence are consistently high (Bucks et al., 2009; Hommel & Baldassano, 2010).

When pediatric patients do not follow their medication regimen as prescribed or are non-adherent to their medications, many serious complications may occur, such as increased medication dosage, increased disease activity, drug resistance, drug reactions, higher health care costs, reduced health-related quality of life, frequent hospitalizations, and even death (Dew et al., 2001; Falkenstein, Flynn, Kirkpatrick, Casa-Melley, & Dunn, 2004; Kelly & Kalichman, 2002; Rohan et al., 2010; Sudan, Shaw, & Langnas, 1997; Van Dyke et al., 2002). For example 78 adolescents with IBD were asked to self-report their medication adherence. Those with lower medication adherence had greater disease activity and lower health-related quality of life. In another study, it was found that among adolescents with CKD, non-adherence accounted for 71% of cases of graft loss and disease progression (Jarzembowski et al., 2004). Overall, non-adherence compromises the health outcomes of pediatric treatments by an average of 33%, and it may be as much as 71% (DiMatteo Giordani, Lepper, & Croghan, 2002). In addition to the negative implications for the patient, non-adherence also affects the health care system and the overall use of societal resources (Bronfenbrenner, 1979; Pai & Drotar, 2010). The increased patient demands caused by non-adherence reduce the amount of time healthcare providers have for other appointments or patients (Bender & Rand, 2004). Also across all ages, reported annual hospitalization costs due to medication non-adherence total from US$735 million in Ontario, Canada (Iskedjian, Addis, & Einarson, 1998) up to US$13.35 billion in the U.S. (Sullivan,

Kreling, & Hazlet, 1990). Overall, these findings suggest a clear cost of non-adherence in terms of monetary value and negative health implications.

Whereas the negative outcomes of non-adherence have been well documented, the best way to operationalize and measure non-adherence is less clear. Across studies, there is not a common definition of non-adherence. Some authors conceptualize non-adherence as a continuous variable while other authors determine a critical 'cut-point' and operationalize adherence and non-adherence as a dichotomous variable. For example in the diabetes and asthma literature, if a patient misses approximately 15 or 20% of their medications, they are considered non-adherent (Dracup & Meleis, 1982). However in the HIV and transplant literature, a patient only needs to miss approximately 5 or 10% of their medications to be considered non-adherent (Osterberg & Blaschke, 2005). A number of problems may arise from using a dichotomous definition. For example, someone who misses 70% of their medications and someone who misses 30% of their medications would both be considered non-adherent; however, their pattern of medication taking is clearly quite different. Given this limitation, non-adherence may be most accurately understood as a continuous variable. Conceptualizing non-adherence along a continuum may allow more information about the person's medication regimen to be conveyed.

Even if an agreed upon definition of non-adherence is derived, there are a number of different ways that information about non-adherence can be collected, thus impacting estimates of non-adherence. Assessments of non-adherence can include a person's self-report, doctor's report, parent's repot, drug levels (the amount of medication in the person's blood), digitized pill caps (a medication top that records each time it is opened), or pharmacy refill rate (contacting the pharmacy and obtaining information regarding the refill history). These different approaches attempt to capture the construct of non-adherence, but these varying methods typically have quite

different results (Nakonezny et al., 2010). Comparing objective measures (e.g., pill caps, blood levels, pharmacy refill rates) and subjective measures (e.g., self-report, doctor report, parent report) of adherence, findings indicate that studies using subjective measures are more numerous and yield lower average non-adherence scores than studies using objective measures (Dimatteo, 2004). This phenomenon has been observed in a number of studies, yet the exact mechanism accounting for these findings has not been examined. It has been proposed that high levels of social desirability may result in participants minimizing their self-reported non-adherence (Malee et al., 2009). A number of studies in other areas have shown that social desirability results in participants modifying their answer to reflect what they perceive as the more socially desirable response (Arnold & Feldman, 1981; Mortel, 2008). If this were the case, it would suggest that self-reported non-adherence is not as accurate as some of the alternate methods of gathering non-adherence data. Alternatively self-reported data might be a valid assessment strategy and may be higher because people are, in fact, being less non-adherent than what other methods indicate. Overall, the mechanism accounting for lower self-reported non-adherence needs to be elucidated, and there is not a clear understanding of the best way to measure non-adherence. As a result of this uncertainty in measurement, many researchers use a multi-method approach and obtain a number of different measures of non-adherence.

Despite these methodological shortcomings, the negative implications of non-adherence for a patient's physical and mental health have been well established. One group at particular risk for negative health outcomes are adolescents. When compared with younger children or older adults, adolescents are at significantly greater risk for non-adherence (Dobbels et al., 2005; Rianthavorn & Ettenger, 2005) and at higher risk for disease progression due to this non-adherence (Gordeuk et al., 2008; Seiffge-Krenke, 1998; Sweet et al., 2006).

Non-Adherence in Adolescence

Adolescence typically is a time of uncertainty about the future with increased independence, decision making, peer criticism, and risk taking (Arnett, 1992; Duncan, 1993; Holmbeck & O'Donnell, 1991). For adolescents with a chronic illness, medication non-adherence may be another domain of risk taking. Additionally, there are a number of pathophysiological changes that occur during adolescence, that subsequently increase the likelihood of negative health outcomes. For example, there is a steep decline in renal function as adolescents go through puberty and 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 sex hormones or an imbalance between the kidney's size and a rapidly growing body size (Warady & Chadha, 2007). This increased risk for disease progression also occurs in adolescents with diabetes, transplant recipients, and sickle cell disease (Gordeuk et al., 2008; Seiffge-Krenke, 1998; Sweet et al., 2006). At the time when physiologically it is most important to be adherent to their medications, adolescents might be the most likely to take risks and be non-adherent.

In addition to the behavioral and physiological changes that occur during adolescence, adolescents are beginning to take more responsibility for their health and overall healthcare. Specifically, they are taking a more active role in their illness management, healthcare decision making, and self-advocacy (Institute of Medicine, 2007). In fact, the majority of adolescents report that they are the primary person in charge of their medications (e.g., remembering to take them, calling in refills; Shemesh et al., 2004). Because the adolescent is the main person deciding whether to take her/his medication, their cognitions about the positive and negative implications of the medication may play a key role in influencing non-adherence. Studies have examined whether objective facts or subjective thoughts and beliefs play more of a role in an

adolescent's non-adherence, and the findings suggest that the subjective thoughts may be more significant. For example, in a sample of 45 adolescents with IBD, a patient's objective disease severity (as measured by examining their medical record) was not predictive of their medication non-adherence, whereas the adolescent's perceived disease severity was a significant predictor (Reed-Knight et al., 2010). Other studies have found that some objective barriers are not predictive of non-adherence, whereas perceived barriers to medication taking (e.g., not wanting to be seen as different) have been found to be significant predictors of non-adherence (Rudy, Murphy, Harris, Muenz, & Ellen, 2010; Zelikovsky, Schast, Palmer, & Meyers, 2008). These studies suggest that the adolescent's thoughts and beliefs may predict non-adherence more accurately than objective factors.

To better understand the role of thoughts and beliefs in medication non-adherence, it is helpful to have an overall framework and conceptualization of the behavior (La Greca, 1990). A model has been defined as, "A set of general or abstract principles based on experimentally established relationships among events to explain a phenomenon" (Johnston & Pennypacker, 1993, pp. 371). While the idea of incorporating models for non-adherence has been proposed in the literature, few authors in the pediatric field have applied models when designing or conceptualizing studies examining non-adherence. However, the adult literature has several theories that have been proposed to conceptualize how psychosocial factors, cognitive factors, and environment factors influence non-adherence.

The Child Health Belief Model

The more highly regarded models used to understand adult health behaviors include: the Social-Cognitive Theory (Bandura, 1986), Theory of Reasoned Action and Planned Behavior (Montaño, Kasprzyk, & Taplin, 1997), Transtheoretical Model (Prochaska, 1979), the Applied

Behavior Analytic Model (Rapoff, 1996; Zifferblatt, 1975), and the Health Belief Model (Janz &

Becker, 1984; Rosenstock, 1974). Each of these models has important strengths, but over the

past five decades, the Health Belief Model (HBM) has emerged as one of the most empirically

supported and frequently used models in the health behavior literature (Clark & Houle, 2009;

Strecher & Rosenstock, 1997).

It is important to review the history of the HBM to highlight how the changes and

modifications made over time have led to the current version. The original HBM had five main

components (perceived susceptibility, perceived severity, perceived benefits, perceived barriers,

and cues to action), and it was later modified to include self-efficacy (Strecher & Rosenstock,

1997). The model was originally developed to understand why adults failed to take advantage of

preventive health services, such as immunizations and screenings for hypertension or breast

cancer (Fink, Shapiro, & Lewison, 1968; Haefner & Kirscht, 1970; Johnson, 1962). The HBM

was later extended to conceptualize non-adherence within adult populations (Barclay et al.,

2007). Once the HBM was extended to understand why adults may not follow their prescribed

medication regimen, it was also used to understand children's medication non-adherence

(Gochman, 1981). The HBM has been adapted for use specifically in pre-adolescent populations,

and it is called the Child Health Belief Model (CHBM; Bush & Iannotti, 1990). This model

includes the same dimensions as the HBM (except cues to action), and it also incorporates the

child's perceived familial support. The factors in the CHBM are not drastically different from the

HBM; however, the CHBM provides a developmentally appropriate way to conceptualize the

factors influencing children's health behaviors. Thus, the creation of the CHBM was an

innovative and significant contribution.

The HBM and the CHBM are two ways to understand how adults and children with a chronic illness think and feel about their medications and how these thoughts and feelings influence their decision to be non-adherent. While adolescence is the developmental period when non-adherence is most likely to occur (Dobbels, Van Damme-Lombaert, Vanhaecke, & Geest, 2005; Rianthavorn & Ettenger, 2005), no models to date have been created or modified for adolescents. Without a developmentally appropriate model to conceptualize adolescent non-adherence, the majority of studies conducted to date have not used any model. Given that many adolescents report that they are primarily in charge of their medications and that cognitive factors are especially important in adolescents (Reyna & Farley, 2006), it may be that the CHBM should be expanded for use in adolescents. A few studies have used components of the CHBM when examining adolescent non-adherence; however, no studies to date have examined all factors of the CHBM at once. Nor has anyone assessed whether there is strong empirical support for the use of the CHBM in adolescents when all conducted studies are examined. The studies conducted to date that have assessed one or two factors of the CHBM give important information regarding the current empirical support for the CHBM in adolescents.

The next six sections will review investigations that examine CHBM factors and non-adherence in adolescents. The findings demonstrate that while there are mixed results regarding whether there is a positive or negative relationship between some of the factors and non-adherence, there is clear support for the use of the CHBM in adolescents. Next, two additional factors (peer support and perceived control) will be proposed as developmentally appropriate additions to the CHBM. This new more complete model will be referred to as the Adolescent Health Belief Model.

Perceived susceptibility is one's subjective perception of personal susceptibility to a negative health outcome if non-adherent (Bush & Iannotti, 1990; Janz & Becker, 1984; Rosenstock, 1974). Multiple studies have shown that most people, under most conditions, view their own chances of misfortune as lower than those of other people (Weinstein, 1998). This phenomenon occurs across all ages; however, in adolescence this low perceived susceptibility is most likely to translate into higher rates of risk taking (Kisker, 1985; Tauer, 1983).

Three studies to date have examined the relationship between perceived susceptibility and non-adherence. The results have consistently found a significant relationship; however, there is a different pattern of findings across the studies. The results from two of the studies indicate that when adolescents perceived more susceptibility, they were less likely to be non-adherent (Brownlee-Duffeck et al., 1987; Foster et al., 2011). However in the third study, higher perceived susceptibility was positively related to both objective and subjective non-adherence (Bond, Aiken, & Somerville, 1992). These mixed findings suggest that while a relationship exists between perceived susceptibility and non-adherence, at the present time, the specific direction of the relationship is uncertain.

To better understand the influence that perceived susceptibility has on non-adherence, it is important to examine why these mixed findings may occur. Therefore, two alternate explanations will be examined: measurement issues and moderators. A measurement issue may account for these discrepant findings. The three previous studies used different scales, two of which were developed for the individual study. Thus, it may be that the discrepant findings are due to the fact that while all three of the scales were attempting to capture the construct of perceived susceptibility, they were not, in fact, doing so or did so in substantially different ways.

11

A second explanation for these discrepant findings may be that there is a moderator occurring (i.e., coping style). This suggests that although they might have equally high levels of perceived susceptibility, some adolescents engage in one type of coping while other adolescents engage in another type of coping. These different types of coping strategies then result in different levels of non-adherence. For example, it may be that when some adolescents experience high perceived susceptibility, they engage in positive problem solving and are more likely to take their medications (Tercyak, Goldman, Smith, & Audrain, 2002). Other adolescents however, may experience high perceived susceptibility and use the coping strategy of denial, which in turn would make them less likely to take their medications. Studies have shown that when adolescents react with denial, they have poorer disease management and more medication non-adherence (Jaser & White, 2011). Investigations also have demonstrated that when adolescents engage in positive problem solving, they have better disease management (Hill-Briggs, 2003) and less medication non-adherence (Thomas, Peterson, & Goldstein, 1997). The role of coping strategies in the relationship between perceived susceptibility and medication non-adherence has not been examined to date, thus providing an important focus for future investigations.

The second cognitive variable included in the CHBM is perceived disease severity, which refers to one's feelings concerning the seriousness of medical or clinical consequences if a person is non-adherent (Bush & Iannotti, 1990; Janz & Becker, 1984; Rosenstock, 1974). Perceived susceptibility examines how likely it is that a negative health outcome will happen to you; perceived disease severity addresses how adverse the negative outcome will be, given that a negative health outcome may occur (if you do not treat your illness), The domain of perceived susceptibility asks an adolescent to examine the odds of a negative outcome occurring, whereas perceived disease severity asks the adolescent to assess the magnitude of a negative outcome.

Few investigators have examined perceived disease severity in adolescent populations. The existing studies consistently suggest that perceived disease severity is a significant predictor of medication non-adherence; however, the pattern of findings differs among investigations. One study reported that self-reported perceived disease severity was significantly negatively associated with non-adherence (Brownlee-Duffeck et al., 1987). However, two other investigations found that higher perceived disease severity was predictive of higher medication non-adherence (Bond et al., 1992; Reed-Knight et al., 2010). These discrepant findings may be occurring because of measurement issues or a moderator as described above (e.g., coping style). A potential next step may be for researchers to ensure the use of previously used scales and examine the role that coping styles may be playing in this relationship.

The third variable in the CHBM is perceived benefits, which refers to the adolescent's perception that the recommended health action (i.e., the prescribed medication) is efficacious (Bush & Iannotti, 1990; Janz & Becker, 1984; Rosenstock, 1974). For example, a question focused on examining perceived benefits may ask, "How much do you think your medications can help your illness?" A study on risk taking found that among adolescents, perceived benefits are better determinants of behavior change for risk taking behaviors than are perceived risks (Parsons, Siegel, & Cousins, 1997). Despite this finding, only two studies to date have examined perceived benefits in adolescents, which make it the least researched component of the CHBM. Results indicated that when adolescents had higher perceived benefits, they were significantly less non-adherent (Bucks et al., 2009; Zugelj et al., 2010). These two studies suggest that perceived benefits play a role in medication non-adherence; however, given that few studies have examined perceived benefits, these results should be interpreted with caution.

The fourth and final component of the original CHBM is perceived barriers. This refers to the perceived costs or negative consequences of taking medications (e.g., expense, side effects, perceptions of being different, taste of the medication; Bush & Iannotti, 1990; Janz & Becker, 1984; Rosenstock, 1974). Perceived barriers and structural barriers are two different types of barriers that researchers have examined. Structural barriers refer to factors in everyday life that can result in non-adherence. These factors may include medical insurance, the cost of the medications, transportation to get medications, and difficulties getting the medications filled (Rudy, Murphy, Harris, Muenz, & Ellen, 2010). Patients frequently self-identify structural barriers as a factor contributing to their non-adherence (Evans et al., 2010); however, even when studies have accounted for structural barriers, non-adherence still occurs (Gincherman, Moloney, & Mckee, 2010). This suggests that while structural barriers may be contributing to non-adherence, perceived barriers are also playing a role.

The most studied domain in the original child health belief model is perceived barriers. Thus far, nine studies have examined the relationship between perceived barriers and non-adherence. These studies have been conducted across a range of chronic illness populations (inflammatory bowel disease, transplantation, type 1 diabetes, human immunodeficiency virus, transplant candidates, and asthma), and all the studies have found that when adolescents have higher levels of perceived barriers, they are more non-adherent to their medications (Hommel & Baldassano, 2010; Ingerski, Baldassano, Denson, & Hommel, 2010; Ratcliff, Blount, & Mee, 2010; Simons, McCormick, Devine, & Blount, 2010; Simons, McCormick, Mee, & Blount, 2009; Zelikovsky, Schast, Palmer, & Meyers, 2008).

The Four Original Components of the Child Health Belief Model

The studies discussed thus far suggest that an adolescent's thoughts play an important role in medication non-adherence. When adolescents perceive their medications as beneficial and identify few barriers to taking their medications, they are less non-adherent. Whereas there is a different pattern of findings across studies for perceived susceptibility and perceived severity, it is clear that the thoughts adolescents have about their susceptibility to negative health outcomes and the severity of those negative health outcomes play a role in medication non-adherence. These findings provide important information when trying to understand why one adolescent is adherent and another is not. Additionally, these findings suggest that there is clear empirical evidence for the use of the four original components of the CHBM when examining medication non-adherence in adolescents.

Family support was the final component added to the CHBM. This factor differs from the prior factors in that it does not focus on individuals' thoughts and feelings about the medication, the possible negative consequences if they do not take their medications, or their perceived ability to implement the medication regimen. Rather, this domain focuses on the adolescent's perception of *other* people's thoughts and behaviors, specifically, the family's support in facilitating medication taking (Bush & Iannotti, 1990). For example, when assessing family support in this context, a clinician may be interested in understanding how family members emphasize or minimize the importance of the adolescent taking their medications. This domain was added to the CHBM as children are rarely fully in charge of taking their own medications; they may not be able to drive to the store to get the medications, and they may not be old enough to comprehend the purpose of the medications. Among children and adolescents with a chronic illness, family functioning more broadly has been shown consistently to negatively predict

medication non-adherence (Grey, Boland, Sullivan-Bolyai, & Tamborlane, 1998; Hsin, La Greca, Valenzuela, Moine, & Delamater, 2010; La Grecca & Auslander, 1995). Few authors however, have specifically examined the family's support for medication taking. Four studies have examined this specific type of family support and found that with adolescents, higher family support for medication significantly negatively predicts medication non-adherence (Hsin, La Greca, Valenzuela, Moine, & Delamater, 2010; Lewin et al., 2006; Reed-Knight, Lewis, & Blount, 2010; Tucker et al., 2002). These findings suggest that family support more broadly, as well as familial support for medication taking specifically, are both important predictors of an adolescent's non-adherence.

The second version of the HBM was modified to include self-efficacy. Bandura defines self-efficacy as the belief that one can carry out specific behaviors in specific situations (1997). There are two different ways in which self-efficacy can influence the likelihood that one will engage in a behavior. First, someone will be less likely to engage in a behavior (i.e., taking their medications) if they see themselves as less able to perform the behavior (i.e., think they will not take them correctly). Second, if an individual's self-efficacy for the behavior is low, and they encounter an obstacle, the probability that the individual will successfully perform the behavior is decreased. Specifically, this individual will tend to exert less effort for a shorter period of time than an individual with higher perceived self-efficacy for the behavior (Bandura, 1977). For example, if an adolescent is scheduled to go to the nurse's office to take their medications and they forget, a person with low self-efficacy might spend less time and effort trying to come up with an alternate plan to take them later in the day. Overall, studies have found that self-efficacy is an important factor in influencing short-term and long-term health behavior changes in both children and young adults (Holden, Moncher, Schinke, & Barker, 1990; Holden, 1991). Four

studies to date have examined the relationship between self-efficacy and non-adherence. The findings across the four existing studies have indicated consistently that when adolescents have higher levels of self-efficacy, they have lower levels of medication non-adherence (Berg et al., 2011; Rudy, Murphy, Harris, Muenz, & Ellen, 2010; Stewart et al., 2003; Tucker et al., 2002).

Bandura proposed that not only is self-efficacy or the belief that one can carry out specific behaviors important in influencing a person's behavior, but a person's perception of their personal control also needs to be considered.

Adolescent Health Belief Model

Looking across the six components of the CHBM, there is compelling empirical support for the use of this model in adolescents. Specifically, cognitions about perceived severity, perceived susceptibility, perceived benefits, perceived barriers, self-efficacy, and familial support, are each playing a role in the adolescent medication-taking process. Although there is strong empirical evidence for each of these components, using a model that was designed for pre-adolescents in adolescents may ignore two developmentally unique factors. Thus, it is proposed that the addition of two new factors, perceived control and peer support, should be added to the CHBM and that this more complete model, AHBM, will more fully explain the phenomenon of adolescent non-adherence.

Personal control is the extent to which someone feels that their behaviors can influence and change a given outcome. Someone with high personal control would operate with the view that a given outcome can be modified based on their actions; however, someone with low personal control would think that regardless of what they do, a given outcome cannot be influenced (Bandura, 1993). For example, a person with high personal control for their illness may think that by taking their medications they can influence the course of their disease

progression or control the symptoms of their illness. Someone with low personal control for their illness may think that taking their medications will not influence the course of their disease progression or change their symptoms.

The concept of personal control, sometimes also referred to as outcome expectations, is similar yet distinct from self-efficacy. Self-efficacy is the belief that one can carry out a specific behavior whereas personal control refers to a person's thoughts about the influence of engaging in that specific behavior. Thus, a person could have high or low self-efficacy and high or low personal control. Knowing about a person's self-efficacy does not provide information about a person's personal control. Studies have found that when predicting health behaviors, knowing both a person's self-efficacy and a person's personal control predicts significantly more variance than knowing either of these factors alone (Bandura, 1997). Despite these findings, only one study to date has examined the role of personal control in medication non-adherence. The findings indicated that when an adolescent has higher personal control, they were less non-adherent to their diabetes regimen (Iannotti et al., 2006). Across studies, the results suggest that an adolescent's perceived control and self-efficacy are both important factors to understand when attempting to gain a complete picture of the cognitive factors influencing non-adherence.

As youth move from late childhood to early adolescence, their main source of social support changes. Specifically, peer relationships begin to gain increasing significance (Kerns, Contreras, & Neal-Barnett, 2000). Additionally, during this developmental period, the amount of time spent with friends increases, and there is a dramatic drop in the amount of time adolescents spend with their parents (Larson & Richards, 1991). The important role that peer social support can provide has been demonstrated across a range of domains. For example among adolescents, peer social support has been shown to play a significant role in overall adjustment, well-being,

emotional adjustment, self-esteem, and physical adjustment (Buchanan & Bowen, 2008; Matlin, Molock, & Tebes, 2011; Weiss et al., 2002). Conceptualizing the medication taking process for adolescents within a broader developmental framework, it may be that peers also play an important role in influencing medication non-adherence.

The time spent with peers can influence an adolescent in both positive and negative ways. Peers can positively influence academic achievement and prosocial behaviors (Mounts & Steinberg, 1995; Wentzel & Caldwell, 1997); however, peers also can promote maladaptive behavior such as drug and alcohol use, cigarette smoking, and delinquency (La Greca, Prinstein, & Fetter, 2001; Urberg et al., 1997). The majority of research examining the role that peers play during adolescence has focused on health-risk behaviors (La Greca, 1990; Spirito, DeLawyer, & Stark, 1991). This may be a result of the tendency to view peers as obstacles to, rather than facilitators of, good health practices (e.g., Chassin, Presson, Sherman, Montello, & McGrew, 1986; Gross, Johnson, Wildman, & Mullet, 1981). Thus, there is a need to further examine the potentially positive influence that friends may have in adolescent's disease management and adaptive health behaviors such as low non-adherence.

Two studies to date have examined the association between adolescents' peer relationships and health-promoting behaviors. One such study was conducted with 74 adolescents with diabetes. Participants completed the diabetes social support questionnaire for friends, and results indicated that peer support was predictive of higher levels of exercise and more frequent blood glucose testing (Bearman & La Greca, 2002). In another study, 38 adolescents with Irritable Bowel Disease completed the Social Experience Questionnaire (Crick & Grotpeter, 1996) and self-reported their medication non-adherence. When adolescents perceived higher levels of prosocial peer support, they were less non-adherent to their

medications (Janicke et al., 2009). While these are the only two studies conducted in adolescents, studies in both younger children and adults have each found a significant association between peer support and medication non-adherence (e.g., Heisler, Vijan, Makki, & Piette, 2010; Levers-Landis et al., 2002). Given these findings and the developmental stage of adolescence, peer social support is an additional factor that should be included when examining adolescent non-adherence.

Overall, the health belief model has not been examined in a manner that takes all of the proposed factors into account simultaneously in predicting important outcomes such as medication non-adherence. The current investigation examined all components of the CHBM and the expanded AHBM. Another aspect of this model that has been neglected, involves examining how the model may operate differently in different disease populations. To date no investigators have proposed ways in which the components of the model may be differentially important based on disease symptomology.

Evaluating the Adolescent Health Belief Model in CKD and IBD

One key factor that may influence an adolescents' thought processes about their medications is the short term and long term consequences associated with medication non-adherence, i.e., symptoms. It may be that for illnesses where patients experience immediate, aversive symptoms if they are non-adherent, different factors are important compared to illnesses in which these immediate symptoms do not occur. For example if a patient with IBD is non-adherent to their medications, there is an immediate physiological repercussion-- they likely end up in the restroom. Conversely if a patient with CKD does not take their medications, there are no immediate aversive consequences; rather, it is in the long term that they experience disease progression and increased symptomology. To better understand how these short and long term

20

consequences may play a role in the AHBM, it is important to first review the characteristics, symptoms, and treatment for both IBD and CKD.

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 onset of CKD can 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). These patients often have a shorter stature and delayed puberty. One of the most common medications used to treat CKD is an oral steroid. Steroids can result in facial swelling, increased

acne, hair growth, and emotional lability. Thus, often patients may feel worse after taking their medications, and they do not experience any immediate positive effect. Another illness in which oral steroids are the typical medication used to treat the disease is IBD. However, in this illness, there are immediate consequences for taking or not taking medications.

IBD has a relapsing and remitting course, with the most common symptoms in children including frequent diarrhea, abdominal pain, and weight loss or growth delay. Associated symptoms can include fever, fatigue, decreased appetite, arthritis, perianal disease, and delayed puberty. IBD is generally divided into two subtypes, Crohn's disease and ulcerative colitis, which differ primarily in the anatomical location, nature of the inflammation, and possibly the underlying causative mechanisms. Crohn's disease may occur anywhere in the intestinal tract, but ulcerative colitis is found only in the colon (large intestine). In ulcerative colitis, the intestinal inflammation is confined to the innermost layer of the intestinal wall, while the inflammation of Crohn's disease can extend through the entire thickness of the intestinal wall. The specific etiologies are unknown, although both genetic and microbial factors are known to be involved (Rice & Chuang, 1999). An interaction between a dysregulated intestinal immune system and intestinal bacteria is thought to lead to the uncontrolled inflammation seen in IBD, although different immunological pathways are involved in Crohn's disease and ulcerative colitis.

The treatment of IBD has many characteristics similar to the treatment of CKD. There is a comparable and complex daily regimen required to manage the illness. This regimen consists of frequent medications, food restrictions, and frequent visits to the doctor. These patients also often have a shorter stature and delayed puberty. Additionally, the most common medication used to treat IBD is oral steroids. However, unlike patients with CKD, those with IBD have an

immediate positive effect after taking their medications-- it helps control their GI track and subsequent bowel movements. Thus, often patients feel better after taking their medications.

The immediate physiological cue that adolescents with IBD experience when they are non-adherent to their medications may be a significant factor in determining an adolescent's non-adherence. Both perceived benefits and perceived severity are two components of the AHBM that focus on immediate short-term beliefs. As previously mentioned, when an adolescent with IBD takes their medication, they experience an immediate positive effect -- it helps control their GI track and subsequent bowel movements. This is not the case for adolescents with CKD. For those with CKD, the medication helps control the long term progression of the illness but does not have any short term, immediate benefits. Therefore the perceived short-term benefits of taking their medications may be a significant factor in predicting medication non-adherence for adolescents with IBD, but it may not be for those with CKD. In addition to the short-term benefits that adolescents experience when they take their medications, they also experience multiple relatively severe negative consequences if they do not take their mediations. Specifically, if adolescents with IBD do not take their medications, they may have uncontrollable bowel movements. This differs from CKD in that there are no immediate negative side effects if adolescents do not take their medications. In fact CKD is largely asymptomatic in its early stages. This suggests that in adolescents with IBD, the perceived severity of these negative consequences would be a significant predictor of non-adherence and that for those with CKD, this would not be the case.

Personal control is the extent to which someone feels that their behaviors can influence and change a given outcome. It may be possible that if participants with CKD think that taking the medication will in the long term decrease their disease progression, they will have lower

levels of non-adherence. Conversely, if they think that taking the medication will not influence their long term disease progression, they will have higher levels of non-adherence. For patients with IBD, their perceived long term personal control may not be important; there are such potent, short term benefits and consequences associated with taking or not taking their medications that long term personal control may not be playing a role.

Current Study Aims and Hypotheses

As was previously discussed, the AHBM may operate differently for the two illness populations. The subsequent hypotheses took this into account when appropriate. The first two hypotheses controlled for disease type. These two hypotheses focused on the definition of non-adherence and the model as a whole; therefore, the differential role of the factors across the two diseases was not of primary interest. The third hypothesis examined whether the coping style of positive problem solving and denial moderate the relationship between susceptibility, severity, and non-adherence. This relationship was thought to hold true in both illness groups; therefore, the illness type was not controlled for. The final hypothesis examined how the various factors in the AHBM might be differentially important in the two illness populations. Thus, this hypothesis examined the possible moderating role that illness type could play in the relationship between the AHBM factors and non-adherence.

Hypothesis 1. As previously discussed, there is not a gold standard method for measuring non-adherence. This study, therefore, employed four different methods to obtain non-adherence information: self-report, doctor report, caregiver report, and pharmacy refill information (used to calculate the medication possession ratio; MPR). Given these four different measures of non-adherence, the aim of the first hypothesis was to characterize the relationships

among the four different measures of non-adherence and determine which measure(s) of medication non-adherence should be used in the subsequent hypotheses.

While many previous investigators ran their hypotheses employing each different measure of non-adherence, this is problematic for two reasons. First, it increases the likelihood of type I error. Additionally, if each measure of non-adherence is conceptualized as a measure of the same underlying latent variable, then the data should be examined to determine if this is in fact the case. In order to characterize the relationships among the four different measures of non-adherence and determine appropriate non-adherence measures for further analyses, three aims were put forth.

The first aim was to examine the average non-adherence obtained by the four different measures of non-adherence. This allowed for a descriptive understanding of the four non-adherence measures. Objective measures of adherence (MPR) typically indicate higher average levels of non-adherence than subjective measures of non-adherence (self-report, caregiver report, and doctor report). Hypothesis 1A proposed that non-adherence obtained by the MPR would be the highest, followed by the average non-adherence by doctor report, caregiver report, and that non-adherence by self-report would be the lowest. The four measures of non-adherence employed the same scaling approach, and each measure examined what percent of time the participant did not take their medications. Therefore the four measures could be directly compared with each other. It was hypothesized that self-reported non-adherence would he lowest as it has been suggested that social desirability significantly influences self-report such that individuals want to appear compliant in their ratings (Malee et al., 2009).

Hypothesis 1B stated that social desirability would be a significant negative predictor of self-reported, caregiver reported, and doctor reported medication non-adherence. It was

hypothesized that social desirability would not be a significant predictor of the MPR calculated non-adherence. If social desirability is found to be a significant predictor of non-adherence, then subsequent hypotheses will control for social desirability.

The third aim was to determine if all four measures of non-adherence represent the same underlying latent variable (using confirmatory factor analysis; CFA) and determine what measures of non-adherence to use in the subsequent analyses. While a different pattern of findings were expected such that self-reported non-adherence would be lower than caregiver reported, doctor reported, or pharmacy obtained non-adherence (hypothesis 1A), it was anticipated that all four measures would be at least moderately correlated. Hypothesis 1C stated that there would be significant medium correlations among the four different measures and that a CFA model would have good fit indices (Figure 1).

Based on the findings of hypothesis 1C, non-adherence will be operationalized in one of the following three ways. The first way would be if the CFA model had good fit indices and social desirability was not a significant predictor of any of the 4 non-adherence measures. In this case, the CFA would be used to combine the four measures of non-adherence into one overall variable (factor score). This is discussed at greater length in the data analysis section. The second possibility would be if the CFA model had good fit indices and social desirability was a significant predictor of any of the 3 non-adherence measures. In this case, all subsequent hypotheses would control for social desirability. The third outcome would be if the four measures of non-adherence did not have good fit indices, and, therefore, CFA is not an appropriate data analytic strategy. If this occurred, each subsequent hypothesis would be run with each individual non-adherence measure. For each of the four measures of non-adherence, if social desirability was a significant predictor of that particular non-adherence measure, it would

26

also be included in the model. Particular attention would be paid to the analyses run with the MPR since this is the most objective measure of non-adherence. This is discussed at greater length in the data analysis section.

Hypothesis 2. In hypothesis 2A and 2B, first the total variance explained in medication non-adherence for the model was examined. Next, each factor in the model was examined to determine which factors were significant predictors of non-adherence. Within the Child Health Belief Model, Hypothesis 2A stated that that perceived susceptibility, perceived severity, higher perceived benefits, lower perceived barriers, higher family support, and higher self-efficacy would predict lower levels of medication non-adherence when disease type is controlled for. Hypothesis 2B examined whether the two new factors added to form the Adolescent Heath Belief Model were significant predictors of non-adherence. Specifically, Hypothesis 2B stated that personal control and peer support would be significant negative predictors of non-adherence when they were added to the model listed in Hypothesis 2A. Finally, the Adolescent Health Belief Model was developed as a developmentally appropriate and more complete way to conceptualize adolescent non-adherence. Hypothesis 2C stated that the Adolescent Health Belief Model (hypothesis 2B) would explain significantly more variance in medication non-adherence than the Child Health Belief Model (hypothesis 2A).

Hypothesis 3. Hypothesis 3 examined a possible explanation for the different pattern of findings shown across the factors of perceived susceptibility and perceived severity. Some prior studies found a positive relationship between susceptibility, severity, and non-adherence, whereas other studies found a negative relationship between susceptibility, severity, and non-adherence. Thus, this hypothesis examined whether the coping styles of positive problem solving and denial moderate the relationships among susceptibility, severity, and non-adherence.

Hypothesis 3 stated that when participants experience perceived susceptibility or severity and engage in denial, they will have high non-adherence. However, when participants experience perceived susceptibility or severity but engage in positive problem solving, they will have low medication non-adherence.

Hypothesis 4. Across the two chronic illnesses being examined in this investigation, there are multiple differences in both the short-term and long-term consequences of non-adherence. This secondary hypothesis examined if some of the AHBM factors are differentially important across the two illness groups. Because individuals with IBD experience strong negative, immediate consequences when non-adherent, the perceived severity of these short-term consequences and the perceived benefits of the medication may be particularity important factors. Hypothesis 4A stated that the relationship between the perceived severity of the short-term consequences and non-adherence would be moderated by disease type. For participants with IBD, there would be a strong relationship between perceived severity of the short-term consequences and non-adherence; however, this would not be the case for those with CKD. Additionally, Hypothesis 4B stated that the relationship between perceived benefits and non-adherence would be moderated by disease type. More specifically for participants with IBD, there would be a strong relationship between perceived benefits and non-adherence; however, this will not be the case for those with CKD.

Hypothesis 4C stated that the relationship between personal control and non-adherence would be moderated by disease type. For participants with CKD, the long-term consequences of personal control would be more important when predicting medication non-adherence compared to individuals with IBD.

CHAPTER 2: METHOD

Participants

Recruitment occurred at the UNC Chapel Hill Pediatric outpatient and inpatient Kidney Clinic and Gastroenterological (GI) Services. All patients 13 to 21 years old who had a diagnosis of chronic kidney disease or inflammatory bowel disease for at least three months were approached to participate. If an individual (or their caregiver 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. This study recruited 110 patients. Medical eligibility was determined by consulting with the patient's physician and/or a chart review. Those with CKD stage 3 or higher or a diagnosis of IBD were eligible to participate regardless of how long they have received treatment at UNC.

The patients at the UNC Kidney Center live an average of 75 miles (one way) away from the clinic. At the present time, there are approximately 100 patients with CKD stage 1-4; 100 patients who have received a kidney transplant; and 10 who are currently on dialysis. On average the adolescents in this population take approximately 9.1 (*SD*=5.8) medications per day. There is a large prevalence of minorities in the Kidney clinic, which is reflective of the larger population of individuals who are diagnosed with CKD. Conversely, patients at the GI Clinic typically live close to the hospital as there are more GI doctors across the state. At the present time, there are approximately 150 patients with IBD being treated at UNC. On average the adolescents in this population take a similarly high number of medications per day as those with CKD. The majority

of patients being treated for IBD at UNC are Caucasian which is reflective of the larger population of individuals who are diagnosed with IBD.

Procedure

After full approval from the institutional review board was obtained, potential participants were recruited in one of two ways, either from the UNC outpatient clinic or over the phone. Recruitment at the UNC Chapel Hill Pediatric outpatient clinic proceeded as follows. Once the potential participant and their caregiver were brought out of the clinic waiting area and into a private room, the primary investigator (PI) or a research assistant approached the family. They waited until the patient had entered a private room helped to ensure confidentiality and privacy. The study was briefly described to the potential participant and their caregiver if they were less than 18 years old or to the young adult alone if they were 18 or older. The study was described as being conducted to better understand how a person's thoughts and feelings influence their medication taking. Next, it was explained that as a thank you they would receive a 10$ gift-card for participating and that, hopefully, the results of the study will allow doctors and psychologists who work with CKD/IBD patients to better understand their experience. Subsequently, the patients were told that approximately 30-45 minutes would be needed for them to complete all of the questionnaires. Finally, the primary investigator waited silently in the room for a minute to allow the potential participant (and their caregiver 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 participants and guardians, as appropriate. The scales as well as the consent forms were completed on computers through the web survey tool 'Qualtrics.' Every effort was made 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 were administered the scales. The patient completed scales that gather information about their perceived susceptibility, severity, benefits, barriers, family support, self-efficacy, personal control, peer social support, social-desirability, coping strategies, demographics, and medication non-adherence. The participant's pharmacy was also called to obtain a record of their medication refill history for the past year. Finally, the participant's physician was approached and asked to rate the patient's non-adherence and disease severity.

The second way in which participants were recruited was over the phone. This was completed for patients at the UNC Kidney and GI Center who did not have an appointment scheduled during the recruitment period. This was fairly common as many patients only have one appointment every six months. Adolescents were called, and if they expressed interest in participating, they were e-mailed the link to access the Qualtrics website. Additionally, they were provided a confidential study ID number and the PI's study phone number. Participants were prompted for the ID upon logging into Qualtrics. The study ID allowed confidentiality to be maintained, while at the same time allowing the PI to match the study IDs with participants' names when the chart review was being completed. The PI's study phone number was provided so that if participants had any questions or concerns, they could have these concerns addressed prior to beginning the study. For those potential participants who were less than 18 years old, Qualtrics prompted the participant to get their caregiver. Their caregiver must have agreed to the study consent form and HIPAA form in order for their child to be allowed to participate. Next, the patient was prompted to review their own consent and HIPAA form. They had to agree to the

study consent form as well as the HIPAA form to be allowed to participate. If they agreed to both forms, the study questionnaires appeared.

As previously mentioned, after study completion, the participant's pharmacy was called to obtain a record of their medication refill history for the past year. Additionally, the participant's physician was approached and asked to rate the patient's non-adherence and disease severity.

Measures

The measures used to assess the factors of the Adolescent Health Belief Model, coping strategies, and social desirability are all self-report scales that have been validated in chronic illness populations. Also, scales assessing the physician's report of the participant's non-adherence and disease severity will be discussed. Finally, the exact procedure used to obtain and calculate the medication possession ratio will be discussed.

Perceived susceptibility. This scale was created for the current investigation based on several previously published scales (Vollrath, Knoch, & Cassano, 1999; Weinstein, 1984). This five question self-report questionnaire asked participants to rate how likely they are to experience a number of different negative outcomes when they compare themselves to peers with a similar illness. For example one question asked, "Compared to other with a similar illness, if I don't take my medications as prescribed, my chances of developing complications where I have to spend multiple days in the hospital are." Participants responded on a 7-point scale that ranged from "much below average" to "much above average."

Perceived severity and perceived benefits. The Beliefs About Medication Scale (BMQ; Riekert & Drotar, 2002) consists of 17 questions. These questions assessed two domains: perceived severity and perceived benefits of the medications. An example of a question that

assessed perceived benefits is, "I have a lot to gain from taking my medicine the way the doctor says I should." An example question from the perceived severity subscale is, "If I do not take my medicine the way I should, I will get sicker." Participants indicated their degree of agreement with each statement on a 5-point Likert scale, ranging from 1-5 (strongly disagree to strongly agree). The subscales demonstrate good reliability as evidenced by Cronbach's alphas of .79–.87, mean item-total correlations of .44–.53, and 3-week test-retest results of .71–.77. The severity questions in this scale all tapped into long term consequences of non-adherence (Riekert & Drotar). As the two illness populations have different long term and short term consequences of non-adherence, it was important to understand the differential influence that these consequences might have in influencing non-adherence. Therefore, four questions examining the perceived severity of short-term consequences were added to the questionnaire. For example, one question that was added asks, "If I do not take my medicine the way I should, I quickly begin to feel poorly."

Perceived barriers. The Adolescent Medication Barriers Scale (AMBS; Simons & Blount, 2007). The AMBS is a self-report measure designed to assess adolescent-perceived barriers to medication adherence. An example question is, "I do not want other people to notice me taking the medicine." All items are rated on a 5-point Likert-like scale from, ''strongly disagree'' to ''strongly agree.'' The AMBS consists of 17 items with a maximum score of 85. The sample mean for the scale is 38.1 (SD = 10.7). The Cronbach's alpha of the total scale was .86 indicating strong internal consistency. There are three subscales: disease frustration/adolescent issues (α = .84), ingestion issues (α = .70), and regimen adaptation/cognitive issues (α = .76; Simons & Blount, 2007). An example of a question from the disease frustration/adolescent issues subscale is, "I feel that it gets in the way of my activities." A question from the ingestion issues subscale

is, "I don't like how the medicine tastes." The subscale assessing regimen adaptation/cognitive issues includes question such as, "I am not organized about when and how to take the medicine."

Self-efficacy. The Brief Measure of Diabetes Self-Efficacy (Iannotti et al., 2006). This 10 item short scale was created for participants with Diabetes; therefore, the questions were slightly modified to reflect IBD and CKD. Specifically in each question, the words *your diabetes* was replaced with *your illness*. For example, all questions began with, "How sure are you that you can do each of the following, almost all the time?" The original survey next stated, "Identify things that could get in the way of managing your diabetes." In the version used for this study, the questions read "Identify things that could get in the way of managing your illness." Participants responded on a 10-point scale ranging from, "not sure at all" to "a lot". Cronbach's alpha for this scale is high (.90), and the test-retest intraclass correlation coefficient for the measure is .89. The mean for the scale is 7.52 (SD =1.58). Additionally, a scree plot indicated that all items have a factor loading of at least .53 (Iannotti et al.).

Family support. The Diabetes Social Support Questionnaire-Family Version (DSSQ-family; La Grecca & Bearman, 2002) is a self-administered 58 question measure that assesses adolescents' perceptions of their family's behaviors relative to their disease. The scale included questions about both instrumental support and emotional support. Many of the questions in the original scale asked about tasks not relevant to the care of CKD or IBD (i.e., asked about the results of blood tests); thus, all non-relevant questions were eliminated, and the version used in this study included 13 questions. This shorter version has also been used in prior investigations (Hsin, La Greca, Valenzuela, & Delamater, 2010). There is high internal consistency across the 13 items (α = .91). The concurrent validity of the measure indicates that adolescents who report more frequent family support for their illness view their families as more emotionally supportive

($r = .47$, $p < .001$), and more cohesive ($r = .34$, $p < .01$) than adolescents who report less frequent family support (La Grecca & Bearman, 2002). As the questionnaire was originally designed to be used with adolescents who have diabetes, each relevant question replaced the word diabetes with your illness. For example, in the question (*How often does a family member)* understand when you sometimes make mistakes in taking care of your diabetes, *diabetes* was changed to *your illness.*

When completing the measure, participants were first asked the frequency with which each behavior occurs ("How often does a family member……?") from 0 to 5 (where 0 = never and 5 = at least once a day). Next, participants were asked to provide a rating of the perceived supportiveness of the behavior ("How does this make you feel?") from -1 to 3 (-1 = not supportive and 3 = very supportive).

Personal control. The Perceived Control subscale from the Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002) was employed. This six question self-report sub-scale asked participants about their level of perceived control over their illness. For example one question states, "The course of my illness depends on me." Responses are on a 5-point Likert-like scale from "strongly disagree" to "strongly agree." Higher scores indicate a higher level of perceived control. This sub-scale has good internal reliability (.81) and good test-retest reliability (.57; Moss-Morris et al.).

Peer support. The Diabetes Social Support Questionnaire-Friend Version (DSSQ-Friends; Bearman & La Greca, 2002) is a self-administered questionnaire that assesses adolescents' perceived peer support for taking their medications. The scale includes four questions about emotional support. As the questionnaire was originally designed to be used with adolescents who have diabetes, each question replaced the word *diabetes* with *your illness*. For example, in

the question (*How often does a friend)* let you know they understand how important it is for you to take medications for your diabetes, *diabetes* was changed to *illness*.

Similar to the DDSQ-Family, when completing the measure, participants were first asked the frequency with which each behavior occurs ("How often does a friend……?") from 0-5 (0= never and 5= at least once a day). Next, participants were asked to provide a rating of the perceived supportiveness of the behavior ("How does this make you feel?") from -1- 3 (-1= not supportive and 3= very supportive). The scale has acceptable levels of internal consistency (rs > .70), the re-test correlations are high (.78 - .94) (Bearman & La Greca).

Social desirability. The Marlow-Crown Social Desirability Scale, Short-Form (Reynolds, 1982) is a13 item self-report scale that examines a person's level of social desirability. For example, participants answered true or false to multiple statements such as, "I sometimes feel resentful when I don't get my way." The item to total score correlations range from .32 - .47, and the scale is highly correlated with the Marlow-Crown standard form (.93). The total mean is 5.31 (SD = 2.90). All items have a factor loading of .4 or above (Ballard, 1992).

Coping. This scale was created for the current investigation based on the KidCope (Spirito, Stark, & Williams, 1988). The adolescent was first asked to think about taking their medications. Then, they were asked about the coping strategies used to manage taking their medications. Only the coping styles of positive problem solving and denial were included in this study. The coping strategies that the children endorse are used to create a frequency score (how often did you do this?) and an efficacy score (how much did this help?). Each of these responses are given on a 4-point Likert-type scale ranging from, "not at all" to "almost all the time" for the frequency question, and "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; Spirito et al., 1988). Moderate to high construct validity was found (.33 - .77; Patterson & McCubbin, 1987; Spirito et al., 1988; Tobin, 19991).

Disease severity. Severity of Illness Scale (Young-Salem & Prevatt, 2001). This six question scale asked the doctor to report on a number of different disease characteristics, so that an overall disease severity estimate could be obtained. The responses range from 1-7 with 1 representing lower disease severity and 7 representing higher disease severity. For example, one question states, "How many times a year does this child require a hospitalization," a response of 1 indicates 0 hospitalizations and a response of 7 indicated multiple hospitalizations. The scale has good reliability with a Cronbach's Alpha of .79; additionally, the mean usefulness rating from 1-5 was a 4.97 (Young-Salem & Prevatt).

Demographic information. This self-report questionnaire was created for the current study. It asked patients their demographic information such as age, race, gender, age at diagnosis, and insurance status.

Non-adherence. The following methods each sought to measure what percent of the time participants did not take their medications. This percentage was derived in the following three different ways:

Self-reported non-adherence. The Medication Adherence Measure (MAM; Zelikovsky, Schast, Palmer, & Meyers, 2002) was used to assess medication non-adherence. Participants first reported the name of each medication that they were prescribed, and if they could not remember all their medications, they were reminded of them (obtained by chart review). Next, participants

self-reported how many doses of each medication they missed in the previous seven days. The number of missed doses, divided by the number of prescribed doses, times 100, yielded the percentage of missed doses. The MAM is one of the most frequently used methods to assess self-reported adherence. Data on the MAM suggest adequate convergent validity with established measures of non-adherence. For example, in one study of outcomes among renal transplant recipients, the percent of missed doses identified on the MAM was associated with the number of documented acute rejection episodes by year 2 post-transplant ($r = 0.62$, $p < 0.001$), suggesting good predictive validity of clinical outcomes (Schast, Palmer, & Meyers, 2002).

Caregiver rated non-adherence. The adolescent's caregiver was asked to confidentially rate what percent of the time they think the participant does not take their medications.

Physician rated non-adherence. The physician was asked to confidentially rate what percent of the time they think the participant does not take their medications. Asking the physician one question as an estimate of participant adherence is a common method across studies (Cluss & Epstein, 1985; La Greca, 1988a; Mathews & Christophersen, 1988).

Medication Possession Ratio (MPR) – objective adherence. The participant's pharmacy refill record for one year prior to the date of study participation was obtained and used to calculate the 3 month MPR. Prior studies have found that the MPR for a 3 month period is representative of the patient's typical adherence (Andrade, Kahler, Frech, & Chan, 2006); thus, this time period was also used for the current study. The pharmacy refill record includes a list of medications and each date that it was (re-)filled at that pharmacy. MPR in this study was defined as the proportion of medications obtained by the participant during a specific time period (MPR = (number of days the participant did not have a supply of the medication during the observation period / number of days in observation period) * 100). For example, if a participant obtained a 30

day supply of their medication and filled the first dose on 1/1/12, the second dose on 2/7/12 and the third dose on 3/20/12, there would be 19 days where the participant did not have the needed medication. It can therefore be inferred that the participant was non-adherent for these 19 days. Using the equation mentioned above, 19 is divided by 90 (90 days in 3 months) and then this number is multiplied by 100. This person is non-adherent, therefore, 21.1 percent of the time. This methodology is consistent with multiple other studies (e.g., Andrade, Kahler, Frech, & Chan, 2006). Different studies have included different medications in the MPR analyses. As this investigation is examining non-adherence across two illnesses which have very different types of prescribed medications, all prescription medications were included.

CHAPTER 3: DATA ANALYSIS

A total of 110 participants completed all portions of the study. Twenty-three participants began the study but did not complete the on-line portion at home (23/140=16.43%). Two participants completed the study, but it was later determined that they were ineligible. Therefore they were not included in any further analyses (2/140=1.43%). Five individuals refused to participate in the study (5/140=96.43% participation rate).

The sample consisted of 51 males and 59 females. The majority of the sample had private insurance (n=61), followed by public insurance (n=42). A few participants did not have any insurance (n=4) or had both public and private insurance (n=3). The majority of the sample was Caucasian (n=62), followed by African American (n=34), and Hispanic (n=9). The average age of the sample was $16.92(\pm1.93)$. The majority of the sample reported that they did not have a job (n=80), followed by a part-time seasonal job (n=11), and a year round part-time job (n=13).

The composition of the CKD (n=55) and IBD (n=55) samples were not significantly different in terms of gender ($F_{(1, 108)} = .91$, $p = .34$), or whether the participant had a job ($F_{(1, 108)} = .20$, $p = .66$). There was a significant difference between the ethnic composition of the two samples ($F_{(1, 108)} = 15.71$, $p = .00$), such that there were significantly more African Americans in the CKD sample than in the IBD sample. Additionally, there were significantly more Hispanic individuals in the CKD sample than in the IBD sample. These results reflect the broader population of participants with CKD and IBD being treated at the UNC Hospital. There was also a significant difference between the type of insurance that the two samples had ($F_{(1, 108)} = 18.06$, $p = .00$), such that the CKD sample had significantly more public insurance and

significantly less private insurance. Finally, the average age between the two samples was significantly different (F(1, 108) = 4.66, p =.03), such that the CKD sample was older than the IBD sample (CKD is .78 of a year older on average).

When comparing the disease characteristics of the two samples, results indicated that the CKD (μ=6.36, ±3.65) sample was prescribed significantly more medications than the IBD sample (μ=3.67, ±2.02; F(1, 108) = 22.91, p <.001). Additionally, the providers' rating of the participants' disease severity was significantly different F(1, 79) = 3.84, p=.05. On average the CKD sample (μ=18.08, ±6.72) was rated as having more disease severity than the IBD sample (μ=15.52, ±3.56; Table 1).

Hypothesis 1. The aim of the originally proposed hypothesis was to characterize the associations among the four different measures of non-adherence (caregiver rating, doctor rating, adolescent rating, and MPR) and determine which measure(s) of medication non-adherence should be used in the subsequent hypotheses. First, descriptive information about each of the four different measures of non-adherence is provided below.

Caregiver non-adherence ratings were obtained on 105 participants. Two caregivers did not speak English; one caregiver was unable to be reached despite multiple attempts, and two caregivers reported that because their child did not live at home, they felt uncomfortable providing an estimate of non-adherence. Overall the caregiver's estimated that their adolescent is non-adherent 13.95% (range 0-100, ±20.08) of the time. This information was primarily provided by the adolescent's mother (n=73), followed by their father (n=25), and other caregivers (grandfather (n=1), grandmother (n=2, aunt (n=2), and guardian (n=2)). The caregivers reported that most frequently the adolescent is in charge of their medications (n=58), followed by their mother (n=39), father (n=4), grandmother (n=2), and aunt (n=2). Results

indicated that the average non-adherence rating provided by the caregivers of adolescent's with

CKD (μ=1422, $\pm$22.30) were not significantly different from those with IBD (μ=13.70, $\pm$17.94; F(1, 103) = .02, p =.90; Table 2).

The adolescents' rating of their own non-adherence was obtained by all 110 participants. The average rating of non-adherence was 16.91% (range 20-100; $\pm$16.18). Results indicated that the average non-adherence rating provided by the adolescents with CKD (18.00% ($\pm$14.71)) and those with IBD (15.82% ($\pm$17.61)) were not significantly different (F(1, 108) = .50, p =.48; Table 2). The adolescents reported that most frequently they are in charge of their medications (n=75), followed by their mother (n=24), father (n=6), grandfather (n=2), grandmother (n=1), and aunt (n=1). This information could not be obtained from one adolescent.

A doctor's rating of non-adherence was obtained for 107 of the participants. Three participants were only occasionally seen at UNC and, therefore, did not have a provider who knew them well enough to provide a non-adherence rating. The average rating of non-adherence was 18.46% (range 0-100; $\pm$19.03). Results indicate that the doctors provided similar ratings of non-adherence across both the CKD sample (19.53($\pm$21.11)) and the IBD sample (17.41($\pm$16.87); F(1, 105) = .33, p =.57; Table 2).

The MPR was calculated for 99 participants. Six participants had the incorrect pharmacy listed in their electronic medical record and, despite multiple attempts, the updated information could not be obtained. Two participants obtained their medications from a pharmacy that changed ownership and no longer had the prescription refill history. We were unable to obtain the record for 3 participants because the pharmacy did not provide the information after multiple contacts. All medications were used to calculate an overall MPR. The MPR results indicated that, on average, the sample was non-adherent to their medications 44.17%($\pm$30.00) of the time.

There was not a significant difference between the MPR obtained for the participants with CKD (44.93 ($\pm$31.40)) and those with IBD (43.36($\pm$29.73); (F(1,97) = .07, p=.80).

Hypothesis 1A. Hypothesis 1A stated that non-adherence obtained by MPR would be highest (μ=44.17), followed by non-adherence by doctor report (μ=18.46), adolescent self-report (μ=16.91), and caregiver report (μ=13.95).

To examine if the means of the different measures of non-adherence were significantly different from each other, a repeated measures ANOVA was conducted. It was found that there was a significant difference among the different measures of non-adherence (F(2.26, 207.74)= 40.61, p=.00; Table 2). Specifically, there was a significant difference between the non-adherence obtained by MPR and the caregiver (p<.001), adolescent (p<.001), and the doctor (p<.001). The repeated measures ANOVA also indicated that the caregiver rating was not significantly different from the doctor rating (p=.41) or adolescent rating (p=1.00); nor was the doctor rating significantly different from the adolescent rating (p=1.00). This suggests that the objective measure of non-adherence (as calculated by MPR) is significantly different from the subjective measures of non-adherence (doctor, caregiver, adolescent report). Furthermore, the three subjective measures of non-adherence were not significantly different from each other. Thus Hypothesis 1A was partially supported.

Non-adherence using the Medicaid portal. (employed as a accuracy check of the data) The Medicaid portal is an on-line system that tracks the refill history for all Medicaid patients in the state of North Carolina. The portal includes refill information from all medications billed through Medicaid, regardless of what pharmacy the prescriptions were refilled at. There were only 22 patients with information in the Medicaid portal; therefore, this information is only being used as a way to check the accuracy of the MPR data. Whereas the MPR is being used as the

objective measure of non-adherence, MPR data are subject to errors if participants refill their medications at multiple different pharmacies or if they changed pharmacies without the awareness of UNC hospital. The Medicaid portal on the other hand is statewide, so it is not subject to this potential error; however, it is subject to other types of errors. The results indicated that the Medicaid non-adherence score was not significantly related to the caregiver's score (r= .23, p= .30), the doctor's score (r=.25, p=.27), the adolescent's score (r= .19, p= .41), or the MPR (r= .35, p= .12). These findings suggest that the two "objective" measures of non-adherence (the MPR score and the Medicaid portal) are different from each other.

Hypothesis 1B. Hypothesis 1B stated that social desirability would be a significant negative predictor of self-reported, caregiver reported, and doctor-reported medication non-adherence. It also was anticipated that social desirability would not be a significant predictor of the MPR calculated non-adherence. These hypotheses were examined by correlating social desirability with each of the four different measures of non-adherence. The results of these analyses indicated that:

The average self-reported social desirability score was 20.64($\pm$2.86; range 13-26). When comparing the participants with CKD 20.56($\pm$2.70) and participants with IBD 20.71($\pm$3.03), the level of social desirability was not significantly different ($F(1, 108)$ =.07, p= .79). Contrary to hypothesis 1B, social desirability was not found to be significantly correlated with the adolescent's self-reported non-adherence (r =.14, p =.15), the doctor's non-adherence rating (r =-.04, p =.68), or the caregiver's non-adherence rating (r =.08, p =.45). As anticipated, social desirability was not a significant predictor of the MPR calculated non-adherence (r = -.10, p =.34). As social desirability was not a significant predictor of any of the measures of non-adherence, it was not included in any additional analyses.

Hypothesis 1C. Hypothesis 1C stated that all four measures of non-adherence would represent the same underlying latent variable. First, the correlations among the four non-adherence measures were examined. Results indicated that the caregiver's rating was significantly positively correlated with the doctor's rating (r=.23, *p*=.02) and adolescent's rating of non-adherence (r=.41, *p*=.00). The doctor's rating, however, was not significantly related to the adolescent's rating (r=.16, *p*=.09). The MPR score was significantly related to the adolescent's (r=.24, *p*=.02) non-adherence rating.

Next, M+ software was used to conduct a confirmatory factor analysis (CFA). This allowed for a more thorough examination of the relationships among the variables to determine whether all non-adherence indicators are statistically reliable representations of the latent construct under investigation. CFA affords several advantages over other analytic techniques in that it allows the specification of causal relationships between observed variables and latent constructs while simultaneously accounting for item-level measurement error (Bryant & Yarnold, 1995). Results indicated that the model is an acceptable fit for the data ($\chi^2(108)$=2.85, *p*=0.24; Comparative Fit Index =0.966 (CFI: >.90 acceptable, >.95 excellent; Bentler, 1990; Bentler & Bonett, 1980); Tucker Lewis Index=0.897 (TLI: >.90 acceptable, >.95 excellent; Tucker & Lewis, 1973); Root Mean Square error of Approximation=0.062 (RMSEA: <.08 acceptable, <.05 excellent; Brown & Cudeck, 1993). A one-factor solution was derived (Figure 2; Table 3). Although some of the loadings were lower than desired, the overall indices were acceptable and, therefore, it seemed justifiable to use the factor scores in all subsequent analyses as the primary dependent variable.

Hypothesis 2. Hypothesis 2 involved three different components: first to examine the amount of variance explained by the Child Health Belief Model; next to examine the amount of

variance explained by the Adolescent Health Belief Model, and, finally, to determine whether the amount of variance accounted for by the two models was significantly different. It was expected that the Adolescent Health Belief Model would explain significantly more variance in medication non-adherence than the Child Health Belief Model. Additionally, the specific components of the model were examined to determine what individual factors were significant predictors of non-adherence. It was expected that perceived susceptibility, perceived severity, higher perceived benefits, lower perceived barriers, higher family support, higher self-efficacy, higher peer support, and higher personal control would predict lower levels of medication non-adherence when disease type was controlled for.

Due to a glitch in the Qualtrics system that could not be rectified even after significant interaction with Qualtrics staff; the perceived susceptibility data were deleted for 44 people. Despite multiple attempts to restore this data and collaboration with the support team from Qualtrics, it was determined that the data were permanently deleted and unable to be recovered. One common approach to missing data is to omit those cases with missing data and to run the analyses on what remains. This approach is usually called listwise deletion, but it is also known as complete case analysis. Whereas this approach does have important advantages, it would result in a substantial decrease in the sample size available for the analyses and, therefore, is an undesirable method. Another option is to employ a pairwise deletion. The complication with this approach is that the parameters of the model will be based on different sets of data, with different sample sizes and different standard errors. Neither of these options is optimal; however, it was determined that as the primary goal of this project was to examine the CHBM in its entirety, perceived susceptibility should remain in the model and that a pairwise deletion approach would be the best method to use with the missing data.

Hypothesis 2A. Hypothesis 2A stated that perceived susceptibility, perceived severity, higher perceived benefits, lower perceived barriers, higher family support, and higher self-efficacy would predict lower levels of medication non-adherence when disease type was controlled for. The model used to test this hypothesis is written below:

2A) Medication Non-Adherence$_{(old\ model)}$ = B_{0A} + B_{1A}Susceptability + B_{2A}Severity + B_{3A}Benefits + B_{4A}Barriers + B_{5A}Family Support + B_{6A} Self-efficacy + B_{7A}Disease Type + Error

This hypothesis was assessed by regressing perceived susceptibility, perceived severity, perceived benefits, perceived barriers, family support, self-efficacy, and disease type on medication non-adherence. The results of the regression indicated that the seven predictors explained 27.5% of the variance (R^2=.28, $F(7,102)$=7.20, p<.001). Next, each coefficient was examined to see if it was significantly related to medication non-adherence while holding the other HBM variables and disease type constant. As anticipated, perceived benefits (β= -.18, p=.05), perceived barriers (β= .32, p=.001), perceived susceptibility (β= -.08, p=.33), and self-efficacy (β= -.23, p=.02) were each significant predictors of non-adherence. Perceived severity trended towards significance (β= -.15, p=.08). Family support (β = -.03, p= .73) and disease type (β= -.05, p= .55) were not significant predictors of non-adherence (Table 4).

Hypothesis 2B. Hypothesis 2B stated that personal control and peer support would be significant negative predictors of non-adherence when they were added to the model listed in Hypothesis 2A. This hypothesis was assessed by adding personal control and peer support to the regression analysis discussed above. This more complete model forms the Adolescent Health Belief Model, and the resulting prediction was tested through the following equation:

2B) Medication Non-Adherence$_{\text{(new model)}}$ = $B_{0B} + B_{1B}$ Personal Control + B_{2B} Peer

Support + B_{3B}Susceptability + B_{4B}Severity + B_{5B}Benefits + B_{6B}Barriers + B_{7B}Family

Support + B_{8B}Self-Efficacy + B_{9B}Disease Type + Error

The results of the regression indicated that the nine predictors explained 28.5% of the variance (R^2=.29, F(9,100)=5.60, p<.001). Next, the coefficients for personal control and peer support were examined to see if they were significantly related to medication non-adherence while holding the other HBM variables and disease type constant. Contrary to hypothesis 2B, neither personal control (β= -.01, p=.91), nor peer support (β= .08, p=.42) were significant predictors of non-adherence (Table 5).

Hypothesis 2C. The aim of hypothesis 2C was to determine if the amount of variance accounted for when personal control and peer support were included in the model was significantly greater than when they were not included in the model. It was hypothesized that the Adolescent Health Belief Model (2B) would explain significantly more variance than the Child Heath Belief Model (2A). The total variance accounted for by the Child Health Belief Model (2A) was R^2 = 27.5% , and the total variance accounted for by the Adolescent Health Belief Model (2B) was R^2 = 28.5%. The AHBM therefore explained 1% more variance than the CHBM. In order to determine if the amount of variance accounted for in the AHBM was significantly greater than the variance accounted for in the CHBM, the following equation was used:

2C) $F = \dfrac{(\text{Regression SS}_{\text{new.model}} - \text{Regression SS}_{\text{old.model}})/\ df_{\text{new.model}}}{\text{Residual MS}_{AB}}$

The F value (the significance of the difference in R^2 between the old and new model) was $F(1, 109)= .32$, $p=.81$. Contrary to hypothesis 2C, the Adolescent Health Belief Model (2B) did not explain significantly more variance than the Child Heath Belief Model (2A).

After further reflection and review of the items on the family support survey (DSSQ-Family Version) and the peer support survey (DSSQ-Friend Version), it was determined that the peer support and family support surveys included questions about both (a) broader illness support as well as (b) medication taking support. As the factors of the CHBM that were significant focused on thoughts about medication specifically, it could be that family and peer support about medication taking specifically are what is important when understanding non-adherence. Therefore, additional analyses were conducted using the medication subscale of the family support survey (DSSQ-Family Version) and one question from the peer support survey that focused on medication taking (DSSQ-Friend Version). The medication subscale consisted of eight questions which assessed the family's emotional and instrumental support around the adolescent's medication taking. The peer support survey consisted of four questions. Three of these questions focused on broader illness support, and one of question focused on medication taking. These new analyses were completed by regressing perceived severity, perceived benefits, perceived barriers, perceived susceptibility, self-efficacy, personal control, disease type, medication specific peer support, and medication specific family support onto non-adherence. The results of the regression indicated that the nine predictors explained 28.7% of the variance ($R^2=.29$, $F(9,100)=5.88$, $p<.001$). The overall model continued to be significant. The modified variables of medication specific peer support ($\beta= .14$, $p=.13$) and medication specific family support ($\beta= .08$, $p=.43$) again were not significant predictors of non-adherence (Table 6).

When examining the frequency with which adolescents engage in these peer support behaviors, the rates were very low. For each of the four questions about peer support, the majority of participants reported that those behaviors never occur (Table 7). Additionally, when examining the frequency with which the adolescents receive family support behaviors, the rates were also very low. For each of the eight questions about family support, the majority of participants reported that those behaviors never occur (Table 8).

Hypothesis 3. Hypothesis 3 examined the moderating role of two coping strategies (denial and positive problem solving). The first two sub-hypotheses examined the potential moderation of the relationship between perceived susceptibility and medication non-adherence. It was hypothesized that when participants experience high perceived susceptibility and engage in denial, they would have high non-adherence (3A). It was also was hypothesized that when participants experience high perceived susceptibility and engage in positive problem solving, they would have low non-adherence (3B). Hypothesis 3A was tested using the moderation model shown below.
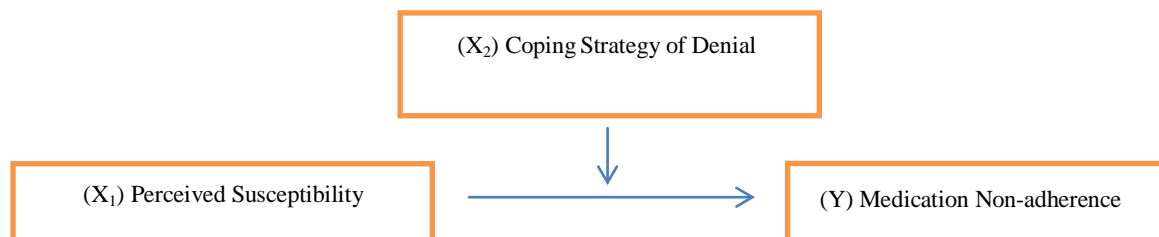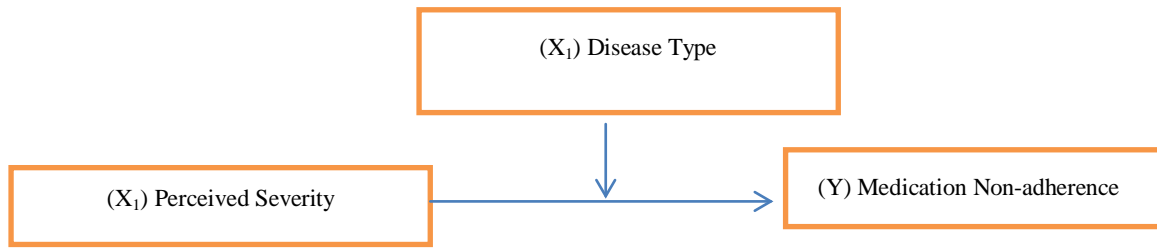

The moderation model stated that perceived susceptibility (X_1) influences medication non-adherence (Y), but the strength of that influence would depend on the value of the moderator – coping strategy of denial (X_2). The regression equation that was used to test the moderation model is written below.

$$\hat{Y} = B_0 + B_1 X_1 + B_2 X_2 + B_3\, X_1\, X_2$$

To determine whether the interaction was statistically significant, the significance level of B_3 was examined. This example illustrated one specific moderator relationship; however, all other moderator relationships were examined in a similar manner. Specifically, for hypothesis 3B these steps were again completed with X_2 being the coping strategy of positive problem solving. Results indicated that neither denial nor positive problem solving moderate the relationship between perceived susceptibility and non-adherence (Table 9).

Hypotheses 3C and 3D examined the potential moderation of the relationship between perceived severity and medication non-adherence. It was hypothesized that when participants experience high perceived severity and engage in denial, they would have high non-adherence (3C). It also was hypothesized that when participants experience high perceived severity and engage in positive problem solving, they would have low non-adherence (3D). The regression equation that was used to test hypothesis 3A and 3B was again used to examine hypothesis 3C and 3D. Specifically, the analyses were completed with X_1 being perceived severity and X_2 being the coping strategy of denial, and again with X_1 being perceived severity and X_2 being the coping strategy of positive problem solving. Results indicated that neither denial nor positive problem solving moderate the relationship between perceived severity and non-adherence (Table 10).

Hypothesis 4. Hypothesis 4 had three different components. Hypothesis 4A stated that the relationship between the perceived severity of short-term consequences and non-adherence would be moderated by disease type. For participants with IBD, it was hypothesized that there would be a significant relationship between perceived severity of the short-term consequences and non-adherence; however, it was hypothesized that this would not be the case for those with CKD. This hypothesis was tested using the moderation model shown below.

The moderation model stated that perceived severity (X_1) would influences medication non-adherence (Y), but the strength of that influence depends on the value of the moderator – disease type (X_2). The regression equation that was used to test the moderation model is written below.

$$\hat{Y} = B_0 + B_1 X_1 + B_2 X_2 + B_3 \ X_1 \ X_2$$

To determine whether the interaction is statistically significant, the significance level of B_3 was examined. The findings support hypothesis 4A (R^2=.12, $F(3,106)$=5.97, p<.001), such that disease type (B_3) moderated the relationship (β=.86, p=.05) between perceived severity and non-adherence (Table 11). For participants with IBD, there was a significant relationship between perceived severity of the short-term consequences and non-adherence; however, this was not the case for those with CKD.

Hypothesis 4B stated that the relationship between perceived benefits and non-adherence would be moderated by disease type. For participants with IBD, it was hypothesized that there would be a significant relationship between perceived benefits and non-adherence; however, it was hypothesized that this would not be the case for those with CKD. The regression equation that was used to test hypothesis 4A also used to examine hypothesis 4B. Specifically, the analyses were completed with X_1 being perceived benefits and X_2 being disease type. To determine whether the interaction is statistically significant, the significance level of the

interaction (B_3) was examined. The findings support hypothesis 4B ($R^2=.19$, F(3,106)=8.39, $p<.001$), such that disease type (B_3) moderated the relationship ($\beta=1.19$, p=.02) between perceived benefits and non-adherence (Table 11). For participants with IBD, there was a significant relationship between perceived benefits and non-adherence; however, this was not the case for those with CKD.

Hypothesis 4C stated that the relationship between personal control and non-adherence would be moderated by disease type. For participants with CKD, it was hypothesized that the long-term consequences of personal control would be more important when predicting medication non-adherence when compared to individuals with IBD. The findings did not support hypothesis 4C ($R^2=.005$, F(3,59)=1.10, $p=.36$). Disease type did not (B_3) moderate the relationship ($\beta=.67$, p=.19) between personal control and non-adherence (Table 12).

CHAPTER 4: DISCUSSION

For individuals with a chronic illness, medication taking has been identified as the key component to successful illness management (Finea et al., 2009). When medication is taken in accordance with a doctor's recommendations, it can aid in symptom management and slow disease progression. Despite the clear benefits that medications can offer, approximately 55% of pediatric populations do not take their medications as prescribed, or are non-adherent (Dunbar-Jacob & Mortimer-Stephens, 2001; La Greca & Bearman, 2003; Rapoff, 1999). Medication non-adherence can be measured and defined in a number of different ways; however, studies consistently indicate that negative consequences such as graft loss, hospitalizations, and death can result (Dew et al., 2001; Falkenstein, Flynn, Kirkpatrick, Casa-Melley, & Dunn, 2004; Kelly & Kalichman, 2002; Rohan et al., 2010; Sudan, Shaw, & Langnas, 1997; Van Dyke et al., 2002). Non-adherence occurs across all ages, but it is most likely to occur during adolescence. Not only is adolescence the age when non-adherence is most likely to occur, it is also the time period when physiologically there is an increased risk for disease progression (Gordeuk et al., 2008; Seiffge-Krenke, 1998; Sweet et al., 2006). Consequently, many national consensus reports and conference proceedings have highlighted the need to better understand factors leading to and preventing against non-adherence in adolescence (Finea et al., 2009). Some authors have proposed that the best way to understand non-adherence is to have a conceptual model of the phenomenon (La Greca, 1990). Despite this call for a conceptual model, adolescents have been widely overlooked in the non-adherence literature, and no models to date have been modified or created to understand adolescent non-adherence.

Thus, the current investigation sought to fill this gap in the literature by first examining how to empirically measure non-adherence, evaluating a currently existing non-adherence model (the child health belief model), and finally by both proposing and evaluating a developmentally appropriate model. First a brief overview of the study's findings will be reviewed. This will be followed by a more through interpretation of the findings, discussion of the study's limitations, and review of potential clinical implications.

As medication non-adherence can be measured in a number of different ways, the first aim of this study was to characterize non-adherence. Results indicated that the four different measures of non-adherence map onto the same underlying latent variable, and, thus, a CFA was used to calculate individual factor scores. Once the measure of non-adherence was established, the CHBM was analyzed. It was determined that the CHBM as a whole was a significant predictor of medication non-adherence and that perceived benefits, barriers, and self- efficacy were each significant predictors of non-adherence. Perceived severity trended towards significance; however, family support and perceived susceptibility were not significant predictors of non-adherence. Thus, there is empirical evidence for using the CHBM in adolescents. Finally, the AHBM was examined. It was determined that the AHBM as a whole was a significant predictor of medication non-adherence, but that it did not account for significantly more variance than the CHBM. Additionally, neither of the two factors added to the AHBM (peer support and personal control) were significant predictors of non-adherence. Thus this study does not provide support for the use of the AHBM over the CHBM.

As the basis of this study was to gain a more complete understanding of factors that predict non-adherence, it was important to first address how to best measure non-adherence. There is not an agreed upon method to measure non-adherence in the literature; nor is there a

gold-standard approach. Some authors propose that subjective measures of non-adherence (self-report, caregiver report) are best, whereas other authors highlight the objective nature of methods such as medication refill rates and blood levels (Nakonezny et al., 2010). As each of these methods have unique strengths and weaknesses, this study incorporated both objective and subjective measures of non-adherence and began by examining how these different methods were related to each other. Prior research indicated that objective measure of non-adherence (MPR) result in higher rates of non-adherence than subjective measures of non-adherence (doctor report, self-report, caregiver report; Dimatteo, 2004). It was hypothesized that rates of non-adherence would be highest when they were gathered by MPR, followed by doctor report, caregiver report, and finally self-report. Results partially supported this hypothesis. The MPR data indicated the highest rate of non-adherence, followed by the doctor report, self-report, and finally caregiver report. The lowest two ratings of non-adherence were the self-report and caregiver report. As prior studies have shown that social desirability influences self-report data, it was hypothesized that the adolescents' non-adherence rating would be influenced by social desirability (Arnold & Feldman, 1981; Mortel, 2008). Additionally, given the current order of the non-adherence data, it may be that adolescents are providing their caregiver's more socially desirable responses when reporting their medication taking. No studies to date have examined if social desirability is a significant predictor of non-adherence; however, many authors have proposed that it may be playing an explanatory role in low non-adherence ratings (Malee et al., 2009).

The results indicate that whereas a number of adolescents were high on social desirability, it was not related to their non-adherence ratings or to their caregiver's non-adherence ratings. This result is contrary to the hypothesis. This finding might suggest that

adolescents are not minimizing their non-adherence report to appear more socially desirable; their reports might, in fact, reflect their subjective experience. When they think back on the last week, they may not remember when they missed their medications; rather, their intention to take them may be more pronounced in their memory. As social desirability was not playing a role in predicting non-adherence, it was not included in any of the subsequent analyses.

The descriptive data obtained regarding the different measures of non-adherence provides a broader understanding of the relationships among the four measures. As these measures of non-adherence are each seeking to capture the same underlying latent variable of true non-adherence, both objective and subjective measures should map onto the same latent variable. Despite this fact, no studies to date have used a CFA to examine multiple measures of non-adherence at once. A CFA affords several advantages over other analytic techniques in that it allows for the specification of causal relationships among observed variables and latent constructs, while simultaneously accounting for item-level measurement error (Bryant & Yarnold, 1995). It was hypothesized that all four factors would load onto the same underlying latent factor. The results supported this hypothesis, as the model is an acceptable fit for the data, and a one-factor solution was derived. Therefore a methodology that incorporates both subjective and objective measures of non-adherence appears to be a valuable approach to employ in future investigations.

Although some of the loadings are lower than desired, the overall indices were acceptable, and, therefore, it seemed justifiable to use the factor scores for further analyses. The factor scores derived from the CFA were used in all subsequent analyses as the primary dependent variable. This innovative approach allows for multiple different reports of non-adherence to be taken into account at once and helps to minimize the likelihood of a type I error occurring. Once it was determined that the factor scores would be used as the primary measure

of non-adherence, the model that incorporates a variety of factors believed to be important in non-adherence was examined.

Many models for understanding health behaviors exist within the health literature. One model that has been frequently used to examine health behaviors is the child health belief model (Bush & Iannotti, 1990). This model examines how cognitive factors may facilitate or hinder a child from engaging in a specific health behavior. This model was originally constructed to conceptualize preventative health behaviors, but it has been expanded to understand non-adherence (Barclay et al., 2007). While the non-adherence literature overall has not been model driven, when a model is employed to investigate non-adherence, the CHBM is most frequently used. Across a number of studies, results support the use of the individual factors of the CHBM in predicting non-adherence. The model as a whole, however, has not been examined in its entirety relative to non-adherence. Rather, only one or two specific factors in the model have been examined at a time. The current investigation allowed for a more comprehensive understanding of medication non-adherence by examining all factors of the CHBM simultaneously. This approach allows for the relative contribution of each factor to be examined, as well as the significance of the overall model itself to be tested.

It was hypothesized that perceived susceptibility, perceived severity, higher perceived benefits, lower perceived barriers, higher family support, and higher self-efficacy would predict lower levels of medication non-adherence when disease type is controlled for. Results indicate that this hypothesis was partially supported. The CHBM as a whole was statistically significant, and the factors of perceived benefits, perceived barriers, and self-efficacy were each statistically significant predictors of non-adherence, above and beyond the other predictors in the model. Perceived severity trended towards significance. Conversely, perceived susceptibility and family

support were not significant. These findings suggest that perceived benefits, barriers, and self-efficacy are the key factors when understanding non-adherence. In order to understand these findings, a conceptual interpretation of the significant factors will be provided first. This will be followed by an explanation of the factors that that were not significant.

The three significant predictors of non-adherence were adolescents' perceived benefits, perceived barriers, and self-efficacy regarding taking their medications. These factors focused on medication specifically, and are both concrete and proximal to the target behavior of not taking a medication as prescribed. The significant predictors focus on how the medication tastes, if the medications are difficult to swallow, if the medications relieve symptoms, and if the adolescents can adhere to their medication regimen even when they are busy. These findings are consistent within a broader context of what is known about adolescents generally. Many studies have indicated that adolescents are more focused on the present than the future. This may be why perceived severity and susceptibility are not significant predictors of non-adherence. Both of these factors require the adolescent to think about future implications and predict the likelihood of an event.

Perceived severity trended towards significance when it was put into the model with the other factors. There are two alternate explanations for why perceived severity appears to be less important in predicting non-adherence. It may be that perceived severity does, in fact, not play a significant role in understanding non-adherence. Prior studies have found that perceived severity is a significant predictor of non-adherence (Bond et al., 1992; Brownlee-Duffeck et al., 1987; Reed-Knight et al., 2010), but this has been one of the least researched factors in the model. Alternatively, the results might be the result of multicollinearity of predictor variables. When perceived severity was entered into the regression model by itself, it was a significant predictor

59

of non-adherence. When it was entered into the multiple regression model with all of the factors of the CHBM, it was not significant. This pattern suggests that multicollinearity is occurring between perceived severity and the other predictor variables. To further understand if multicollinearity was occurring, the correlations among perceived severity and perceived benefits, perceived barriers, self-efficacy were examined. Each correlation was small to moderate; therefore, multicollinearity cannot be ruled out nor can it be identified as the primary reason for the lack of predictability of perceived severity.

The other individual factor that was not a significant predictor of non-adherence is perceived susceptibility. Due to an error in the Qualtrics system that could not be rectified even after significant interaction with Qualtrics staff, the perceived susceptibility data were deleted for 44 people. The power analysis that was conducted prior to the start of this investigation determined that 105 participants were needed for adequate power. Consequently, it may be that there is not enough power to detect a relationship between perceived susceptibility and non-adherence, even if one in fact exists. Future studies will need to examine further whether perceived severity and susceptibility play a unique role in non-adherence, and how to best measure these constructs.

Family support is the final factor that was not a significant predictor of non-adherence. This factor differs from the other factors in that it does not focus on the adolescent's thoughts and feelings about the medication, the possible negative consequences if they do not take their medications, or their perceived ability to implement the medication regimen. Rather, this domain focuses on the adolescent's perception of *other* people's thoughts and behaviors, specifically, their family's support in facilitating medication taking (Bush & Iannotti, 1990). Contrary to what was hypothesized, family support was not a significant predictor of non-adherence. Examining

the frequency with which these behaviors occurred, it was determined to be a relatively rare occurrence. Many adolescents reported that they never or very rarely experience some of these support behaviors. In addition to the medication support questions, the family's broader illness support also was examined. These broader family support behaviors did not predict the adolescent's non-adherence, and they also never or very rarely occur. These findings suggest that the adolescent's individual thoughts and beliefs may be more important than their perception of the family's support. Whereas prior investigations found that the family's support was a significant predictor of non-adherence, these studies were conducted in children (Hsin, La Greca, Valenzuela, Moine, & Delamater, 2010; Lewin et al., 2006; Reed-Knight, Lewis, & Blount, 2010; Tucker et al., 2002). Children may require the family's direct support in a way that is different from adolescents.

There are many clinical implications to the pattern of findings that non-adherence is predicted from concrete, here-and-now issues in adolescents' lives. Interventions targeted to address non-adherence should focus on these concrete and proximal behaviors. For example, if an adolescent reports a specific barrier to taking their medications, such as not liking the taste of the medication, providers should collaborate with the adolescent to solve the barrier. If these barriers cannot be solved, it may be beneficial to encourage the adolescent to identify concrete benefits to taking their medications. Additionally, when adolescents report many barriers and few benefits to their medications, physicians and healthcare providers should know that these adolescents may require additional support to maintain their regimen. Examining the factors of the CHBM allowed this investigation to determine that perceived benefits, barriers, and self-efficacy are critical when predicting non-adherence. At the same time, because these data are

cross sectional, cause-effect relationships cannot be determined, so the above suggestions must be viewed cautiously.

This is the first study to propose a developmentally appropriate model to conceptualize non-adherence in adolescents. Adolescents report being the primary person in charge of their medications, and, therefore, the self-control they feel may be important when predicting non-adherence (Bandura, 1997). Not only do adolescents take more responsibility for their illness and medications than children, they spend less time with their family. In fact, as youth move from late childhood to early adolescence, their main source of social support shifts to their peers (Kerns, Contreras, & Neal-Barnett, 2000). Due to these prior findings, it was hypothesized that personal control and peer support would be significant negative predictors of non-adherence when they were added to the CHBM. This new more complete model (the adolescent health belief model; AHBM) was hypothesized to account for significantly more variance in medication non-adherence than the CHBM.

Results indicate that the AHBM is a significant model for predicting non-adherence; however, neither personal control nor peer support were significant predictors of non-adherence. Additionally, when the variance explained by the AHBM was compared to the variance explained by the CHBM, it was determined that they were not significantly different. This suggests that while the model as a whole remained significant, the addition of peer support and personal control were not supported by the current study's results. Peer support may not have been significant because, similar to family support, it was a behavior that occurred with surprisingly low frequency. In fact, the majority of participants reported that the peer support behaviors occur never and less than 10% reported that they occur daily. These findings might indicate that among adolescents, the topic of taking medications does not surface in conversation

very often. Given that peer support behaviors focused on medication occur so infrequently, they might not have a significant effect on non-adherence. It may be that broader peer support is important, not support for the adolescent's illness or medications specifically. Alternatively, it may be that peer support is not an important factor when predicting non-adherence. Adolescents might believe that taking their medications is important enough that they do not seek out peer support for the behavior and take their medications regardless of what their peers think. Whereas peer relationships are important at this time of life in general, this does not mean that peer support has implications for all domains of functioning among adolescents. Medication might be a domain that does not enter into peer interactions, or peers' responses might not be a salient factor in non-adherence.

Also contrary to what was hypothesized, personal control was not a significant predictor of non-adherence. Prior studies have found that when predicting health behaviors, knowing both a person's self-efficacy and a person's personal control predict significantly more variance than knowing either of these factors alone (Bandura, 1997). However, the results from the current investigation did not support these prior findings. Personal control may not be a significant factor because of multicollinearity among predictors. When personal control was entered into the regression model by itself, it was a significant predictor of non-adherence. When it was entered into the multiple regression model with all of the factors of the AHBM, it was not significant. Additionally, the individual strength of perceived benefits as a predictor decreased when personal control was added to the model. These two variables were significantly moderately correlated with each other; therefore, it may be that personal control is not adding any new information that perceived benefits is not already accounting for. This suggests that personal control and perceived benefits are capturing similar variance when explaining non-adherence.

Upon additional examination of specific items, it appears that both of these scales posed very similar questions. Future research should continue to examine whether personal control plays a unique role in understanding non-adherence.

An additional aim of this study was to examine a possible explanation for previously conflicting results across investigations. Prior research has consistently found significant associations among perceived severity, susceptibility, and non-adherence; however, the pattern of associations among these factors has differed across studies. Some investigations have found a positive relationship whereas others have found a negative relationship. These mixed findings may be the result of a moderator (i.e., coping style) that leads to seemingly inconsistent findings. Exploration of potential moderator effects may provide some insight into the role that perceived susceptibility and severity play in predicting non-adherence. More specifically, different adolescents have equally high levels of perceived susceptibility and severity, but some adolescents engage in one type of coping whereas other adolescents engage in another type of coping. These different coping strategies might then result in different levels of non-adherence.

It was hypothesized that when adolescents experience high perceived susceptibility or severity and engage in positive problem solving, they are more likely to take their medications (Tercyak, Goldman, Smith, & Audrain, 2002). On the other hand, when adolescents experience high perceived susceptibility or severity and use the coping strategy of denial, they will be less likely to take their medications. However, the results did not support these hypotheses. The coping strategies of positive problem solving and denial did not moderate the relationship between perceived susceptibility and non-adherence, or the relationship between perceived severity and non-adherence. These findings may indicate while in theory different coping strategies could account for these discrepant findings from earlier investigations, the hypothesis

64

simply is incorrect. Alternatively, it could be that different coping strategies account for these different findings, but the measures used did not fully capture positive problem solving and denial. Prior investigations have indicated that people most accurately report their coping strategies when they think of a specific event. However, the scale used in this study asked adolescents how they cope with taking their medications in general; asking about specific incidences might have yielded different findings. Additionally, adolescents use a broad range of coping strategies (Thompson & Gustafon, 1996). Whereas the current investigation focused on individual coping strategies, it might be more productive in future studies to examine coping strategies such as wishful thinking, emotional regulation, and cognitive restructuring both individually and in combination.

Across the two chronic illnesses being examined in this investigation, there are multiple differences in both the short-term and long-term consequences of non-adherence. Based on how adolescents might experience these two disorders differently, a secondary hypothesis examined whether specific components of the AHBM model were differentially important in predicting non-adherence across the two illness groups. Because individuals with IBD experience strong negative, immediate consequences when non-adherent, the perceived severity of these short-term consequences and the perceived benefits of the medication may be particularity important factors in predicting non-adherence for this group. It was hypothesized that the relationship between the perceived severity of the short-term consequences and non-adherence would be moderated by disease type. For participants with IBD, it was proposed that there would be a strong relationship between the perceived severity of short-term consequences and non-adherence; however, this was not thought to be the case for those with CKD. Results supported this hypothesis. Additionally, it was hypothesized that the relationship between the perceived benefits of the

short-term consequences and non-adherence would be moderated by disease type. More specifically, for participants with IBD, it was predicted that there would be a strong relationship between the perceived benefits of short-term consequences and non-adherence; however, this would not be the case for those with CKD. Results also supported this hypothesis. These results indicate that for adolescents with IBD, the perceived benefits and the severity of short-term consequences are especially important. When patients with IBD do not take their medications, they have multiple, direct, adverse physiological reactions that remind them to take their medications. If adolescents perceive these consequences to be severe and their medications to help, they may have lower rates of non-adherence. These findings indicate that some disease specific factors should be taken into account when trying to understand whether adolescents will adhere to medication plans. However, other factors may not be differentially important across diseases. While it was hypothesized that for participants with CKD, the long-term consequences of personal control would be more important when compared to individuals with IBD, these findings were not supported. This may suggest that personal control does not operate differentially across these two illnesses.

Whereas the above findings provide increased understand of medication non-adherence among adolescents with different chronic diseases, there also are limitations in the current study that merit discussion. First, this investigation is a cross-sectional examination of the factors in the CHBM and the AHBM that relate to non-adherence. Whereas the hypotheses are predicated upon a causal process in which the factors of the CHBM or the AHBM influence the adolescent's medication non-adherence, 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 non-adherence of the adolescent

influences their thoughts and beliefs about their medications. Likewise some unexplored third variable could explain the above associations. 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 catchment area for the hospital is quite large given its role in the treatment of adolescents in NC. Patients' families often drive from long distances to reach the hospital, and the sample includes a range of economic statuses, races, ages, as well as two illness populations. In addition, the results should not be generalized to adolescents with other chronic illnesses or multiple co-morbid chronic illnesses as both the current findings and previous studies suggest that non-adherence may operate differently in different illness populations (Lewis & Klieweser, 1996; Miller et al., 2009). Future studies should include multi-site investigations, along with adolescents with other chronic illnesses or multiple co-morbid chronic illnesses. Such investigations would allow for exploring factors within the CHBM and the AHBM that are common across diseases as well as factors unique to each disease.

In addition to these limitations, the current investigation also incorporates a number of unique and innovative components. This study is the most comprehensive examination of non-adherence conducted to date. It took into account both caregiver-report, provider-report, adolescent-report, and MPR while also conducting a CFA to examine if these factors represent the same underlying latent variable. No previous investigations to date have examined non-adherence using a CFA data analysis strategy. Also, the non-adherence literature generally has not relied upon theoretical models to predict non-adherence. This is the first study to examine the

entire CHBM at once when predicting non-adherence. As a result, the relative contribution of each factor in the model could be examined as well as the model as a whole could be evaluated. The current study also is the first to propose a developmentally appropriate model to conceptualize non-adherence among adolescents. As adolescence is a unique developmental period, this study incorporated these developmental factors and examined the model in two different illness populations. Finally, this is one of the first studies to examine whether the different short-term and long term consequences of non-adherence resulted in the factors of the CHBM being differentially important for two diseases. The clinical implications of this study are important to note as many factors associated with a chronic illness cannot be changed, but the cognitive factors of the CHBM can be modified to produce better adherence.

Concrete, proximal, cognitive factors may be central when trying to understand an adolescent's non-adherence. This is critical for healthcare providers to know as many physicians emphasize the long term negative consequences that can result if an adolescent does not take his/her medication or future potential side-effects. However, the current results indicate that these factors may not be of central importance to the adolescent when considering taking their medication. Instead, the provider should emphasize the current benefits of taking the medication and help the adolescent to problem solve to minimize barriers.

In a field that is rarely theoretically driven, this study provides empirical evidence for the value of using models when designing and implementing studies examining non-adherence. The cognitive factors in the CHBM are relevant across different disease populations, and the various components of the model are differentially important given the specific symptoms of the illness. For illnesses with immediate consequences of non-adherence short term factors such as short-term severity and benefits are especially important. This innovative study has important

implications for how to best measure, conceptualize, and provide interventions for medication

non-adherence among adolescents.

Table 1

Descriptive Data on the Total Sample, the Chronic Kidney Disease (CKD) Sample and the Inflammatory Bowel Disease (IBD) Sample

Demographic characteristic	Total Sample (n=110)	CKD (n=55)	IBD (n=55)	ANOVA results – comparing CKD sample to IBD sample
Race				$F(1, 108) = 15.71$, p <.001
White	62	18	44	
AFAM	34	26	8	
Hispanic	9	9	0	
Native American	4	1	3	
Asian	1	1	0	
Gender				$F(1, 108) = .91$, p =.34
Male	51	28	23	
Female	59	27	32	
Age				$F(1, 108) = 4.66$, p =.03
Mean	16.92	17.31	16.53	
Standard deviation	(±1.93)	(±2.05)	(±1.74)	
Insurance				$F(1, 108) = 18.06$, p <.001
Private	61	19	42	
Public	42	30	12	
Self-pay	4	4	0	
Public & Private	3	2	1	
Do you have a job?				$F(1, 108) = .20$, p =.66
Yes, full time	5	5	0	
Yes, part-time	13	4	9	
Yes, part-time seasonal	11	4	7	
No	81	42	39	
Number of medications				$F(1, 108) = 22.91$, p <.001
Mean	5.02	6.36	3.67	
Standard deviation	(±3.23)	(±3.65)	(±2.02)	
Provider rating disease severity				$F(1, 79) = 3.84$, p=.05
Mean	17.10	18.08	15.52	
Standard deviation	(±5.83)	(±6.72)	(±3.56)	
Stage of CKD				--
Stage 5	-	25	-	
Dialysis	-	5	-	
Transplant	-	20	-	
Transplant & Dialysis	-	1	-	
Stage 4	-	8	-	
Stage 3	-	10	-	
Stage 2	-	12	-	

Table 2

Percent Non-Adherence

Type of non-adherence measured	Total Sample	CKD	IBD	ANOVA results – comparing CKD sample to IBD sample

Caregiver's % non- adherence:
    Mean
    Standard deviation
	13.95
	(±20.08)
		14.22
		(±22.30)
			13.70
			(±17.94)
				F(1, 103) = .02, p =.90

Adolescent's % non- adherence:
    Mean
    Standard Deviation
	16.91
	(±16.18)
		18.00
		(±14.71)
			15.82
			(±17.61)
				F(1, 108) = .50, p =.48

Doctor's % non-adherence:
    Mean
    Standard Deviation
	18.46
	(±19.03)
		19.53
		(±21.11)
			17.41
			(±16.87)
				F(1, 105) = .33, p =.57

Non-adherence % calculated by MPR:
    Mean
    Standard Deviation
	44.17
	(±30.00)
		44.93
		(±31.40)
			43.36
			(±29.73)
				F(1, 97) = .07, p=.80

Non-adherence % calculated by Medicaid portal:
    Mean
    Standard Deviation
	22.36
	(±22.44)
		22.86
		(±23.72)
			21.87
			(±20.64)
				F(1, 20) = .124, p= .93

Table 3

Confirmatory Factor Analysis (CFA) Model Results

	Standardized Model Results		Unstandardized Model Results	
Factor	Estimate (S.E.)	p value	Estimate (S.E.)	p value
MPR	.27(±.12)	.018	8.24(±3.63)	.023
Adolescent	.81(±.25)	.001	13.29(±4.26)	.002
Doctor	.22(±.15)	.143	4.13(±2.86)	.149
Caregiver	.53(±.18)	.002	10.67(±3.71)	.004

Table 4

Analysis of Hypothesis 2A - The Child Health Belief Model

Variable	B	SE	β
Perceived benefits	-.023	.012	-.182**
Perceived barriers	.024	.007	.316***
Perceived susceptibility	-.019	.019	.082
Perceived severity	-.025	.014	-.152*
Self-efficacy	-.011	.005	-.232**
Family support	-.001	.003	-.031
Disease type	-.086	.144	-.051

*p≤ .10, **p ≤ .05, ***p ≤ .001.

Table 5

Analysis of Hypothesis 2B - The Adolescent Health Belief Model

Variable	B	SE	β
Perceived benefits	-.024	.013	-.186*
Perceived barriers	.024	.007	.317***
Perceived susceptibility	.016	.019	.071
Perceived severity	-.026	.014	-.158*
Self-efficacy	-.012	.005	-.244**
Family support	-.002	.003	-.055
Disease type	-.065	.149	-.039
Peer support	.022	.028	.075
Personal control	-.002	.021	-.011

*p≤ .10, **p ≤ .05, ***p ≤ .001.

Table 6

Analysis of Model Including Medication Specific Peer and Family Support

Variable	B	SE	β
Perceived benefits	-.022	.013	-.174*
Perceived barriers	.024	.007	.321***
Perceived susceptibility	.014	.019	.062
Perceived severity	-.027	.014	-.164**
Self-efficacy	-.013	.005	-.261**
Family support medication specific	-.003	.003	-.076
Disease type	-.045	.148	-.027
Peer support medication specific	.035	.022	.140
Personal control	-.001	.021	-.006

*p≤ .10, **p ≤ .05, ***p ≤ .001.

Table 7

Frequency of Peer Support Behaviors

Question:	The number of people who selected each response (total n=110)					
----	Never	< 2 times a month	2 times a month	Once a week	Several times a week	Once a day
How often does a friend listen to concerns or worries about your illness?	33	17	11	17	21	11
How often does a friend encourage you to do a good job taking care of your illness?	40	11	14	16	18	11
How often does a friend understand when you sometimes make mistakes in taking care of your illness?	50	16	7	8	19	10
How often does a friend understand how important it is for you to take your medications?	41	7	16	19	17	10

Table 8

Frequency of Family Support Behaviors

Question:	The number of people who selected each response (total n=110)					
----	Never	< 2 times a month	2 times a month	Once a week	Several times a week	Once a day
How often does a family member let you know they appreciate how difficult it is to take medications?5	30	16	12	18	18	16
How often does a family member praise you for taking your medications correctly or on time? 6	40	8	11	13	21	17
How often does a family member give you your medications?7	71	7	3	12	10	7
How often does a family member remind you to take your medications?8	30	12	10	22	22	14
How often does a family member help out when you take your medications?9	59	7	8	12	12	12
How often does a family member wake up so that you can take your morning medications on time? 10	73	6	4	6	10	11
How often does a family member change their own schedule to get an early start too, when you have to take morning medications?11	76	7	2	5	10	10
How often does a family member check after you've taken our medications to make sure you have done it?12	40	12	4	15	15	24

Table 9

Hypothesis 3A and 3B - Regression Results Examining if Denial or Positive Problem Solving were Moderating the Relationship Between Perceived Susceptibility and Non-Adherence

Variable	B	SE	B
Perceived susceptibility	-.024	.026	-.106
Denial	.022	.123	.043
Perceived susceptibility by denial	-.002	.009	-.044

Dependent variable: medication non-adherence
*p≤ .10, **p ≤ .05, ***p ≤ .001.

Variable	B	SE	β
Perceived susceptibility	-.042	.028	-.185
Positive problem solving	-.068	.060	-.199
Perceived susceptibility by positive problem solving	.005	.006	.137

Dependent variable: medication non-adherence
*p≤ .10, **p ≤ .05, ***p ≤ .001.

Table 10

Hypothesis 3C and 3D - *Regression Results Examining if Denial or Positive Problem Solving were Moderating the Relationship Between Perceived Severity and Non-Adherence*

Variable	B	SE	β
Perceived severity	.001	.018	.005
Denial	.073	.157	.139
Perceived severity by denial	-.004	.007	-.151

Dependent variable: medication non-adherence
*p≤ .10, **p ≤ .05, ***p ≤ .001.

Variable	B	SE	β
Perceived severity	-.016	.018	-.101
Positive problem solving	-.187	.124	-.543
Perceived severity by positive problem solving	.009	.007	.483

Dependent variable: medication non-adherence
*p≤ .10, **p ≤ .05, ***p ≤ .001.

Table 11

Hypothesis 4A and 4B- Regression Results Examining if Disease Type was Moderating the Relationship Between Perceived Severity or Perceived Benefits and Non-Adherence.

Variable	B	SE	β
Perceived severity	.026	.038	.188
Disease type	1.001	.606	.598
Perceived severity by disease type	-.049	.025	-.860**

Dependent variable: medication non-adherence
*p≤ .10, **p ≤ .05, ***p ≤ .001.

Variable	B	SE	β
Perceived benefits	.025	.034	.199
Disease type	1.602	.779	.957**
Perceived benefits by disease type	-.053	.023	1.190**

Dependent variable: medication non-adherence
*p≤ .10, **p ≤ .05, ***p ≤ .001.

Table 12

Hypothesis 4C- Regression Results Examining if Disease Type was Moderating the Relationship Between Personal Control and Non-Adherence.

Variable	B	SE	β
Personal control	.064	.072	.368
Disease type	.582	.536	.342
Personal control by disease type	.059	.044	.671

Dependent variable: medication non-adherence
*p≤ .10, **p ≤ .05, ***p ≤ .001.

Figure 1

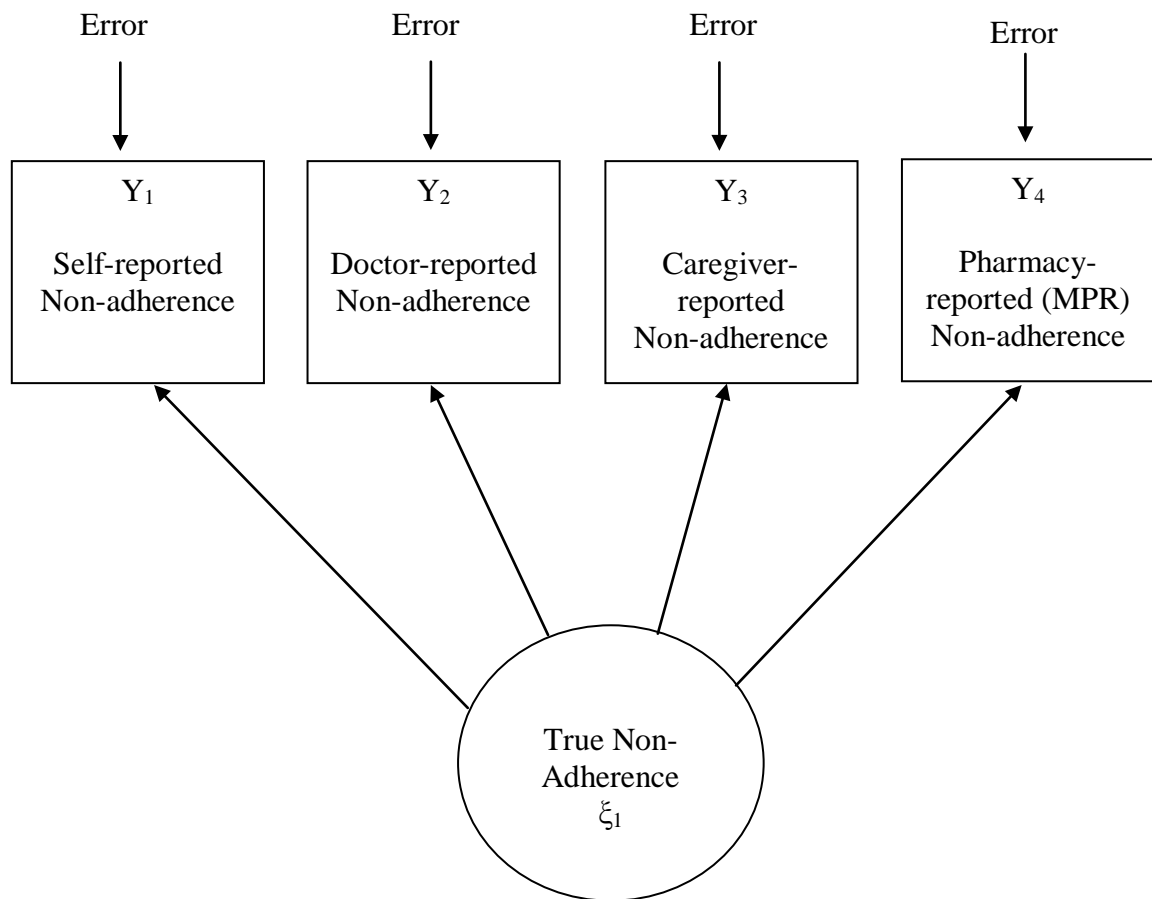*Depiction of the Four Non-Adherence Variables Loading onto the One Latent Construct*
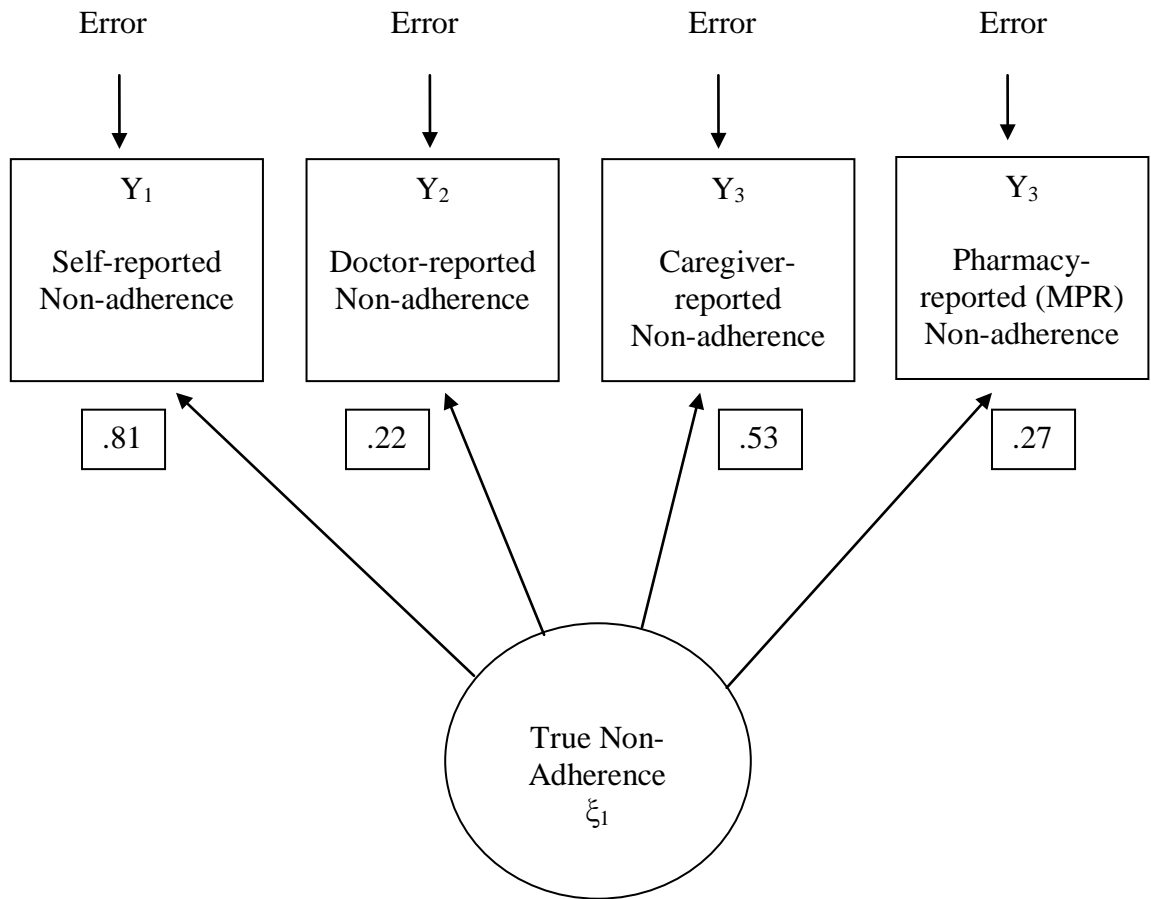
Figure 2

Depiction of the Four Non-Adherence Variables with the Standardized Factor Loadings

REFERENCES

Andrade, S. E., Kahler, K, H., Frech, F., & Chan, K. A. (2006). Methods for evaluation of medication adherence and persistence using automated databases. *Pharmacological Epidemiological Drugs, 15*(8), 565-74.

Ardissino, G., Daccò, V., Testa, S., Bonaudo, R., Claris-Appiani, A., Taioli, E., Marra, G., Edefonti, A., & Sereni, A. (2003). Epidemiology of chronic renal failure in children: Data from the ItalKid project. *Pediatrics, 111(4),* e382 -e387. doi:10.1542/peds.111.4.e382

Arnett, J. (1992). Reckless behavior in adolescence: A developmental perspective. *Developmental Reviews, 12,* 339–373. doi:10.1016/0273-2297(92)90013-R

Arnold, H. J., & Feldman, D. C. (1981). Social desirability response bias in self-report choice situations. *The Academy of Management Journal, 24*(2), 377-385.

Ballard., L. (1992). Short forms of the Marlowe-Crowne social desirability scale. *Psychological Reports, 71,* 1155-1160.

Bandura, A. (1986). Social foundations of thought and action: A social cognitive theory. Englewood Cliffs, NJ: Prentice-Hall.

Bandura, A. (1997). Self-Efficacy: The Exercise of Control. New York: W.H. Freeman.

Barclay, T. R., Hinkin, C. H., Castellon, S. A., Mason, K. I., Reinhard, M. J., & Marion, S. D. (2007). Age associated predictors of medication adherence in HIV-positive adults: Health beliefs, self-efficacy, and neuro-cognitive status. *Health Psychology, 26(1),* 40-49. doi:10.1037/0278-6133.26.1.40

Bartlett, M. S. (1950). Tests of significance in factor analysis. *British Journal of Statistical Psychology, 3,* 77-85.

Bearman, K., & La Greca, A. (2002). Assessing friend support of adolescents' diabetes care: The diabetes social support questionnaire-friends version. *Journal of Pediatric Psychology, 27(5), 417-428.* doi: 10.1093/jpepsy/27.5.417

Beck, A. T. (1997). The past and future of cognitive therapy. *Journal of Psychotherapy Practice and Research*, *6,* 276–284.

Bender, B.G., & Rand, C. (2004). Medication non-adherence and asthma treatment cost. *Current Opinion in Allergy and Clinical Immunology, 4,* 191–195. doi:10.1097/00130832-200406000-00009

Bender, B., Wamboldt, F. S., O'Connor, S. L., Rand, C., Szefler, S., Milgrom, H., et al. (2000).

Measurement of children's asthma medication adherence by self report, mother report, canister weight, and Doser CT. *Annals of Allergy, Asthma, & Immunology, 85,* 416– 421. doi:10.1016/S1081-1206(10)62557-4

Bond, G. G., Aiken, L. S., & Somerville, S. C. (1992). The health belief model and adolescents with insulin dependent diabetes mellitus. *Health Psychology, 11,* 190–198. doi:10.1037/0278-6133.11.3.190

Brener, N., Kann, L., Garcia, D., MacDonald, G., Ramsey, F., Honeycutt, S., et al. (2007). Youth risk behavior surveillance—Selected steps communities, 2005. *MMWR Surveillance Summary, 56(2),* 1–16.

Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The brief illness perception questionnaire (BIPQ). *Journal of Psychosomatic Research, 60,* 631–637. doi:10.1016/j.jpsychores.2005.10.020

Bronfenbrenner, U. (1979). The ecology of human development. Cambridge, MA: Harvard University Press.

Brownlee-Duffeck, M., Peterson, L., Simonds, J. F., Goldstein, D., Kilo, C., & Hoette, S. (1987). The role of health beliefs in the regimen adherence and metabolic control of adolescents and adults with diabetes mellitus. *Journal of Consulting and Clinical Psychology, 55,* 139–144. doi:10.1037/0022-006X.55.2.139

Buchanan, R. L., & Bowen, G. L. (2008). In the context of adult support: The influence of peer support on the psychological well-being of middle-school students. *The Journal of Child and Adolescent Social Work, 25,* 397–407. doi:10.1007/s10560-008-0143-z

Bucks, R. S., Hawkins, K., Skinner, D. T., Horn, S., Seddon, P., & Horne, R. (2009). Adherence to treatment in adolescents with cystic fibrosis: The role of illness perceptions and treatment beliefs. *Journal of Pediatric Psychology, 34,* 893–902. doi:10.1093/jpepsy/jsn135

Burkhart, P. V., & Rayens, M. K. (2005). Self-concept and health locus of control: Factors related to children's adherence to recommended asthma regimen. *Pediatric Nursing, 31(5),* 404-411.

Bush, P. J., & Iannotti, R. J. (1990). A children's health belief model. *Medical Care, 28*, 69–86. doi:10.1097/00005650-199001000-00008

Chassin, L., Presson, C. C., Sherman, S. J., Montello, D., & McGrew, J. (1986). Changes in peer and caregiver influence during adolescence: Longitudinal versus cross-sectional perspectives on smoking initiation. *Developmental Psychology, 22(3),* 327-334. doi:10.1037/0012-1649.22.3.327

Christensen, A. J. (2004). Patient adherence to medical treatment regimens. New Haven and

London: Yale University Press.

Clark, N. M., & Houle, C. R. (2009). Theoretical models and strategies for improving disease management by patients. In S. A. Shumaker, J. K. Ockene, & K. A. Riekert (Eds.), *The handbook of health behavior change* (3rd ed., pp. 19–37). New York: Springer.

Crick, N., & Grotpeter, J. (1996). Children's treatment by peers: victims of relational and overt aggression. *Developmental Psychopathology, 8,* 367–380. doi:10.1017/S0954579400007148

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. doi:10.1111/j.1475-6773.2004.00215.x

Dew, M. A., Dunbar, J. J., Switzer, G. E., DiMartini, A. F., Stilley, C., & Kormos, R. L. (2001). Adherence to the medical regimen in transplantation. In J. R. Rodrigue (Ed.), Biopsychosocial perspectives in transplantation (pp. 93–124). New York: Kluwer Academic Publishers/Plenum Publishers.

DiMatteo, M. R. (2004). Variations in patients' adherence to medical recommendations: A quantitative review of 50 years of research. *Medical Care, 42,* 200–209. doi:10.1097/01.mlr.0000114908.90348.f9

DiMatteo, M. R., Giordani, P. J., Lepper, H. S., & Croghan, T. W. (2002). Patient adherence and medical treatment outcomes: A meta-analysis. *Medical Care, 40(9),* 794–811.

Dobbels, F., Van Damme-Lombaert, R., Vanhaecke, J., & De Geest, S. (2005). Growing pains: Non-adherence with the immunosuppressive regimen in adolescent transplant recipients. *Pediatric Transplantation, 9,* 381–390. doi:10.1111/j.1399-3046.2005.00356.x

Dracup, K. A., & Meleis, A. I. (1982). Compliance: An interactionist approach. *Nursing Research*, *31,* 31–56 64.

Dunbar-Jacob, J., & Mortimer-Stephens, M. K. (2001). Treatment adherence in chronic disease. *Journal of Clinical Epidemiology, 54(S1),* S57–S60. doi:10.1016/S0895-4356(01)004577

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.

Evans, R. W., Applegate, W. H., Briscoe, D. M., Cohen, D. J., Rorick, C. C., Murphy, B. T., & Madsen, J. C. (2010). Cost-related immunosuppressive medication non-adherence among kidney transplant recipients. *Clinical Journal of the American Society of Nephrology, 5,* 2323–2328. doi:10.2215/CJN.04220510

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. doi:10.1111/j.1399-3046.2004.00136.x

Feinstein, A. R. (1990). On white-coat effects and the electronic monitoring of compliance. *Archives of Internal Medicine, 150,* 1377-1378. doi:10.1001/archinte.150.7.1377

Ferris, M.., Harward, D., Bickford, K.., Fenton, N., Gipson, D., Layton, J. B., Ferris, M.T., Maslow, G., McCoy, L., Jennette, C., Hogan, S., Bozik, K., Gibson, K., & Ford, C. (2011). The Development of the UNC TRxANSITION Scale™: A tool to Diagnose and Measure the process of Health Care Transition. *Clinical journal of American society of nephrology (In Press).*

Finea, Y., Beckerb, S., De Geestc, H., Eisend, R., Ettengere, R., Evansf, D., Lapointe Rudowg, D., McKayh, A., Neui, T., Nevinsj, J., Reyesk, J., Wrayl, F., & Dobbelsm (2009). Non-adherence consensus conference summary report. *American Journal of Transplantation, 9,* 35–41.

Fink, R., Shapiro, S., & Lewison, J. (1968). The reluctant participant in breast cancer screening programs. *Public Health Report, 83,* 479-490.

Fisher, E. B., La. Grecca, A., & Greco, P. (1997). Directive and non-directive social support in diabetes management. *International Journal of Behavioral Medicine, 4(2),* 131-144. doi:10.1207/s15327558ijbm0402_3

Foster, J. M., Smith, L., Bosnic-Anticevich, S. Z., Usherwood, T., Sawyer, S. M., Rand, C. S., & Reddel H. K. (2011). Identifying patient-specific beliefs and behaviors for conversations about adherence in Asthma. *Internal Medicine Journal, 41,* 6-39. DOI: 10.1111/j.1445-5994.2011.02541.x

Gincherman, Y., Moloney, K., & Mckee, C. (2010). Assessment of adherence to cinacalcet by prescription refill rates in hemodialysis patients. *Hemodialysis International, 14,* 68–72.

Gochman, D. S. (1981). Some correlates of children's health beliefs and potential health behavior. *Journal of Health and Social Behavior, 12,* 148-154.

Gochman, D. S. (1981). Development and demography of perceived vulnerability in youngsters. Los Angeles, CA: American Psychological Association, 1981.

Gordeuk, V. R., Sachdev, V., Taylor, J. G., Gladwin, M. T., Kato, G., & Castro, O. L. (2008). Relative systemic hypertension in patients with sickle cell disease is associated with risk of pulmonary hypertension and renal insufficiency. *American Journal of Hematology, 83(1),* 15-8. doi:10.1002/ajh.21016

Greenley, R. N., Doughty, A., Stephens, M., & Kugathasan, S. (2009). Brief report:

Development of the Inflammatory Bowel Disease Family Responsibility Questionnaire. *Journal of Pediatric Psychology, 35,* 183–187.

Grey, M., Boland, E., Yu, C., Sullivan-Bolyai, S., & Tamborlane, W. (1998). Personal and family factors associated with quality of life in adolescents with diabetes. *Diabetes Care, 21,* 909–914. doi:10.2337/diacare.21.6.909

Gritz, E. R., Prokhorov, A. V., Hudmon, K. S., Jones, M. M., Rosenblum, C., Chung-Chi, C., et al. (2003). Predictors of susceptibility to smoking and ever smoking: A longitudinal study in a triethnic sample of adolescents. *Nicotine & Tobacco Research, 5(4),* 493–506. doi:10.1080/14622200307242

Gross, W.G., Johnson, H.E., Wildman M., & Mullett. (1981). Coping skills training with insulin dependent preadolescent diabetics. *Child Behavior Therapy, 3,* 141–153.

Haefner, D., & Kirscht, J. P. (1970). Motivational and behavioral effects of modifying health beliefs. *Public Health Report, 85,* 478-489.

Harris, R., & Linn, M. W. (1985). Health beliefs, compliance, and control of diabetes mellitus. *Southern Medical Journal, 78,* 162-166. doi:10.1097/00007611-198502000-00011

Hartup, W. W. (1996). The company they keep: Friendships and their developmental significance. *Child Development, 67,* 1-13. doi:10.2307/1131681

Haynes, R. B., Taylor, D. W., & Sackett, D. L. (1979). Compliance in Healthcare. Baltimore: Johns Hopkins University Press.

Heisler, M., Vijan, S., Makki, F., & Piette, J. D. (2010). Diabetes control with reciprocal peer support versus nurse care management. *Annals of Internal Medicine, 153(8),* 507-518.

Hill-Briggs, F. (2003). Problem solving in diabetes self-management: A model of chronic illness self-management behavior. *Annals of Behavioral Medicine, 23(3),* 182-193. doi:10.1207/S15324796ABM2503_04

Holden, G., Moncher, M. S., Schinke, S. P., & Barker, K. M. (1990). Self-efficacy of children and adolescents: A meta-analysis. *Psychological Reports, 66,* 1044-1046.

Holden G. (1991). The relationship of self-efficacy appraisals to subsequent health related outcomes: a meta-analysis. *Social Work in Health Care, 16,* 53-93.

Holmbeck, G. N., & O'Donnell, K. (1991). Discrepancies between perceptions of decision making and behavioral autonomy. *New Directions for Child Development, 51,* 51–69. doi:10.1002/cd.23219915105

Hommel, K. & Baldassano, R. (2010). Brief report: Barriers to treatment adherence in pediatric

Inflammatory Bowel Disease. *Journal of Pediatric Psychology, 35(9),* 1005–1010. doi:10.1093/jpepsy/jsp126

Horne, R., & Weinman, J. (2002). Self-regulation and self-management in asthma: exploring the role of illness perceptions and treatment beliefs in explaining non-adherence to preventer medication. *Psychology and Health, 17,* 13–32. doi:10.1080/08870440290001502

Hosek, S. G., Harper, G. W., & Domanico, R. (2005). Predictors of medication adherence among HIV-infected youth Psychology. *Psychology, Health, and Medicine, 10(2),* 166 – 179. doi:10.1080/1354350042000326584

Hsin, O., La Greca, A., Valenzuela, J., Moine, C. T., & Delamater, A. (2010). Adherence and glycemic control among Hispanic youth with type 1 diabetes. *Journal of Pediatric Psychology, 35(2),* 156–166. doi:10.1093/jpepsy/jsp045

Iannotti, R. J., Schneider, S., Nansel, T. R., Haynie, D. L., Plotnick, L. P, Clark, L. M., & Imons-Morton, B. (2006). Self-efficacy, outcome expectations, and diabetes self-management in adolescents with type 1diabetes. *Journal of Developmental and Behavioral Pediatrics, 27(2),* 98–105. doi:10.1097/00004703-200604000-00003

Ingerski, L. M., Baldassano, R. N., Denson, L. A., & Hommel, K. A. (2010). Barriers to oral medication adherence for adolescents with inflammatory bowel disease. *Journal of Pediatric Psychology, 35(6),* 683–691. doi:10.1093/jpepsy/jsp085

Institute of Medicine (2007). The future of disability in America. Washington, DC: The National Academies Press.

Iskedjian, M., Addis, A., & Einarson, T. R. (1998). Estimating the cost of hospital admissions due to patient non-adherence in Ontario, Canada. *Pharmacoepidemiology and Drug Safety, 7,* S92-93.

Janicke, D. M., Gray, W. N., Kahhan, N. A., Junger, K. B., Marciel, K. K., Storch, E. A., & Jolley, C. D. (2009). Brief report: The association between peer victimization, prosocial support, and treatment adherence in children and adolescents with inflammatory bowel disease. *Journal of Pediatric Psychology, 34*(7), 769–773. doi:10.1093/jpepsy/jsn116

Jarzembowski, T., John, E., Panaro, F., Heiliczer, J., Kraft, K., Bogetti, D., et al. (2004). Impact of noncompliance on outcome after pediatric kidney transplantation: An analysis in racial subgroups. Pediatric Transplantation, 8, 367–371.

Jaser, S. S., & White, L. E. (2011). Coping and resilience in adolescents with type 1 diabetes. *Child Care Health and Development, 37(3),* 335-342. doi:10.1111/j.1365-2214.2010.011

Johnson, A. J., et al. (1962). Epidemiology of Polio Vaccine Acceptance: A Social and Psychological Analysis. Jacksonville, Fla.: Florida State Board of Health, (Monograph 3).

Judson, L. (2004). Global childhood chronic illness. *Nurses Administration Quarterly, 28,* 60–66.

Kaniasty, K. (2011). Predicting social psychological well-being following trauma: The role of postdisaster social support. *Psychological Trauma: Theory, Research, Practice,and Policy*. Advance online publication. doi: 10.1037/a0021412

Kelly, J. A., & Kalichman, S. C. (2002). Behavioral research in HIV/AIDS primary and secondary prevention: recent advances and future directions. *Journal of Consulting and Clinical Psychology, 70(3),* 626–639. doi:10.1037/0022-006X.70.3.626

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.

Kisker, E. (1985). Teenagers talk about sex, pregnancy, and contraception. *Family Planning Perspectives*, *17*, 83-90.

Kugler, C, Gottlieb, J, Dierich, M, Haverich, A, Strueber, M, Welte, T, & Simon, A. (2010). Significance of patient self-monitoring for long-term outcomes after lung transplantation. *Clinical Transplantation, 24,* 709–716. doi:10.1111/j.1399-0012.2009.01197.x

La Greca, A. M. (1988). Adherence to prescribed medical regimens. In D. K. Routh (Ed.), *Handbook of pediatric psychology* (pp. 299-320). New York: The Guilford Press.

La Greca, A. (1990). Issues in adherence with pediatric regimens. *Journal of Pediatric Psychology, 15(4),* 423-436. doi:10.1093/jpepsy/15.4.423

La Grecca, A., & Auslander, W. S. (1995). I get by with a little help from my family and friends: Adolescents' support for diabetes care. *Journal of Pediatric Psychology, 20(4),* 449-476. doi:10.1093/jpepsy/20.4.449

La Greca, A. M., & Bearman, K. J. (2002). The Diabetes Social Support Questionnaire-Family Version: Evaluating adolescents' diabetes-specific support from family members. *Journal of Pediatric Psychology, 27,* 665–676. doi:10.1093/jpepsy/27.8.665

La Greca, A. M., & Bearman, K. J. (2003). Adherence to prescribed medical regimens. In M. C. Roberts (Ed.), Handbook of pediatric psychology (3rd ed., pp. 119–140). New York: Guilford.

Laraque, D., Mclean, D. E., Brown-Peterside, P., Ashton, D., & Diamond, B. (1997). Predictors of reported condom use in central Harlem youth as conceptualized by the Health Belief Model. *Journal of Adolescent Health, 21,* 318-327. doi:10.1016/S1054-139X(97)00142-0

Larson, R., & Richards, M. H. (1991). Daily companionship in late childhood and early adolescence: Changing developmental contexts. *Child Development, 62,* 284–300. doi:10.2307/1131003

Lawrence, D. B., Allison, W., Chen, J. C., & Demand, M. (2008). Improving medication adherence with a targeted, technology-driven disease management intervention. *Disease Management, 11(3),* 141-146. doi:10.1089/dis.2007.0013

Leventhal, H. (1965). Fear communications in the acceptance of preventive health practices. *Academic Medicine, 41,* 1144-1154.

Levers-Landis, C. E., Burant, C., Drotar, D., Morgan, L., Trapl, E. S., & Kwoh, C. K. (2002). Social support, knowledge, and self-efficacy as correlates of osteoporosis preventive behaviors among preadolescent females. *Journal of Pediatric Psychology, 28,* 335-345.

Lewin, A. B., Heidgerken, A. D. , Geffken,G. R., Williams, L. B., Storch, E. A., Gelfand, K. M., & Silverstein, J. H. (2006). The relation between family factors and metabolic control: The role of diabetes adherence. *Journal of Pediatric Psychology, 31*(2), 174–183.

Logan, D., Zelikovsky, N., Labay, L. & Spergel, J. (2003). The illness management survey: Identifying adolescents' perceptions of barriers to adherence. *Journal of Pediatric Psychology, 28,* 383-392. doi:10.1093/jpepsy/jsg028

MacCallum, R., Widaman, K., Zhang, S., & Hong, S. (1999). Sample size in factor analysis. *Psychological Methods, 4*(1), 84-99.

Malee, K., Williams, P. L., Montepiedra, G., Nichols, S., Sirois, P. A., Storm, D., Farley, D., & Kammerer, B. (2009). The role of cognitive functioning in medication adherence of children and adolescents with HIV infection. *Journal of Pediatric Psychology, 34*(2), 164–175.

Matlin, S. L., Molock, S. D., & Tebes, J. K. (2011). Suicidality and depression among African American adolescents: The role of family and peer support and community connectedness. *American Journal of Orthopsychiatry, 81*, 108–117. doi:10.1111/j.1939

McQuaid, E. L., Kopel, S. J., Fritz, G. K., Nassau, J. H., & Klein, R. B. (1999). Adherence to inhaled asthma medications across the transition to adolescence. Paper presented at the Seventh Florida Conference on Child Health Psychology, Gainesville.

McQuaid, E. L., Kopel, S. J., Klein, R. B., & Fritz, G. K. (2000). Medication adherence in pediatric asthma: Reasoning, responsibility, and behavior. *Journal of Pediatric Psychology, 28,* 323-333. doi:10.1093/jpepsy/jsg022

Meyers, K. E., Thomson, P. D., & Weiland, H. (1996). Noncompliance in children and adolescents after renal transplantation. *Transplantation, 62,* 186–189. doi:10.1097/0 0007890-199607270-00007

Montaño, D. E., Kasprzyk, K. D., & Taplin, S. H. (1997). The theory of reasoned action and the

theory of planned behavior. In K. Glanz, F. Lewis, & B. K. Rimer (Eds.), *Health behavior and health education: Theory, research, and practice* (2nd ed., pp. 85–112). San Francisco: Jossey-Bass.

Mortel, T. F. (2008). Faking it: Social desirability response bias in self-report research. Australian Journal of Advanced Nursing, 25, 40-49.

Moss-Morris, R., Weinman, J., Petrie, K. J., Horne, R., Cameron, L. D., & Buick, D. (2002). The revised illness perception questionnaire (IPQ-R). *Psychology and Health, 17,* 1–16. doi:10.1080/08870440290001494

Mounts, N. S., & Steinberg, L. (1995). An ecological analysis of peer influence on adolescent grade point average and drug use. *Developmental Psychology, 31,* 915–22. doi:10.1037/0012-1649.31.6.915

Murphy, D. A., Sarr, M., Durako, S. J., Moscicki, A., Wilson, C. M., Muenz, L. R. (2003). Barriers to HAART adherence among human immunodeficiency virus–infected adolescents. *Archives of Pediatric and Adolescent Medicine, 157,* 249-255.

Nakonezny, P. A., Hughes, C. W., Mayes, T. L., Sternweis-Yang, K .H., Kennard, B. D., Byerly, M. J., & Emslie, G. J. (2010). A comparison of various methods of measuring antidepressant medication adherence among children and adolescents with major depressive disorder in a 12-week open trial of Fluoxetine. *Journal of Child and Adolescent Psychopharmacology, 20(5),* 431-443. doi:10.1089/cap.2009.0108

Ochieng, B. (2011). The effect of kin, social network and neighborhood support on individual well-being. *Health and Social Care in the Community, 19(4),* 429–437. doi:10.1111/j.1365-2524.2011.00992.x

Osterberg, L., & Blaschke, T. (2005). Medicaiton Adherence. *New England Journal of Medicine, 353,* 487-497. doi:10.1056/NEJMra050100

Pai, A. L., & Drotar, D. (2010). Treatment adherence impact: The systematic assessment and quantification of the impact of treatment adherence on pediatric medical and psychological outcomes. *Journal of Pediatric Psychology, 35(4),* 383–393. doi:10.1093/jpepsy/jsp073

Parcel, G., & Meyer, M. (1978). Development of an instrument to measure children's health locus of control. *Health Education Monographs, 6,* 149-168.

Parsons, J. T., Siegel, A. W., & Cousins, J. H. (1997). Late adolescent risk-taking: effects of perceived benefits and perceived risks on behavioral intentions and behavioral change. *Journal of Adolescence, 20,* 381-392. doi:10.1006/jado.1997.0094

Prochaska, J. O. (1979). *Systems of psychotherapy: A transtheoretical analysis*. Homewood, IL: Dorsey.

Rapoff, M. A. (1996). Why comply? Theories in pediatric medical adherence research. *Progress Notes: Newsletter of the Society of Pediatric Psychology, 20*(6), 3–4.

Rapoff, M. A. (1999). Adherence to pediatric medical regimens. New York: Kluwer Press.

Ratcliff, M. B., Blount, R. L., & Mee, L. L. (2010). The relationship between adolescent renal transplant recipients' perceived adversity, coping, and medical adherence. *Journal of Clinical Psychology in Medical Settings, 17,* 116–124. doi:10.1007/s10880-010-9194-3

Reed-Knight, B., Lewis, J. D., & Blount, R. L. (2010). Association of disease, adolescent, and family factors with medication adherence in pediatric inflammatory bowel disease. *Journal of Pediatric Psychology, 2,* 1–10. doi:10.1093/jpepsy/jsq076

Reyna, V. F., & Farley, F. (2006). Risk and rationality in adolescent decision making implications for theory, practice, and public policy. *Psychological Science and the Public Interest, 7(1),* 1-44.

Reynolds, W. M. (1982). Development of reliable and valid short forms of the Marlowe-Crowne Social Desirability Scale. *Journu1 of Clinical Psychology, 38, 119-125.*

Rianthavorn, P., & Ettenger, R. B. (2005). Medication non-adherence in the adolescent renal transplant recipient: A clinician's viewpoint. *Pediatric Transplantation, 9,* 398–407. doi:10.1111/j.1399-3046.2005.00358.x

Rice, H. E., & Chuang, E. (1999). Current management of pediatric inflammatory bowel disease. Seminars in Pediatric Surgery, 8, 221–228.

Ricker, J. H., Delamater, A. M., & Hsu, J. (1998). Correlates of regimen adherence in cystic fibrosis. *Journal of Clinical Psychology in Medical Settings, 5(2),* 159-173.

Riekert, K. A., & Drotar, D. (2002). The Beliefs about Medication Scale: development, reliability and validity. *Journal of Clinical Psychology in Medical Settings, 9,* 177–184.

Rohan, J., Drotar, D., McNally, K., Schluchter, M., Riekert, K., Vavrek, P., Schmidt, A., Redline, S., & Kercsmar, C. (2010). Adherence to pediatric asthma treatment in economically disadvantaged African-American children and adolescents: An application of growth curve analysis. *Journal of Pediatric Psychology, 35(4),* 394–404. doi:10.1093/jpepsy/jsp074

Romer, D. (Ed.). (2003). *Reducing adolescent risk: Toward an integrated approach.* Thousand Oaks, CA: Sage.

Rosenstock, I. M. (1974). Historical origins of the health belief model. *Health Education Monographs, 2,* 328-335.

Rudy, B. J., Murphy, D. A., Harris, R., Muenz, L., & Ellen, J. (2010). Prevalence and

interactions of patient-related risks for non-adherence to antiretroviral therapy among perinatally infected youth in the United States. *AIDS patient care and STD's*, *24,* 97-104. doi:10.1089/apc.2009.0198

Sabate, E. (2003). Adherence to long-term therapies: evidence for action. Geneva: World Health Organizations. *Hippokratia, 15,* 1790-1809.

Schafer-Keller, P., Steiger, J., Bock, A., Denhaerynck, K., & De Geest, S. (2008). Diagnostic accuracy of measurement methods to assess non-adherence to immunosuppressive drugs in kidney transplant recipients. *American Journal of Transplantation, 8,* 616–626. doi:10.1111/j.1600-6143.2007.02127.x

Schurman, J. V., Cushing, C. C., Carpenter, E., & Christenson, K. (2011). Volitional and accidental Non-adherence to pediatric inflammatory bowel disease treatment plans: Initial investigation of associations with quality of life and disease activity. Journal of Pediatric Psychology, 36(1), 116–125.

Seiffge-Krenke, I. (1998). Chronic disease and perceived developmental progression in adolescence. *Developmental Psychology, 34(5),* 1073-1084. doi:10.1037/0012-1649.34.5

Shemesh, E., Shneider, B. L., Savitzky, L. K., Arnott, L., Gondolesi, G. E., Krieger, N. R., Kerkar, N., Magid, M. S., Stuber, M. L., Schmeidler, J., Yehuda, R., & Emre, S. (2004). Medication adherence in pediatric and adolescent liver transplant recipients. *Pediatrics, 113,* 825-832.

Simons, L. E., & Blount, R. L. (2007). Identifying barriers to medication adherence in adolescent transplant recipients. *Journal of Pediatric Psychology, 32(7),* 831–844. doi:10.1093/jpepsy/jsm030

Simons , L. E., McCormick, M. L., Devine, K., & Blount, R. L. (2010). Medication barriers predict adolescent transplant recipients' adherence and clinical outcomes at 18-month follow-up. *Journal of Pediatric Psychology, 35(9),* 1038–1048. doi:10.1093/jpepsy/jsq02

Simons, L. E., McCormick, M. L., Mee, L. L., & Blount, R. L. (2009). Parent and patient perspectives on barriers to medication adherence in adolescent transplant recipients. *Pediatric Transplantation, 13,* 338–347. doi:10.1111/j.1399-3046.2008.00940.x

Skinner, T. C., M. John, & Hampson, S. E. (2000). Social support and personal models of diabetes as predictors of self-care and well-being: A longitudinal study of adolescents with diabetes. *Journal of Pediatric Psychology, 25(4),* 257-267. doi:10.1093/jpepsy/25.4.

Steinberg, L. (2011). Demystifying the adolescent brain. *Educational Leadership, 4,* 41-46.

Strecher, V. J., & Rosenstock, I. M. (1997). The health belief model. In K. Glanz, F. M. Lewis, & B. K. Rimer (Eds.), *Health behavior and health education: Theory, research, and practice* (2nd ed., pp. 41–59). San Francisco: Jossey-Bass.

Sudan, D. L., Shaw, B. W., & Langnas, A. N. (1997). Causes of late mortality in pediatric liver recipients. *Annals of Surgery, 29,* 430–431.

Sullivan, S. D., Kreling, D. H., & Hazlet, T. K. (1990). Non-compliance with medication regimens and subsequent hospitalizations: A literature analysis and cost of hospitalization estimate. *Journal of Research in Pharmaco-Economics, 2,* 19-33.

Sweet, S. C., Wong, H. H., & Webber, S. A. (2006). Pediatric transplantation in the United States, 1995-2004. *American Journal of Transplantation, 6*, 1132-1152. doi:10.1111/j.1600-6143.2006.01271.x

Tauer, K. (1983). Promoting effective decision making in sexually active adolescents. *Nursing Clinics of North America*, *18*(2), 275-292.

Tercyak, K. P., Goldman, P., Smith, A., & Audrain, J. (2002). Interacting effects of depression and tobacco advertising receptivity in adolescent smoking. *Journal of Pediatric Psychology, 2,* 145-154. doi:10.1093/jpepsy/27.2.145

Thomas, A.M., Peterson, L., & Goldstein, D. (1997). Problem solving and diabetes regimen adherence by children and adolescents with IDDM in social pressure situations: A reflection of normal development. *Journal of Pediatric Psychology, 22(4),* 541-561. doi:10.1093/jpepsy/22.4.541

Thissen, D., Steinberg, L., & Kuang, D. (2002). Quick and easy implementation of the Benjamini- Hochberg procedure for controlling the false positive rate in multiple comparisons. Journal of Educational and Behavioral Statistics, 27(1) 77-83.

Tucker, C. M., Fennell, R. S., Pederson, T., Higley, B. P., Wallack, C. E., & Peterson, S. (2002). Associations with medication adherence Medication non-adherence in adolescents among ethnically different pediatric patients with renal transplants. *Pediatric Nephrology, 17,* 251–256. doi:10.1007/s00467-001-0806-x

Urquhart, J., & Vrijens, B. (2005). New findings about patient adherence to prescribed drug dosing regimens: An introduction to pharmionics. *European Journal of Hospital Pharmacy, 11,* 103–106.

Van Dyke, R. B., Lee, S., Johnson, G. M., Wiznia, A., Mohan, K., Stanley, K., et al. (2002). Reported adherence as a determinant of response to highly active antiretroviral therapy in children who have human immunodeficiency virus infection. *Pediatrics, 109,* 1–7. doi:10.1542/peds.109.4.e61

Vollrath, M., Knoch, D., & Cassano, L. (1999). Personality, risky health behavior, and perceived susceptibility to health risks. *European Journal of Personality, 13,* 39-50.

Warady, B. A., Mudge, C., Wiser, B., Wiser, M., & Rader, B. (1996). Transplant allograft loss in the adolescent patient. *Advances in Renal Replacement Therapy, 3,* 154–165.

Weinstein, N. D. (1984). Why it won't happen to me: perceptions of risk factors and Susceptibility. *Health Psychology, 3,* 431-457.

Weinstein, N. D. (1998) Accuracy of smokers' risk perceptions. *Annals of Behavioral Medicine, 20,* 135–140. doi:10.1007/BF02884459

Weisenberg, M. S., Kegeles, S., & Lund, A. L. (1980). Children's health beliefs and acceptance of a dental preventive activity. *Journal of Health and Social Behavior, 21,* 59-74.

Weiss, R. T., Rapoff, M. A., Varni, J. W., Lindsley, C, B., Olson, N. Y., & Madson, K. L. (2002). Daily hassles and social support as predictors of adjustment in children with jeuvenile rheumatoid arthritis. *Journal of Pediatric Psychology, 27,* 155-165.

Wentzel, K. R., & Caldwell, K. (1997). Friendships, peer acceptance, and group membership: relations to academic achievement in middle school. *Child Development, 68,* 1198–209. doi:10.2307/1132301

Young-Salem, T. K., & Prevatt, F. F. (2001). Brief Report: Psychometric evaluation of the severity of illness scale in a pediatric oncology sample. *Journal of Pediatric Psychology, 26,* 55-60.

Youngstrom, E., Loeber, R., & Stouthamer-Loeber, M. (2000). Patterns and correlates of agreement between parent, teacher, and male adolescent ratings of externalizing and internalizing problems. Journal of Consulting and Clinical Psychology, 68(6), 1038-1050. doi: 10.1037//0022-006X.68.6.1038

Zelikovsky, N., & Schast, A. (2008). Eliciting accurate reports of adherence in a clinical interview: development of the Medical Adherence Measure. *Pediatric Nursing, 34,* 141-146.

Zelikovsky, N., Schast, A. P., Palmer, J. A., & Meyers, K. E. C. (2008). Perceived barriers to adherence among adolescent renal transplant candidates. *Pediatric Transplantation, 12,* 300–308. doi:10.1111/j.1399-3046.2007.00886.x

Zifferblatt, S. M. (1975). Increasing patient compliance through the applied analysis of behavior. *Preventive Medicine, 4*, 173–182. doi:10.1016/0091-7435(75)90082-1

Zugelj, U., Zupancic, M., Komidar, L., Kenda, R., Varda, N. M., & Gregoric, A. (2010). Self-reported adherence behavior in adolescent hypertensive patients: The role of illness representations and personality. *Journal of Pediatric Psychology, 35(9),* 1049–1060. doi:10.1093/jpepsy/jsq027