ADHERENCE TO DAILY CONTROLLER MEDICATION IN PEDIATRIC ASTHMA

by

CARRAH LEI JAMES

(Under the Direction of Jonathan M. Campbell)

ABSTRACT

This dissertation was undertaken with two related aims. First, a review of the literature was conducted to determine existing theoretical frameworks suitable for studying medical treatment adherence in children with chronic illness. Four models of health behavior with sufficient research to make reasonable inferences regarding potential utility of application to pediatric adherence were identified: (a) Transtheoretical model, (b) Social-Cognitive theory, (c) Health Belief model, and (d) the Theory of Planned Behavior (TPB). Each model offers theoretical and practical advantages and disadvantages. While much research using these four models has been generated, little has been achieved toward validating a unified framework for adherence research in children with chronic illness. Of the four models reviewed, the Theory of Planned Behavior appears to hold the most promise as a theoretical framework for medical treatment adherence in children for the following reasons: (a) the TPB possesses an extensive literature including explicit guidance for methodological integrity, (b) results of previous studies suggest that TPB variables are significantly predictive for a number of health behaviors, and (c) parsimony of design lends itself to practical research and application. The second aim of this dissertation was to determine whether the TPB model demonstrates utility as a framework for adherence behavior of children with asthma, the most prevalent pediatric chronic illness. A

descriptive study was conducted using self-report questionnaires to measure children's attitudes, subjective norms, perceived behavioral control (PBC), intentions, and adherence behavior. Relationships between variables were analyzed using two multiple regression models aligned with TPB theoretical predictions. Findings provided general support for the overall model; however, PBC was the only significant independent predictor of Intention, and Intention was the only significant independent predictor of self-rated adherence behavior. Results suggest that the TPB provides a sturdy foundation on which to build a more comprehensive framework for explaining and predicting adherence in children with asthma; however, the TPB will likely require modifications to achieve clinically useful explanatory/predictive power in this population. The constructs of subjective norm and PBC in particular, may require developmentally-tailored operationalization and/or differing methods of assessment (e.g., measures of perspective-taking, parent variables, perceived responsibility) in children.

INDEX WORDS: Asthma; Adherence, Medication compliance, Theory of Planned Behavior, Pediatric psychology; Health behavior, Child health, Chronic illness

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DEDICATION

To my Grandpa and Grandma, whose perseverance and character gave me the inspiration to dream.

To my mom, whose faith and resilience gave me the courage to pursue.

And to Jon Campbell, whose integrity and wisdom gave me the strength to succeed.

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CHAPTER 1

DISSERTATION INTRODUCTION

Background

In children, Asthma is one of the most prevalent chronic diseases, with child-lifetime prevalence estimates approaching 13% in 2005 (National Center for Health Statistics, 2006; NCHS). Despite reduced morbidity and mortality rates of many health problems through advances in medical care and technology, asthma morbidity and mortality rates do not appear to be decreasing (Akinbami & Schoendorf, 2002). In fact, significant increases in morbidity and mortality were noted throughout the 80's and into the 90's (Akinbami & Schoendorf, 2002). While asthma is manageable with medications and avoidance of triggers (Asthma and Allergy Foundation of America, n.d.; Beers & Berkow, 1999), non-adherence to treatment in children with asthma is a significant problem, both in terms of frequency of occurrence and severity of consequences (NCHS, 2006). Each year, children miss over 12 million school days due to asthma (NCHS, 2006). Additionally, the emergency healthcare required when children do not adhere to treatment is costly, with over 700,000 ER visits per year. Poor adherence is also related to increased symptoms, compromised functioning, and mortality in asthma (Riekert & Drotar, 2000).

While the physical and structural barriers to adherence are evident (e.g., costs and healthcare access), much less is known about the psychological and social correlates of non-adherence. Additionally, adherence research with children is especially lacking. The bulk of adherence literature is not theory driven, although this is improving (e.g., McQuaid, Kopel, Klein, & Fritz, 2003). With over 200 factors hypothesized to affect adherence (Vermeire,

Hearnshaw, Van Royen, & Denekens, 2001), interventions cannot be implemented in an efficient or cost-effective manner. This is unfortunate given that behavioral medicine could, arguably, be making the most substantial and long-standing impact by targeting adherence interventions to children. While many models exist for explaining health behaviors (e.g., Health Beliefs Model, Transtheoretical Model, and the Theory of Planned Behavior), a model explaining daily medication adherence in children with asthma has yet to be tested. Because little is known about the psychosocial variables affecting adherence in children, there is no unifying framework for such variables. Yet, due to the serious consequences of non-adherence in children with asthma, research in this area is crucial to form a foundation for practical interventions.

Purpose

This dissertation has two overarching aims and will produce two mansucripts to be submitted after completion. The first aim is to review the literature on psycho-social models of adherence in children with chronic illness. The second aim is to determine whether a specific behavioral model, the Theory of Planned Behavior (Ajzen, 1985), may serve as a useful theoretical framework for adherence behavior of children with asthma. To that end, this study will examine the extent to which children's attitudes toward adherence (medication taking), subjective norms of adherence, perceived behavioral control, and behavioral control (reported barriers) over adherence account for variance in children's intentions to adhere to treatment. Additionally, the relationship between intent to adhere and retrospective reports of adherence will be addressed. Results of such a study will provide important information about the social and psychological factors involved in adherence while providing information about the utility of a particular behavioral model of adherence in children with asthma. Ultimately, interventions

guided by research such as this remain the best hope to address the many causes of non-adherence, and help children to live fuller, healthier lives.

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CHAPTER 2

CONCEPTUALIZING ADHERENCE IN PEDIATRIC CHRONIC ILLNESS: A REVIEW OF THEORETICAL FRAMEWORKS

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Abstract

Objective: Authors reviewed four potential frameworks suitable for studying medical treatment adherence in children with chronic illness: (a) Transtheoretical model, (b) Social Cognitive model, (c) Health Belief model, and (d) Theory of Planned Behavior were examined.

Methods: Georgia Interconnected Library catalog and online databases (e.g., Psycinfo and PubMed) were searched without date constraints.

Results: While much research using these four models has been generated, little has been achieved toward validating a unified framework for adherence research in children with chronic illness. Each model offers theoretical and practical advantages and disadvantages.

Conclusions: Of the models examined, the most promising framework for medical treatment adherence in children may be the Theory of Planned Behavior, based on an extensive literature for research guidance, amount of variance explained in previous studies, and parsimony of design. Well-designed studies to validate frameworks for adherence research in children with chronic illness are needed.

KEY WORDS: Chronic illness, Adherence, Medication compliance, Theory of Planned Behavior, Transtheoretical Model, Social-Cognitive Model, Health Behavior Model, Pediatric psychology, Child health

Background

Advances in care and treatments, especially in medical technology and pharmacotherapy, have made the attaiment of drastically improved health outcomes possible for children with chronic illness. Unfortunately, adherence to treatment in children with chronic illness is variable, and average adherence rates for many chronic illnesses are quite low. For example, rates of adherence to prescribed asthma treatments in children have been shown to be less than 50% (Celano, Geller, Phillips, & Ziman, 1998; Coutts, Gibson, & Paton, 1992; Finkelstein, Lozano, Farber, Miroshnik, & Lieu, 2002). Non-adherence to treatment causes substantial and unnecessary financial costs, reduction in quality of life, and increases in morbidity and mortality (Lemanek & Brown, 2004; Lemanek, Kamps, & Chung, 2001; Quittner, Espelage, Ievers-Landis, & Drotar, 2000). There are many factors thought to affect adherence and this topic becomes even more complex with children, who have only limited direct control over their medical care. While physical and structural barriers (e.g., health care costs and access) certainly contribute to nonadherence, much less is known about the psychological and social correlates of non-adherence. Further, a large factor inhibiting the creation of successful interventions for non-adherence is that much of the adherence research is not theory driven (Vermeire, Hearnshaw, Van Royen, & Denekens, 2001a). Though this is improving, especially with psychology's increasing contributions to the study of health behaviors (e.g., McQuaid et al., 2003), much work still needs to be done. With over 200 factors hypothesized to affect adherence (Vermeire et al., 2001a), the lack of a unified framework is a significant barrier to cost-effective and time-efficient interventions. Validated theoretical models of adherence in children with chronic illness would allow behavioral medicine to offer targeted interventions to improve adherence for children with chronic illness. Research in this area is therefore crucial in order to form a

foundation for practical interventions for three reasons: (a) little is known about the psychosocial variables affecting adherence in children with chronic illness, (b) no validated unifying framework for such variables exists, and (c) the consequences of non-adherence in children with chronic illness can be very serious, even life-threatening.

Purpose

The purpose of the present paper is to compare four theories of health-related behavior as applied to children's adherence to medical treatment and evaluate the potential utility of each as models of children's adherence. To accomplish these goals, the authors conducted a systematic literature search of the following term combinations: children and adherence, children and compliance, social learning theory and compliance, social learning theory and adherence, social cognitive theory and adherence, social cognitive theory and compliance, theory of planned behavior/behaviour and adherence, theory of planned behavior/behaviour and compliance, transtheoretical model and adherence, transtheoretical model and compliance, stages of change and adherence, stages of change and compliance, health belief model and adherence, health belief model and compliance. Georgia Interconnected Library catalog, online databases (e.g., Psycinfo and PubMed), and reference lists of relevent publications (e.g., book chapters on adherence) were searched without date constraints. Studies were selected for inclusion in the review according to the following four-stage hierarchy: (a) empirical test of theory as applied to children's adherence, (b) empirical test of theory as applied to children's health-related behavior, (c) empirical test of theory as applied to adult's adherence, and (d) empirical test of theory as applied to adult's health-related behavior.

Factors Affecting Children's Adherence

Psychosocial factors hypothesized to affect adherence in children with chronic illness are many and diverse. Logan, Zelikovsky, Labay, and Spergel (2003) found that adolescents with asthma perceived that lack of social support, family problems, and denial, among other factors, were barriers to adherence. Family cohesiveness has been associated with adherence in children with diabetes (Cohen, Lumley, Naar-King, Partridge, & Cakan, 2004). In a survey of parents and their children with cystic fibrosis or asthma, Modi and Quittner (2006) found that forgetting and oppositional behaviors contributed to non-adherence. To further complicate the myriad of social and psychological variables that influence children's adherence, psychological and social characteristics of a child's parents must also be included. In a study of parent characteristics affecting treatment adherence of children with HIV, Naar-King and colleagues (2006) found that illicit substance use of the parent was related to poorer adherence of the child. Further, while dissatisfaction with the medical establishment was not directly linked to adherence, it was related to increased substance use. In addition to environmental or physical barriers (e.g., no transportation to the pharmacy), maladaptive behavior and coping (e.g., oppositional behavior and denial) and social issues (e.g., family and peer support), adherence is also affected by psychological and psychophysical factors such as learning, memory, and cognitive resources in general. For example, forgetting might occur due to the complexity of the regimen and/or due to cognitive impairment (e.g., as a result of brain injury, late effects of cancer treatment, etc). Considering the multitude of factors associated with children's adherence, a social-ecological framework that considers environmental, social, psychological, and physiological influences may be the best approach to studying adherence. Several studies of adherence to treatment in children

with chronic illness provide support for this assertion (Mellins, Brackis-Cott, Dolezal, & Abrams, 2004; Naar-King et al., 2006; Penza-Clyve, Mansell, & McQuaid, 2004).

Models of Health Behavior

Several models exist for organizing variables related to health behaviors (e.g., Health Beliefs Model, Transtheoretical Model, and the Theory of Planned Behavior); however research on these models' applicability to adherent behavior in *children* with chronic illness is sparse at best. Many, if not most, health behavior models can be classified under the broader category of an expectancy-value framework. Expectancy-value models predict motivation using a multiplicative formula; that is, an individual's expectation of an outcome is multiplied by the value the individual places on the outcome to arrive at a prediction of motivation. If either component is zero, the product will be zero. For example, suppose I highly value not having seizures, but have zero expectancy that my seizure medication will prevent seizures (perhaps due to prior experience). Therefore, despite valuing seizure prevention, I have no motivation to take my medication because my expectation that it will prevent seizures is zero. Further, it is worth noting that each of the models presented here except the Health Belief Model include the construct of self-efficacy or a conceptually similar construct. Self-efficacy of a specific behavior is a person's belief that he or she has the power to accomplish the behavior. In this way, self-efficacy is a certain type of expectancy. While self-efficacy is not explicitly included in the original Health Belief Model, the original authors of the model have proposed a revision which incorporates self-efficacy (Rosenstock, Strecher, & Becker, 1988).

Theoretical Frameworks

Transtheoretical Model. The transtheoretical model (Prochaska & DiClemente, 1992;TTM) of behavior change, sometimes also called the stages of change model, is

conceptually distinct from the other models examined here and is also the least studied. The TTM is focused on behavior change (e.g., adopting healthy behaviors or stopping unhealthy behaviors) and considers behavior change to occur through a process or progression. According to the model, individuals proceed through stages that correspond to varying levels of readiness to change a behavior. The stages are: precontemplation, contemplation, preparation, action, and maintenance (see Table 2.1). Progression does not need to be linear and any of the stages feedback to a previous stage if the individual relapses. The model includes three other main components: self-efficacy, decisional-balance (i.e., weighing pros and cons), and processes of change (a set of coping skills). The TTM is most often studied in connection with the cessation of harmful behaviors such as smoking (DiClemente, Schlundt, & Gemmell, 2004; DiClemente, Story, & Murray, 2000; Prochaska & DiClemente, 1984; Siqueira, Rolnitzky, & Rickert, 2001).

Johnson, Grimley, and Prochaska (1998) found the TTM to be a good predictor of adherence to oral contraceptives in a study of 306 well-educated, adult women. The two samples of women were young (mean ages of 21 and 24 years, respectively) and most participants were Caucasian (91.7% and 86.5%, respectively). Stage of change was found to be a significant predictor of non-adherence in both samples, with more advanced stages associated with higher adherence. Overall, the TTM variables accounted for over 40% of the variance of adherence behavior in each study. Additionally, in a review of the literature (1999) and creation of a measure (2000), Willey posits the effectiveness of the TTM in improving adherence to medication in adults with chronic illness. While we were unable to find studies applying the TTM to adherence behaviors in children with chronic illness, the stages of change were significant predictors of pregnancy and disease prevention in adolescents (Hacker, Brown,

Cabral, & Dodds, 2005). Further, Ruggiero (1998) suggests using the TTM stages of change to produce interventions for treatment non-adherence in children with cancer.

The main benefit of the TTM in the area of children's adherence to treatments for chronic illness is that it provides immediate implications for treatment and provides guidance to allocation of resources. For example, a child non-adherent to her sickle cell treatment who is in the precontemplation stage may benefit more from psychoeducational intervention about the relationship between her illness and adherence, whereas the same child in the action phase may receive more benefit from tangible supports (e.g., an alarm to remind her to take her medication). Another benefit is the ease of assessing an individual's stage of change. However, although attempts have been made to validate one and two-item measures of the stages of change with adults (Cook & Perri, 2004; Willey et al., 2000), a factor analysis by Cook and Perri (2004) showed only three reliable factors. Further, the stages of change questionnaires may not be developmentally appropriate for children as the measures rely on a certain degree of self-reflection regarding internal states. Overall, as documented by Ficke and Farris (2005) in a review of the TTM applied to medication use, while promising, too few empirical studies are available to make a recommendation for the use of the model in medication adherence intervention.

Social Cognitive Model. Social cognitive theory (Bandura, 1986) is probably the most studied of the frameworks presented here, and certainly has the longest history in the general psychology literature. The model, which was recently modified by Bandura for the purposes of explaining health behaviors (Bandura, 2004), includes the self (e.g., a person's knowledge and self-efficacy), three areas of outcome expectations (i.e., physical, social, and self-evaluative), goals, and socio-structural factors (e.g., facilitators/impediments). In this model, self-efficacy is

the most influential construct due to its multiple points of impact, on both the behavior itself as well as on the other factors. Bandura (2004) argues that effective health behavior interventions for children based on the social cognitive model would include knowledge building, development of self-management and social skills, fostering self-efficacy, and providing social support. This model of intervention is decidedly more comprehensive than the targeted interventions indicated by the TTM. Although Bandura does not indicate any specific measures with which to assess children, disease-specific knowledge (e.g., Quittner et al., 2000) and self-efficacy (e.g., Bartholomew, Parcel, Swank, & Czyzewski, 1993; Bursch, Schwankovsky, Gilbert, & Zeiger, 1999; Schlosser & Havermans, 1992) questionnaires may measure individual constructs of the model.

A longitudinal study of a social-cognitive model as related to healthy eating behavior in a sample of 800 adults in Germany showed that self-efficacy and positive outcome expectation, but not risk perception, were significant predictors of later healthy eating behaviors in both men and women (Schwarzer & Fuchs, 1996). In a self-efficacy intervention study designed to improve adherence in adults with HIV, the intervention group was significantly more adherent than the control group, 94% vs. 69% (Tuldra et al., 2000). Resnick, Wehren, and Orwig (2003) found that, while self-efficacy predicted 15% of the variance in adherence to preventive behaviors and treatments for osteoporosis among 152 adults, outcome expectations accounted for only 2% of the variance. Results of studies of adherent behavior for children are similarly mixed. In a study designed to test a self-efficacy intervention to improve adherence in a small sample of children with asthma (N = 15), the group increased their adherence from 28.6 to 54.1% (Bartlett, Lukk, Butz, Lampros-Klein, & Rand, 2002). Although findings indicated an increase in adherence, the rate of adherence (54%) was still quite low. In a study of 77 adolescents with

asthma, Zebracki and Drotar (2004) found self-efficacy of asthma prevention, but not outcome expectations, to be a significant predictor of adherence.

The principal benefit of the social cognitive model is the extensive research, particularly in children, and theoretical history this framework enjoys. Thoreson and Kirmil-Gray (1983) proposed an expanded social cognitive model for intervening with adherence behaviors in children with asthma. These authors emphasized the utility of multi-directional influence, characteristic of Bandura's 'reciprocal determinism' (i.e., individuals both affect and are affected by their environment), for conceptualizing self-care in children with asthma; however, they also noted that the complexity of such a model makes it difficult to test. Indeed, assessing the components of this model in children with chronic illness may be somewhat complex and time-consuming, as a unified measure of the social cognitive constructs of adherence behaviors could not be identified. Additionally, as highlighted above, social cognitive constructs have produced mixed results with regard to prediction of adherence behaviors.

Health Belief Model. The Health Belief Model (Figure 2.1; HBM) was modified by the original authors in order to explain medical regimen adherence (Becker & Maiman, 1975; Becker et al., 1978). Specific to medical regimen adherence, the model consists of four main components thought to predict the likelihood of action. The first component is 'threat', which consists of perceptions of susceptibility to the illness and perceptions of severity of consequences of the illness. The second component is a cost analysis consisting of perceived benefits and costs associated with performing the action (adhering to treatment in this case). The third component is health motivation, which is an individual's proclivity toward healthful behavior. Theoretically, the highest adherence would be predicted by a combination of high threat, high benefits/low costs, and high motivation. Another component, 'Cues to Action,' which is thought to consist of

internal and external triggers of behavior, ranging from physical sensations to advertisements, does not appear in the reformulated model to describe compliance (Becker, Maiman, Kirscht, Haefner, & Drachman, 1977; Becker et al., 1978). Additionally, in one presentation of the model (Becker et al., 1977), demographic, social, and structural variables (e.g., perceived access, financial burden, difficulty/complexity of regimen) were included as possible mediators between the three main components and behavior; however, in a later representation (Becker et al., 1978), they are absent from the model and only described as having indirect effects on compliance .

The HBM has enjoyed a long history of application and investigation in the field of health psychology and has been used more than the other models presented here to describe health behavior. The current status of research using HBM as a model of adherence behavior in children provides mixed, though promising, results. For example, Brownlee-Duffeck and colleagues (1987), in a study of adherence in predominantly white, middle-class adolescents and adults with insulin-dependent diabetes, found that the model accounted for a significant amount of variance in self-reports of adherence as well as an objective measure of metabolic control. Interestingly, different results were found by age group. In older adults, perceived benefits were the best predictor of adherence and metabolic control. In younger patients, perceived costs were most associated with self-reported adherence, while susceptibility and severity were the best predictors of metabolic control. For the younger group, the HBM accounted for 20% of the variance in metabolic control and 52% of the variance in self-reported adherence. Some studies have shown that increased threat may actually predict reduced adherence, contrary to the theory. For example, Bond, Aiken, and Somerville (1992) found that threat was negatively correlated with adherence and metabolic control in a study of 56 adolescents with insulin-dependent diabetes. One potential cause of such results may be that high threat leads to hopelessness and,

thus, inaction. Further, in another study of 74 minority adolescents with type-1 diabetes, scores on the same health belief measure as used by Brownlee-Duffeck et al. (1987) did not predict adherence or glycemic control (Patino, Sanchez, Eidson, & Delamater, 2005). These results highlight the importance of considering age, socio-economic, and cultural variables when studying models of health behavior.

The biggest limitation of the HBM concerns its debatable utility for designing interventions. For example, if increased threat improves adherence (although this has not held up in research), should practitioners seek to instill fear in children regarding their illness? Alternatively, if the HBM is found to be a consistently significant predictor of adherence behavior, professionals may at least be able to tailor regimens and target interventions to those most likely to be non-adherent. As with the other models, there is a large cognitive component to the HBM, meaning its applicability to younger children is questionable. Patino et al. (2005) notes that demographic differences, such as age, between the sample in her study and the sample in the Brownlee-Duffeck study may explain discrepant findings. Overall, the HBM deserves further study as a framework for adherence behaviors in children with chronic illness.

Theory of Planned Behavior. The Theory of Planned Behavior (TPB; Figure 2.2) is a five component model that posits the prediction of behavior from four variables: attitudes, subjective norms, perceived behavior control (PBC), and intention (Ajzen, 1985). Attitudes are comprised of behavioral beliefs, or what the individual predicts the outcome to be and how they evaluate that outcome. Subjective norms are the individual's perception of how important others view the target behavior. PBC is the individual's judgment of how capable they are of executing the target behavior, a construct that is similar to self-efficacy. To the extent that this construct reflects reality, it is theorized to independently predict behavior (represented by the dotted line in Figure

2.2). Intention is the level of readiness for performing a behavior, and behavior is an observable action.

The TPB has been shown to be a good predictor of children's health intentions and behaviors and of medication adherence in adults. Mummery, Spence, and Hudec (2000) tested the TPB as a model for explaining intention to be physically active in a sample of Canadian children (N = 677). Attitudes, subjective norms, and PBC accounted for 47% of the variance in intention to be physically active, and each of the three components were significant predictors independently. Rhodes, Macdonald, and McKay (2006), found that 75% of intention and 35-50% of behavior was accounted for by the model's variables in a study of physical activity in children. In a study of condom use among African adolescents, the predictor elements of the model accounted for 67% of the variance in intention to use condoms (Giles, Liddell, & Bydawell, 2005). An intervention based on the components of the TPB and designed to increase bicycle helmet use among children resulted in a significant effect on behavior for the intervention group (Quine, Rutter, & Arnold, 2001). Further, Conner, Black, and Stratton (1998) conducted a prospective study of the TPB model's prediction of adherence behavior in a sample of adults diagnosed with psychiatric disorders. They found attitudes, subjective norms, and PBC to account for 67% of the variance in intention to adhere to a medication regimen, while intention and PBC accounted for 38% of the variance in adherence behavior.

The TPB possesses several qualities that make it a reasonable choice for studying adherence in children with chronic illness. First, the TPB model encompasses a vast array of influence with its social-ecological, value-expectancy framework. Second, the TPB model accounts for the theoretically important separation between intention and behavior, a necessary distinction due to the discrepancy between intention to perform a behavior and actual completion

of the behavior. Third, this model includes a component of actual behavioral control. This is a vital element in an adherence model because adherence behaviors are influenced by physical and structural barriers (e.g., transportation, money) in addition to psycho-social barriers. For example, not all families can afford to fill prescriptions or have transportation to the pharmacy. Finally, TPB is a parsimonious framework. The variables of the TPB are theorized to fully mediate the relationship between demographic variables and intention/behavior. Per Ajzen (n.d.),

> Personality traits, intelligence, demographic variables, values, and other variables of this kind are considered "background factors" in the TPB. They are not neglected but assumed to influence intentions and behavior indirectly by affecting behavioral, normative, and/or control beliefs. That is, the components of the TPB are assumed to mediate the effects of background factors on intentions and actions (http://people.umass.edu/aizen/faq.html).

It is important to note, however, that empirical tests of this assertion have produced inconsistent findings (e.g., Armitage, Norman, & Conner, 2002; Christian, Armitage, & Abrams, 2007). A significant problem with use of the TPB appears to lie in statistical analysis of multiplicative composites, as questionnaires of the TPB are often designed to elicit both opinion and strength of opinion (French & Hankins, 2003; Hankins, French, & Horne, 2000). According to French and Hankins (2003), the vast majority of TPB data are analyzed improperly, though they make several suggestions of appropriate statistical methods for studying this particular model. Additionally, there are no standardized measures of TPB because the questionnaires must be tailored to a very specific behavior. Further, questionnaires are often created after conducting a pilot study in which beliefs regarding the behavior are elicited from a sample of individuals

representative of the target population. While this is a time-consuming process, detailed manuals are available to assist researchers in the process of creating TPB questionnaires (Ajzen, 2002; Francis et al., 2004).

Conclusions

As noted by Zebracki and Drotar (2004), it is important to take a developmental perspective when examining the utility of these models with children. This may be particularly true in children with chronic illness as they, for various reasons, may be at even lower developmental levels than would be expected by their age. For example, children with epilepsy may exhibit reduced cognitive functioning due to anti-convulsant medications taken to prevent seizures. Several possible explanations exist for the mixed results found when studying these models. One possibility is that psychological models of health behavior are inappropriate for explaining behavior in children because of developmental constraints. In psychotherapy, it is widely recognized that children under 8 years old are less able to describe internal states, due somewhat to constraints in emotional/affective vocabulary at that age. Further, due to younger children's less-developed cognition and memory, it may be unreasonable for them to remember their medication regimens, particularly if the regimen is complex. Additional developmental issues arise with adolescence. Increased autonomy and peer influence of adolescence may contribute to reduced adherence rates during this developmental period. Another layer of complexity is added to the study of adherence behaviors in children due to children's limited control. Children are most often under the care of others who exert considerable power over such matters as filling prescriptions, keeping therapy appointments, and providing physical access to medications. Consequently, while future studies will certainly want to focus on how theoretical

frameworks fit children's behaviors, researchers will also want to account for the varying degrees of influence caregivers have on children's adherence.

TPB possesses desirable qualities that may provide a good starting place for a framework for adherence research in children with chronic illness. First, the wide interest in TPB has generated many useful tools. From articles on appropriate statistical methods for testing the TPB (French & Hankins, 2003; Hankins et al., 2000) to manuals on questionnaire creation (Ajzen, 2002; Francis et al., 2004), there is a significant amount of reference material to aid in the design of methodologically sound studies of the TPB model. No manuals could be found for the other frameworks presented here. Second, the TPB accounts for a respectable amount of variance in both health behaviors of children (e.g., Rhodes et al., 2006) and in adherence behaviors of adults (e.g., Conner et al., 1998). Although there exist many promising findings within the research on social-cognitive theory, health belief model, and the transtheoretical model, the behavior variance predicted by these models is somewhat less impressive than for the TPB overall (for a review of models applied to adult adherence, see Cook, 2007). Finally, the parsimony of the TPB model makes validation research, as well as assessment and intervention design, a reasonable endeavor. This is less true for social-cognitive theory, which assumes a complicated and constant bi-directional influence However, as with any model, this framework contains weaknesses as well. For example, one area of the TPB that needs to be further explored is the often modest relationship between intention and behavior. Examining the potential mediating effects of actual behavioral control on the relationship between intention and behavior may be a good place to start. After all, as much as someone may want to adhere to treatment, actual barriers would prevent success in achieving that goal.

All researchers who have applied theoretical models to the health behaviors of children with chronic illness should be commended for attempting to tackle such a complex process. At this point, there is no consensus on the best theoretical framework for adherence behaviors in children with chronic illness. In fact, while a unifying framework for adherence is the ideal, models may be differentially suited to different disease states, age groups, ethnicities, socioeconomic statuses, and/or treatment regimens. It appears that new models are on the horizon as well. For example, De Civita and Dobkin (2004), noting a lack of unifying framework for adherence despite increased knowledge and interventions in the area, offer a tripartite model that suggests a multidimensional, dynamic, relational/partnership view of pediatric adherence. Additionally, Williams and colleagues (2005) propose an interesting and inventive framework for promoting medication adherence that is based on the work of educational philosopher Paolo Freire. Research in the field should focus on validation of theoretical frameworks while creatively pursuing new models of adherence behavior in children with chronic illness.

Table 2.1

Transtheoretical Model: Stages of Change Construct Definitions for Adherence Behavior

Stage	Definitions
Precontemplation	The patient is not concerned about poor adherence to treatment regimen and has no intention of changing his/her adherence behavior in the foreseeable future.
Contemplation	The patient is considering changing his/her adherence behavior in the next few months and is somewhat concerned about poor adherence.
Preparation	The patient is more concerned poor adherence and is intending to change his/her behavior in the near future (within the next 30 days).
Action	The patient has successfully started adhering to the prescribed treatment regimen and has been doing so for less than six months.
Maintenance	The patient has continued to successfully adhere to the treatment regimen for more than six months.

Adapted from Cook, C. L.(2007). Models to evaluate patient compliance. In J.E. Fincham (Ed.), *Patient Compliance with Medications: Issues and Opportunities*. Binghamton, NY: Haworth Press.

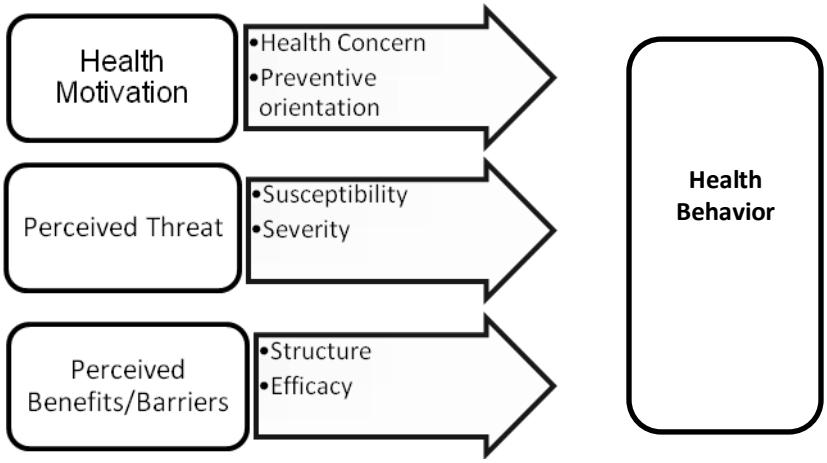

Figure 2.1

Health Behavior Model

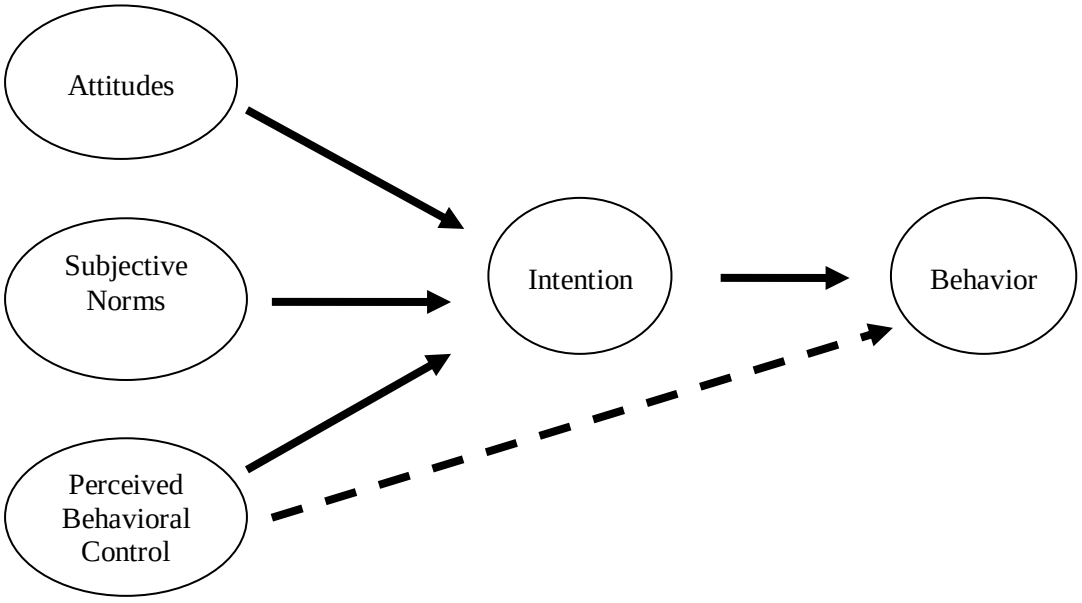

Figure 2.2

Theory of Planned Behavior Model

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CHAPTER 3

THE THEORY OF PLANNED BEHAVIOR AS AN EXPLANATORY MODEL OF MEDICATION ADHERENCE IN CHILDREN WITH ASTHMA

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[1]James, C.L., & Campbell, J.M. To be submitted to *Journal of Pediatric Psychology*.

Abstract

Objective: The purpose of the current study is to determine whether a specific behavioral model, the Theory of Planned Behavior (TPB; Azjen, 1985), may serve as a useful theoretical framework for adherence behavior of children with asthma.

Methods: A descriptive study was conducted using self-report questionnaires to measure children's attitudes, subjective norms, perceived behavioral control (PBC), intentions, and adherence behavior. Relationships between variables were analyzed using two multiple regression models aligned with TPB theoretical predictions.

Results: Multiple regression analyses provided general support for the overall model; however, PBC was the only significant independent predictor of Intention, and Intention was the only significant independent predictor of self-rated adherence behavior.

Conclusion: Results suggest that the TPB provides a useful groundwork on which to build a theoretical framework to explain and predict adherence in children with asthma. The TPB alone, however, appears insufficient to explain/predict child adherence behavior. The constructs of Subjective Norm and PBC, in particular, may require developmentally-tailored operationalization and/or differing methods of assessment (e.g., measures of perspective-taking, parent variables, perceived responsibility, etc.).

KEY WORDS: Asthma, Adherence, Compliance, Theory of Planned Behavior, Attitudes, Pediatric psychology, Health behavior, Chronic illness, Child health

Introduction

In children, Asthma is one of the most prevalent chronic diseases, with child-lifetime prevalence estimates approaching 13% in 2005 (National Center for Health Statistics, 2006; NCHS). Further, despite reduced morbidity and mortality rates of many health problems through advances in medical care and technology, asthma morbidity and mortality rates do not appear to be decreasing (Akinbami & Schoendorf, 2002). In fact, significant increases in asthma morbidity and mortality were noted throughout the 80's and into the 90's (Akinbami & Schoendorf, 2002). While asthma is manageable with medications and avoidance of triggers (Asthma and Allergy Foundation of America, n.d.; Beers & Berkow, 1999; National Heart Lung and Blood Institute, 2006), non-adherence to treatment in children with asthma is a significant problem, both in terms of frequency of occurrence and severity of consequences (NCHS, 2006). Each year, children miss over 12 million school days due to asthma (NCHS, 2006). Although asthma status has not been shown to directly influence academic achievement(Annett, Aylward, Lapidus, Bender, & DuHamel, 2000; Bender, 1999), uncontrolled asthma often reduces sleep quality (Auckley, Moallem, Shaman, & Mustafa, 2008; Verhulst et al., 2007), a factor that increases fatigue (Desager, Nelen, Weyler, & De Backer, 2005), reduces participation in physical activities (Krouse, Yarandi, McIntosh, Cowen, & Selim, 2008) , negatively impacts quality of life (Ekici et al., 2005), and contributes to behavior and attention problems (Mitchell & Kelly, 2006). Additionally, the emergency healthcare required when children do not adhere to treatment is costly, with over 700,000 ER visits reported for children with asthma per year. Poor adherence is also related to increased symptoms, compromised functioning, and mortality for children with asthma (Riekert & Drotar, 2000).

Although there exists a large body of literature regarding physical and structural barriers to treatment adherence (e.g., healthcare access) across a range of health conditions in adult populations, much less is known about the psychological and social correlates of non-adherence, especially in children. Further, much of the existing adherence research in both adult and pediatric populations is not theory driven (as noted in Nichol, Venturini, & Sung, 1999), although this is improving (e.g., McQuaid et al., 2003). With over 200 factors hypothesized to affect adherence (Vermeire et al., 2001b), interventions attempting to account for all factors cannot be implemented in a cost-effective or efficient manner. This is unfortunate given that behavioral medicine could, arguably, be making the most substantial and long-standing impact by targeting adherence interventions to children. Research in this area is therefore crucial in order to form a foundation for practical interventions for three reasons: (a) little is known about the psychosocial variables affecting adherence in children with chronic illness, (b) no validated unifying framework for such variables exists, and (c) the consequences of non-adherence in children with chronic illness can be very serious, even life-threatening.

Many models exist for explaining health behaviors (e.g., Health Beliefs Model, Transtheoretical Model, and the Theory of Planned Behavior); however, a framework explaining daily medication adherence in children with asthma has yet to be established. The Theory of Planned Behavior (TPB; see Figure 3.1) is a five-component model that posits the prediction of behavior from four variables: attitudes, subjective norms, perceived behavior control (PBC), and intention (Ajzen, 1985). Ajzen and others (e.g., Ajzen & Madden, 1986; Francis et al., 2004) provide the following operational definitions of TPB components: Attitudes are defined as an individual's instrumental valuation (e.g., useful/not useful) and experiential attributions (e.g., pleasant/unpleasant) of the behavior in question. Subjective norms constitute the individual's

perception of social pressure, or how important others view the target behavior. Perceived behavioral control is an individual's judgments regarding his or her ability to execute the target behavior. Actual behavioral control is subsumed under PBC due to its theorized relationship with perceptions of control. Actual behavioral control is one's ability to carry out the behavior; for example, an individual may have no transportation to the pharmacy, a genuine physical barrier. To the extent that PBC reflects reality, it is theorized to independently predict behavior (this relationship is represented by the dotted line in Figure 3.1). Intention is the determination to perform a behavior, and behavior is an observable action.

TPB has been widely studied with adults and been shown to be useful in predicting adult health-related behaviors, such as exercising, participating in cancer screenings, and using condoms to prevent sexually transmitted illness (Armitage & Conner, 2001). Research has also demonstrated promise in the TPB's prediction of medication adherence in adults (e.g., Chisholm, Williamson, Lance, & Mulloy, 2007; Conner et al., 1998). For example, Conner, Black, and Stratton (1998) conducted a prospective study of the TPB model's prediction of adherence behavior in a sample of adults diagnosed with psychiatric disorders. The authors found attitudes, subjective norms, and PBC to account for 67% of the variance in intention to adhere to a medication regimen, while intention and PBC accounted for 38% of the variance in adherence behavior. The model has also been tested to determine its utility for prediction of preventive health behaviors in children, with encouraging results. For example, Mummery, Spence, and Hudec (2000) tested the TPB as a model for explaining intention to be physically active in a sample of Canadian children (N = 677). Attitudes, subjective norms, and perceived behavioral control accounted for 47% of the variance in children's intention to be physically active, and all three were significant predictors independently. In a study of condom use among African

adolescents, the predictor elements of the model accounted for 67% of the variance in intention to use condoms (Giles et al., 2005). Additionally, an intervention study designed to increase bicycle helmet use among children using the components of the TPB found a significant effect on behavior for the intervention group (Quine et al., 2001).

The TPB is also appropriate to consider as a model of adherence behavior in children for several reasons. First, the TPB model encompasses a vast array of influence with its social-ecological, value-expectancy framework. Second, the TPB model accounts for the theoretically important separation between intention and behavior, a necessary distinction due to the discrepancy between intention to perform a behavior and completing the behavior. Finally, the model includes a component of actual behavioral control, which is a vital element in an adherence model because adherence behaviors are influenced by physical and structural barriers in addition to psycho-social barriers.

Purpose

The purpose of the current study is to determine whether a specific behavioral model, the Theory of Planned Behavior (Azjen, 1985), may serve as a useful theoretical framework to predict the adherence behavior of children with asthma. To that end, this study examines the extent to which children's attitudes toward adherence (medication taking), subjective norms of adherence, and perceived behavioral control (PBC) over adherence account for variance in children's intentions to adhere to asthma treatment regimens. Additionally, the relationship between intent to adhere and retrospective reports of adherence are investigated. The current study aims to provide important information about the social and psychological factors involved in pediatric adherence while providing information about the utility of a particular behavioral model of adherence in children with asthma. Ultimately, interventions guided by research such

as this remain the best hope to remediate the many causes of non-adherence, and help children to live fuller, healthier lives.

Research Questions and Hypotheses

Based on theoretical predictions of TPB model, the following questions were posed and respective hypotheses were tested:

(a) Are children's attitudes about taking daily asthma medication related to their intentions to do so? A positive relationship between attitude and intention is predicted, such that positive attitude results in higher intention to take medicine as prescribed and negative attitude results in lower intention to take medication as prescribed.

(b) Are children's perceptions of social pressure to take asthma controller medication as prescribed related to their intention to do so? Children's evaluation of important others' attitudes toward adherence (i.e., subjective norms) will predict children's behavioral intentions such that perceptions of decreased social pressure will result in lower intention to adhere, while perception of increased social pressure will result in higher intention to adhere

(c) Are children's perceptions of control over taking daily asthma medication as prescribed related to their intention to do so? Children's perception of control over adherence behavior (i.e., perceived behavioral control; PBC) will predict children's intent to adhere such that perceptions of less control will result in lower intention to adhere and perceptions of greater control will result in greater intention.

(d) Are children's intentions to take daily asthma medication as prescribed related to adherence behavior? Higher intent to adhere will predict higher adherence as indicated by retrospective self-reports.

Methods

Participants

Participants were 29 parent/caregiver-child dyads residing in Northeastern Georgia. Ages of children participating in the study ranged from 8 to 17 years (M = 11 years, SD = 2.1). The inclusion criterion of 8 years was established to improve the likelihood of comprehension of the measures as well as the likelihood that children bear more of the responsibility for adherence when compared to their younger counterparts. Additionally, applicability and viability of the TPB in children younger than 8 is questionable due to difficulties of reliably assessing thoughts and feelings in younger children. Per inclusion criteria, all children were diagnosed with asthma and prescribed a daily controller medication. Participants were ineligible to participate if they could not read and write in English and/or if a diagnosed co-morbid condition that impaired cognitive ability such that the child could not comprehend questions posed in the measure or recall their three-day adherence to medication. Thirty-one dyads agreed to participate, and the data for two children were excluded. Exclusions were made for the following reasons: 1) A dyad in which the child was not diagnosed with asthma but met all other inclusion criteria (daily medication prescribed for allergies) agreed to participate as the initial/practice trial of the procedure within the physician's office. 2) Data of one dyad were excluded on the basis of suspected threats to validity, including: parent reading/comprehension difficulties not apparent until administration of questionnaires, child reading/comprehension difficulties obvious during completion of questionnaires (e.g., circling non-answer items on the page), and both participants' repeated attempts to discuss their respective /potential responses with each other.

Parents completed a demographic questionnaire, the results of which are summarized in Table 3.1. Most children (27 of 29) were diagnosed with allergic rhinitis in addition to asthma. Medication deliveries for assessed controller medication were corticosteroid inhaler (72.5%),

oral/pill (20.7%), and intranasal (6.8%). Most children were prescribed additional medications for rescue (e.g., albuterol) and management of allergy symptoms (e.g., antihistamines) to use as needed. Parents identified their participating child as Caucasian (55.2 %), African-American (27.6 %), Asian (6.9%), or Other/Unanswered (10.3%). Regional race/ethnicity demographics for public school enrollment indicate that Hispanic race/ethnicity, African American/Black race/ethnicity, children from families in lower income categories, and those qualifying for public insurance are underrepresented in the current sample (University of Georgia Center for Agribusiness and Economic Development, n.d.). Further, characteristics are not consistent with Centers for Disease Control and Prevention National Center for Health Statistics asthma prevalence estimates of the general child population (i.e., a greater prevalence of asthma in African American/Black and Hispanic children than in Caucasian children (Akinbami, 2006). Although boys were overrepresented (69%) compared to the general population, this was expected given differential prevalence of asthma by gender (estimated 11% of boys and 7.5% of girls; Akinbami, 2006).

Measures

Demographics. A demographics questionnaire was created by investigators in order to obtain information from parents regarding ethnicity, socioeconomic status, family health history, and family composition. Several of these variables have been shown to be related to asthma management and severity (Gergen, 1996; Mannino et al., 2002). For example, African-American/Black children have consistently higher rates of hospitalization and death from asthma than do white children (Akinbami, 2006).

Adherence. A parent and child adherence questionnaire was developed. For purposes of comparison, the two questionnaires were created to read as similarly as possible. Parent-report of

their child's adherence and child's self-reported adherence were assessed with two questions. The questions asked about adherence over a three-day period. The three day period was chosen because longer periods make recall less accurate and shorter periods are more susceptible to instability. There is no standard time period for recall in the literature, although 24-hours (Marhefka, Tepper, Farley, Sleasman, & Mellins, 2006), 3 days (Murri et al., 2000; Van Dyke et al., 2002), one week (Reddington et al., 2000), and unspecified amounts of time such as always, sometimes, and never (Mears, Charlebois, & Holl, 2006; van Es, Nagelkerke, Colland, Scholten, & Bouter, 2001) have been used in studies of self-reported adherence in children. Caregiver report of child adherence was used as an additional measure of adherence in this study under the premise that the use of multiple raters improves reliability.

There are many methods for measuring adherence, including electronic monitors, chemical assays, self-report, pill count, and pharmacy refill records. Every method for measuring adherence has advantages and disadvantages. As this study is preliminary, use of expensive electronic devices such as the Medication Event Monitoring System (MEMS) caps and the Metered Dose Inhaler-Log (MDI-Log) were not feasible. Further, while electronic devices seem to be the most precise non-invasive objective measures of adherence, they are not perfect. For example, the MEMS cap records openings of a pill bottle, but it does not record whether a person actually took the medication. Similarly for the MDI-Log, patients may actuate medications into the air or other people in the household may use the inhaler, which results in inaccurate adherence data for the index patient. Pill counts and pharmacy records are also flawed means of measuring adherence for similar methodological reasons. Even chemical assays are imprecise, as individuals metabolize substances at different rates.

Among standardized self-report measures of adherence, such as the Morisky Medication Adherence Scale, psychometric properties tend to be weak (Cook, Wade, Martin, & Perri, 2005; Gao & Nau, 2000). The authors found these measures insufficient for the current study. The Morisky Scale, for example, is purported to be a four question measure of adherence but asks only about four barriers to adherence. Thus, the measure seems to be assessing not *whether* people are adherent, but *why*, and only posits four possibilities for non-adherence (i.e., forgetting, carelessness, feeling better, and feeling worse). Therefore, if someone who regularly and purposefully does not take medication due to perceived stigma or weakness associated with medicine (or because it's against her religion, or because she doesn't like the color of the pill, or because her arthritis makes it impossible to open the pill bottle, etc.), that patient might earn the same score as someone who is perfectly adherent. Not surprisingly, reliability of the MMAS has been found to be low ($\alpha = .61$; Morisky, Green, & Levine, 1986). Additionally, both concurrent ($r = .43$; $p < .01$) and predictive validity ($r = .58$; $p < .01$) were unimpressive (Morisky, Green, & Levine, 1986). Another measure, the Brief Medication Questionnaire (Svarstad, Chewning, Sleath, & Claesson, 1999) asks about actual adherence; however, the table format and questions are too complex and inappropriate for children. No standardized measures of general adherence (as opposed to disease/regimen specific adherence) validated with children were found by the authors. While self-report is subject to recall error and falsification, it has been found to correlate moderately to highly with other measures of adherence (Garber, Nau, Erickson, Aikens, & Lawrence, 2004) and physiologic measures (Van Dyke et al., 2002).

Theory of Planned Behavior. There are five components of the TPB (Figure 3.1). One of the components, behavior, is accounted for by the adherence questions described above. The remaining four variables are measured in the TPB Questionnaire; however, PBC questions

relating to actual behavioral control were included in the Adherence Questionnaire. Questions were developed using a manual for creating TPB questionnaires (Francis et al., 2004) and extensive information on the topic retrieved from Ajzen's website (2002). Because the purpose of the current study is to examine relationships among the TPB variables, particularly how much intention is accounted for by attitudes, subjective norms, and perceived behavioral control (rather than understanding the specific types of beliefs that contribute to adherence, for example), an abbreviated questionnaire was created using direct measures only (Francis et al., 2004). In contrast to direct measures, indirect measures typically involve assessing specific beliefs and their strength using a multiplicative scoring formula.

Arguably, the most important factor in creating the TPB questionnaire is operationalizing the specific behavior. In the current study, adherence was defined as "taking the medication exactly as it was prescribed by the doctor," with language altered somewhat to be developmentally appropriate for children. Seven questions were written for each variable (with the exception of behavior construct of adherence, discussed above). For attitude, both instrumental and experiential items were used. Subjective norm questions elicit beliefs about how important others view the target behavior. Parents and friends were included as important others. Perceived control was measured with items regarding the respondents' beliefs about both self-efficacy and control over the behavior. Intention was evaluated with questions regarding the child's plans to take his or her medication exactly as the doctor prescribes. Questions were reviewed for readability and appropriateness of content by a psychologist familiar with the TPB and a pharmacist with expertise in adherence behavior. Readability statistics were calculated using Microsoft Word. The TPB questionnaire produced a Flesch Reading Ease score of 89.7 and a Flesch-Kincaid Grade Level score of 3.1.

Other measures. As mentioned above, the purpose of the intake form was to streamline the recruitment process by determining preliminary eligibility. A checkout form was also used to document information from the child's medical chart or prescription bottles as well as any validity concerns. Using the checkout form, a validity check was completed after participation and a participant's data was excluded if he or she did not appear to understand the questions (*n* =1*)*. The validity check included the researcher's estimation of the child's comprehension during instructions and examples, a visual scan of the child's answers for patterned responding, and the child's level of cooperation with the protocol.

Procedures

Data collection. Initial recruitment efforts took place in a physician's office in a suburban/rural area of Northeastern Georgia. Receptionists and nurses in the physician's office provided an intake form to children's parents when checking in for their appointments. The intake form asked five yes/no questions to determine the child's preliminary eligibility for the study and one question regarding the parent's willingness to speak with a researcher. If the parent answered yes to all six questions, they met with the researcher in a private room in the physician's office so the information regarding the study and their potential participation (details of informed consent and HIPAA forms) could be explained to them. No potential participants declined to participate. An additional recruitment effort via newspaper advertisement yielded only one eligible participant-dyad. Data for this dyad was collected similar to the procedure used for other participants except screening was conducted by phone and data was collected in a university clinic.

Both parents and children agreed to participate by signing the informed consent/assent form. Researchers and graduate student research assistants administered the questionnaires and

completed the checkout form. The parent completed a demographic survey and a questionnaire regarding their child's adherence to daily controller medication for asthma. The child completed the adherence and TPB questionnaires. A script with instructions on completing the questionnaires was read aloud to participants. Participants within each dyad were seated apart during completion of questionnaires (to reduce the likelihood of seeing each other's answers) and were instructed not to discuss their answers during the study. Further, parent-child pairs were informed that the child's responses would not be shared with the parent or doctor but, during debriefing, all dyads were encouraged to routinely engage in open and honest discussions regarding medication adherence. The child questionnaires were read silently by the child unless the child asked for help, in which case the questionnaire was read aloud to the child (n = 2) by the clinician. In these instances, parent and child completed their respective questionnaires in separate rooms in case the child preferred to respond verbally as well. The data collection process involved approximately 15 minutes, including completing informed consent and HIPAA paperwork. When medical charts were reviewed, researchers completed this task immediately following the participants' completion of the study.

Scale refinement. The rationally derived scales designed for the purpose of assessing TPB constructs of Attitude, Subjective Norm, Perceived Behavioral Control (PBC), and Intention in this study were subject to reliability analyses and refinement. All scales included negatively worded items that were reverse scored. Table 3.2 provides a summary of initial and subsequent alpha coefficients for scales and respective item contributions. Of the 28 original items (7 per scale), each scored on 0 to 4 Likert scale (Almost Never to Almost Always), 22 items were retained. More specifically, for the Attitude scale, the initial alpha coefficient of .53 increased to .70 following removal of the "useful" item. Of the original 7 items comprising the

Subjective Norm scale, one item ("My parents don't want me to take my medicine…") could not be analyzed due to zero variance, and two additional items were removed due to poor correlation with other items on the scale, resulting in four items (α = .61). The Subjective Norm scale was the only scale to result in missing values, which were replaced using the linear trend option in SPSS (based on the 7 original scale items). Two of the four retained items originally held one missing value. The original PBC scale was also reduced by two items, resulting in a five item scale (α = .62). All items comprising the original Intention scale were retained (α = .73).

Adherence behavior was assessed by asking the child to indicate how many of the past three days (0-3) they took their medicine exactly as they should. To assess validity of responses, this item was followed by two yes/no items regarding whether they had taken more and/or less of their medication than they should over the past three days. No disagreements were found between rating of adherence behavior and the two follow-up questions. Parent ratings of the participating child's adherence were obtained using the same metric but were not included in the regression analyses.

Results

Adherence

The mean of child-rated adherence was 2.28 days (*SD* = 1.10). The majority of children (69%) rated themselves as adherent to the identified asthma medication for 3 out of 3 days. Seventeen percent rated themselves as adherent for 2 of 3 days, 7% for 1 of 3 days, and 14% for none of the 3 days. In other words, 69% of children endorsed 100% adherence (3 of 3 days), 14% endorsed 0% adherence (0 of 3 days), and 24% of children endorsed partial adherence (1 or 2 of 3 days). Although parent ratings are not included regression analyses, comparison of parent and child ratings of adherence was undertaken for purposes of gaining additional information

regarding (a) inter-rater agreement/reliability of single-item rating to assess child adherence and (b) trends/patterns of within-dyad agreement. The mean of parent-rated adherence was 2.38 days (*SD* = 1.08). Sixty-nine percent of parents rated their participating child as 100% adherent (3 of 3 days), 17% as partially adherent (1 or 2 of 3 days), and 14% of parents rated their participating child as 0% adherent (0 of 3 days). There was a significant correlation between overall child and parent ratings of adherence (r (27) = .63; $p < .001$). Eighteen (62%) of the 29 parent-child pairs were in perfect agreement for number of child-adherent days. Of those in agreement, 14 pairs (77%) agreed the child was adherent 3/3 days, 1 pair agreed the child was adherent 1/3 days (6%), and 3 pairs (17%) agreed the child was adherent 0/3 days.

Scale Correlations

Pearson correlation coefficients were computed between the scales (Table 3.3). Bonferroni correction was applied to control for Type I error across the 10 correlations. As such, correlation coefficients were considered significant at the .05 level if obtained p values were less than .005 (.05/10 = .005). The correlation analyses revealed significant relationships between total scores on the Intention scale and those of the Attitude (p <.05), PBC, (p <.05) and Adherence scales. The correlation between Intention and Adherence (r (27) = .62, p <.05) was the strongest of all relationships between TPB variables.

Multiple Regression Analyses

Per Hankins, French, and Horne's (2000) guidelines, two separate multiple regression analyses were conducted to predict Intention and Adherence (Figure 3.2). The findings of each regression analysis are summarized in Table 3.4 and Table 3.5. The first analysis included total scores from the Attitude, Subjective Norm, and PBC scales as predictors of the Intention scale total score. As a group, Attitude, Subjective Norm, and PBC scores accounted for 45% of the

variance in Intention scores (R^2 =.45, F(3, 25) = 6.80, p = .002). While significant, the model statistics are tempered by information obtained from β coefficients and analysis of residuals. Of the three hypothesized predictors of Intention, only PBC was found to contribute significantly (β = .36; t(28) = 2.39, p = .03).

The second regression analysis included total scores of the PBC and Intention scales as predictors of Adherence. Together, PBC and Intention score accounted for 38% of the variance in Adherence scores (R^2 =.38, F(2, 26) = 8.06, p = .002). Intention was found to be a significant predictor of adherence behavior scores (β = .63; t(28) = 3.53, p = .002), while PBC was not. Figure 3.3 provides a path diagram of the results of both regression analyses. For the predictor variables in the first regression analysis, no significant correlations between the predictor variables were identified after Bonferroni correction (as described above). The two predictor variables in the second regression were significantly correlated (r =.55, p <.05).

Discussion

The primary aim of this study was to test the TPB as an explanatory model of daily medication adherence in children with asthma. Internal consistencies for experimental scales constructed to assess TPB constructs in the current sample (N = 29) produced internal consistency coefficients ranging from .61 to .73 following revisions that resulted in a reduction of the number of items for 3 of the 4 scales. Results of adherence behavior self-report ratings suggest a majority of children (62%) were fully adherent to the identified daily controller medication over the past 3 days. Perfect parent-child agreement on adherence ratings was found for 62% of dyads. Despite the small number of participants, adequate power was achieved to detect moderate to large effect sizes using multiple regression analyses. Two multiple regression analyses were conducted, one for the Intention outcome variable and one for the Adherence

outcome variable. Both analyses produced regression coefficients supportive of the model, but PBC was the only independently significant predictor of Intention, and Intention was the only significant predictor of self-reported adherence behavior in the current sample. When considered within the wider context of health behavior, adherence, and pediatric asthma research literatures, the results of the current study provide support for the following interpretations regarding the TPB model as applied to adherence behavior of children with asthma. First, in its current form, the model's PBC and subjective norm constructs are of questionable applicability to children due to confounds of responsibility/shared control and developmental progression of perspective taking, respectively. Second, with child-appropriate revisions/modifications, the TPB model holds considerable promise as a theoretical framework for better understanding adherence to daily controller medication in older children with asthma.

Interpretation of Findings

Scale properties. The final versions of the TPB scales implemented in the current study did not produce robust internal consistency coefficients. Within the TPB literature, there are several theoretical rationales for low internal consistency reliability for TPB subscales. First, Azjen recommends including belief-based or indirect measures in assessment of TPB constructs, noting that failure to include the belief-based components can result in low internal consistency of scales. Due to statistical problems with including indirect or belief-based measures in TPB construct scales, as elucidated by French and Hankins (2003), the current study employs only direct measures. Second, the attitude construct of the TPB is comprised of affective and cognitive attitudes and scales assessing this construct are to include items representing both types (Ajzen, 2002; Francis et al., 2004). As such, Attitude scale items for the current study included both affective and cognitive statements. Combining the 'types' of attitude may result in lower

total scale alphas. Examination of inter-item correlations in the current study provides partial support of this assertion. Affective items ("like," "hate," and "frustrating") held moderate to strong relationships with each other (*r* range .44 to .77) and were the strongest relationships in the six-item correlation matrix. Cognitive items ("good," "bad," and "waste of time"), however, held weak relationships with each other (*r* range -.17 to .18). Third, a number of studies have found poor psychometric properties of Subjective Norm scales, particularly for children. In the current study, both developmental and measurement characteristics may have contributed to weak inter-item correlations. The Subjective Norm scale was the only scale in the current study to contain missing values. While not especially remarkable in quantity, the contrast (no missing values in other scales) suggests a potential difficulty in comprehension of these items. The apparent randomness of missing values in the Subjective Norm scale, along with poor psychometric properties of similar scales in other research studies (as noted by Armitage & Conner, 2001), suggests an inherent weakness in the construct itself or to the standard approach to measurement of the construct. For example, the current results could be reflective of children's lack of exposure, awareness, or concern of others' thoughts, feelings, and behaviors. This is not altogether surprising given the developmental trajectory of perspective taking and egocentrism, and the wide range of developmental status for the age range assessed in the current sample. Developmental considerations, such as the child's ability to engage in accurate perspective-taking might make important differences in the reliability of the subjective norm construct as applied to children.

Regression results. PBC was found to be the only independently significant predictor of Intention but not a significant predictor of behavior. In other words, PBC predicts Intention, Intention predicts Adherence Behavior, but PBC does not predict Adherence Behavior. Ajzen

theorizes that PBC, to the extent that it reflects actual control, is likely to predict behavior independent of Intention. As such, our results may indicate (not unexpectedly) that children have little 'actual' control over asthma medication adherence and therefore PBC is not expected to be an independent predictor of Adherence Behavior. An additional contributing factor may be a function of the prescriptive nature of the behavior and the age of the child. That is, the responsibility for an individual child's adherence (i.e., health) may be solely the caregiver's, solely the child's, or (more likely in the current sample) shared between the caregiver and child. In this way, as predicted for adults, the child may have high perceptions of control, low actual control, and low adherence; however, in the current sample, the relationship between PBC and Adherence Behavior was not just weak, it was actually slightly negative. The authors question whether, for children, the relationship between PBC (to the extent that it reflects reality) and Adherence Behavior might be developmentally moderated not just in strength, but in directionality (positive versus negative) as well. For example, suppose a six year old holds high PBC and high actual control over medication adherence behavior. It is easy to imagine that, despite high PBC and *due to* high actual control that an inverse relationship between actual control and adherence behavior might be a reasonable hypothesis. Indeed, in a recent study of 49 children with asthma (age 8-18), Simon (2008) found increases in individual responsibility for adherence behavior in adolescence, while adherence behavior itself decreased at this age. Other studies of the nature of the relationship between the effects of parent factors on child health behavior have shown a positive relationship between parent control and child health behavior (e.g., de Bruijn, Kremers, de Vries, van Mechelen, & Brug, 2007), while others have not (e.g., Harakeh, Scholte, Vermulst, de Vries, & Engels, 2004; Hewitt & Stephens, 2007).

Comparisons with Past Research

TPB scales. Although some researchers (Ajzen, 2002; Francis et al., 2004) note theoretical rationale for modest internal consistency coefficients, particularly when assessing attitudes, others have designed scales resulting in alpha coefficients ranging from .80 to over .90 in studies with both adults (e.g., Armitage et al., 2002) and children (e.g., Mummery et al., 2000). Consistent with the results of the current study, Intention scales typically produce a more robust alpha, which is thought to be due to the relatively straight-forward operational definition of the Intention construct. Further, as noted above, construct measurement of PBC and subjective norm in children has been problematic and this appears to be the case in the current study.

Regression findings. Overall, results of the current study are consistent with those of other TPB studies. Again, meta-analysis of studies by Armitage and Conner (2001) suggests that subjective norm is often the weakest predictor of intention. More recent studies have provided additional evidence of non-significant contribution of subjective norm in predicting intention, found in samples of adults (Eng & Martin Ginis, 2007), college students (White, Thomas, Johnston, & Hyde, 2008), and adolescents (de Bruijn, Kremers, Schaalma, van Mechelen, & Brug, 2005). Another finding consistent with previous studies is that, in general, variables predict Intention somewhat better than Behavior. Armitage and Conner's (2001) meta-analysis of 185 independent studies indicate that TPB variables accounted for 39% of variance in intention and 27% variance in behavior; values were 45% and 38%, respectively, in the present study.

Areas of mixed agreement between the results of the current study and those of other studies are the proportions of variance accounted for within the TPB model, varying widely by study. The current study's findings are similar to several other studies in magnitude of variance accounted for. For example, in a longitudinal study of children with asthma (N = 346), the model accounted for 36% of the variance in intention to start smoking cigarettes (with PBC found to be

the strongest predictor of Intention) and intention alone accounted for 16% of the variance in smoking initiation (Van De Ven, Engels, Otten, & Van Den Eijnden, 2007).Other studies, however, have found the variables to account for far more variance in the outcome variables. For example, Giles, Liddell, and Bydawell,(2005) found predictor variables of Attitude, Subjective Norm, and PBC accounted for 67% variance in intention of adolescents in Africa to use condoms; Rhodes, MacDonald, and McKay (2006) found that TPB variables accounted for 75% and 35-50% of the variance in intention and behavior, respectively, in a study of physical activity in children.

Contributions to Literature and Possible Implications of Findings

The current study highlights potential areas for adaptation of the model's applicability to children, particularly in terms of measurement, providing additional support for critical examination of the subjective norm and PBC constructs. Additionally, while not statistically significant, the inverse relationship between PBC and behavior in the second regression warrants attention. At a minimum, it provides a reminder that children are provided varying levels of control over their medication regimens, such that the "who" of responsibility cannot be assumed based solely on age or development. Clarifying, with both child and caregiver present, the level of responsibility for treatment adherence each may help physicians and other educators better tailor their instruction.

Limitations

A major limitation in the current methodology is that the primary outcome variable, adherence, was measured via self report. Within the TPB framework, Armitage and Conner (2001) describe increased variance 'explained' when behavior is self-reported versus when directly observed. That is, the observed relationships between self-reported PBC, intention, and

adherence all share method variance, i.e., self reported, which may have resulted in artificially inflated relationships between TPB variables. Above average adherence of the children in the current study limits generalizability. That is, the sample exhibited a reasonably favorable adherence profile, with most children and parents reporting adherent behavior. It is not clear how well the findings would generalize to samples of children who were less adherent with their medication regimens.

Another potential limitation of scale construction is the lack of a preliminary study to elicit behavioral, normative, and control beliefs. Ajzen advises the elicitation of salient or accessible beliefs about the specific behavior in the population to be tested prior to formal scale construction (2002). Instead, the authors of the current study relied on literature (specific to the behavior and the population) and the expertise of professionals across multiple disciplines (i.e., pharmacy, medicine, child psychology, and measurement/test construction) to provide information about salient beliefs. The rationale for this modification lies in practical application of the TPB. That is, a model requiring preliminary elicitation for each new behavior and population is unlikely to be of clinical utility given the limitless combinations of behaviors and people. As such, the authors acknowledge potential reductions in psychometric qualities for the purpose of increasing ecological validity.

Additional limitations are suggested by the sample characteristics. The current sample is not representative of the general pediatric asthma population, which is comprised of a higher ratio of African-American/Black, Hispanic, and economically disadvantaged children than that of the current study. Additionally, children in the current sample were, by report, mostly adherent. It is unclear whether or in which direction the model fit might change if the children possessed different demographic characteristics and/or were mostly non-adherent. Further, the

size of the sample relative to the number of variables might inflate regression statistics. Overall, results based this small and somewhat homogenous sample cannot be thought generalizable to the pediatric asthma population at large.

Two other general limitations, while ubiquitous in descriptive studies of prescribed behaviors, deserve mention. First, as the outcome variables in the current study hold implicit value judgments (intending to do and actually doing what one is 'supposed to' do) and are self-reported, it is likely that some participants adjusted responses in the direction thought to be socially desirable in that context. In other words, it is reasonable to assume that children in a doctor's office might rate themselves as having higher intentions and adherence in order to appear 'good,' 'nice,' etc. Further, as most children completed questionnaires in the same room with their caregiver, some might have felt uneasy about being totally honest. Although multiple efforts were made to assure children that answers would not be shared with parents or doctors, collecting data in the doctor's office with a parent just across the room may be associated with some degree of 'positive' responding. Second, while statistical analyses were conducted conservatively by following published statistical recommendations specific to analyses of TPB and expectancy-value models, e.g., utilizing corrected *p*-values to minimize error,; relationships/correlations between the predictor variables might artificially inflate the regression statistics and would suggest that a fewer number of variables are being measured (i.e., collinearity).

Implications and Future Directions

The authors recommend that future research utilizing the TPB with children directly measure subjective norm by asking important others about their own attitudes and behaviors. Alternatively, younger children in particular may be unaware of or unconcerned about others'

attitudes. Further, analysis of model by age differences is warranted, as one possibility is that the model 'fit' is different by age group. Another area of study to be considered is the PBC construct as a possible proxy for parent PBC. One way to address this issue would be the addition of direct questions regarding responsibility for behavior. In its current form, the model might, indeed *should* (theoretically) fit differently for persons who are unable/unwilling to assume responsibility for the behavior or, more importantly, unaware of their responsibility. While it could be argued that this is simply a reflection of the extent to which PBC reflects actual control, the argument is of questionable relevance when the theory is applied to children, given the influence of the caregiver's 'actual control.' In other words, a shared responsibility component as part of assessing TPB constructs may further improve the predictive power of the TPB. Further, it is possible that there are actually three separate sets of TPB variables, one for each pertinent actor in prescribed child health behaviors (the child, parent, and physician), acting in complex concert to account for child adherence.

Overall, the TPB appears to hold promise as a theoretical framework for explaining daily medication adherence in children with asthma. Despite significant limitations of sample size and variable psychometric properties of the scales, results were generally consistent with those of other TPB studies. While theoretical and practical problems related to measurement of TPB constructs in children deserve further attention, continued rigorous methodological inquiry is likely to build a theoretically grounded foundation upon which to build pediatric adherence interventions. Indeed, results of the current study highlight the clinical importance of the relationship between a child's attitudes and intentions to adhere to medication. Further, results serve as a reminder that the responsibility of adherence in children (and thus the target of

adherence interventions) cannot be assumed, based on chronological age or apparent developmental status, to fall solely with the parent or solely with the child.

Table 3.1

Participant Characteristics

	n	%
Female	9	31
Race/Ethnicity		
African American	8	27.6
Asian	2	6.9
Caucasian	16	55.2
Other	1	3.4
Unanswered	2	6.9
Medication Delivery		
Inhaled	24	82.7
Intranasal	2	6.9
Oral	3	10.3
Income		
<20,000	1	3.4
20, 000 – 39,999	4	13.8
40,000 – 59,999	5	17.2
>60,000	16	55.2
Unanswered	3	10.3
Insurance Status		
Medicaid/Peachcare	6	20.7
Private Insurance	20	69.0

Self-pay		1	3.4
Other/Unanswered		2	6.8
	M	*SD*	Range
Age	11.17	2.1	8-17

Table 3.2

Internal Consistency Reliability for Attitude, Subjective Norm, Perceived Behavioral Control, and Intention Scales (N = 29)

Scale/Item	α/if [a]	α/if [a]	α/if [a]	*M*	*SD*
Attitude Total Scale	.527	.697		19.69	4.19
It's good to take…	.564	.750			
It's a waste of time to…	.519	.713			
It's frustrating to take…	.379	.631			
I like taking…	.335	.557			
It's bad to take…	.423	.660			
I hate taking…	.312	.553			
It's useful to take…	.697				
Subjective Norm Total Scale	.557	.578	.605	13.90	2.30
My friends take… [b]	.500	.534	.533		
My parents think it's good for me to take…	.573	.594	.690		
People I like want me to take…	.411	.434	.458		
My friends think it's bad to take…	.455	.450	.406		
Kids at school want me to take…	.528	.605			
My family members take… [b]	.578				
My parents don't want me to take… [c]					
PBC Total Scale	.538	.561	.624	16.93	3.25
It's hard to take	.456	.428	.527		
Other people decide whether I take	.527	.479	.580		
I don't know if I can take	.534	.588	.647		
It's easy to take	.450	.451	.539		

I can't take	.438	.487	.544		
It's up to me to take	.529	.624			
If I want to, I can take	.561				
Intention Total Scale	.726			25.24	3.63
I'm going to take	.742				
I want to take	.614				
I mean to take	.772				
I plan to take	.654				
I try to take	.644				
I will take	.699				
I won't take	.697				

Note: All items end with the "my medicine like I should," except where indicated.

[a] = Cronbach's alpha for total scale, alpha if item deleted for items.

[b] = Item phrase ends with "THEIR medicine like they should."

[c] = Item automatically excluded due to zero variance.

Table 3.3

Correlations between TPB Variables (N = 29)

Variable	1	2	3	4	5
1. Attitude	–	.44	.33	.55*	.28
2. Subjective Norm		–	.17	.40	.30
3. Perceived Behavioral Control			–	.51*	.30
4. Intention				–	.62*
5. Adherence					–

* $p < .05$

Table 3.4

Multiple Regression Analysis of Attitude, Subjective Norm, and Perceived Behavioral Control as Predictors of Intention (N = 29)

Variable	*B*	SE *B*	β	Adjusted R^2	Standard Error of Estimate	R^2 Change
Intention				.38	2.85	.45
Attitude	0.30	0.15	.35			
Subjective Norm	0.29	0.26	.19			
PBC	0.41	0.18	.36*			

Note. PBC = Perceived Behavioral Control. * $p < .05$; ** $p < .01$

Table 3.5

Multiple Regression Analyies of Perceived Behavioral Control and Intention as Predictors of Adherence (N = 29)

Variable	*B*	SE *B*	β	Adjusted R^2	Standard Error of Estimate	R^2 Change
Adherence Behavior				.34	0.90	.38
PBC	-0.01	0.06	-.03			
Intention	0.19	0.05	.63**			

Note. PBC = Perceived Behavioral Control. * $p < .05$; ** $p < .01$

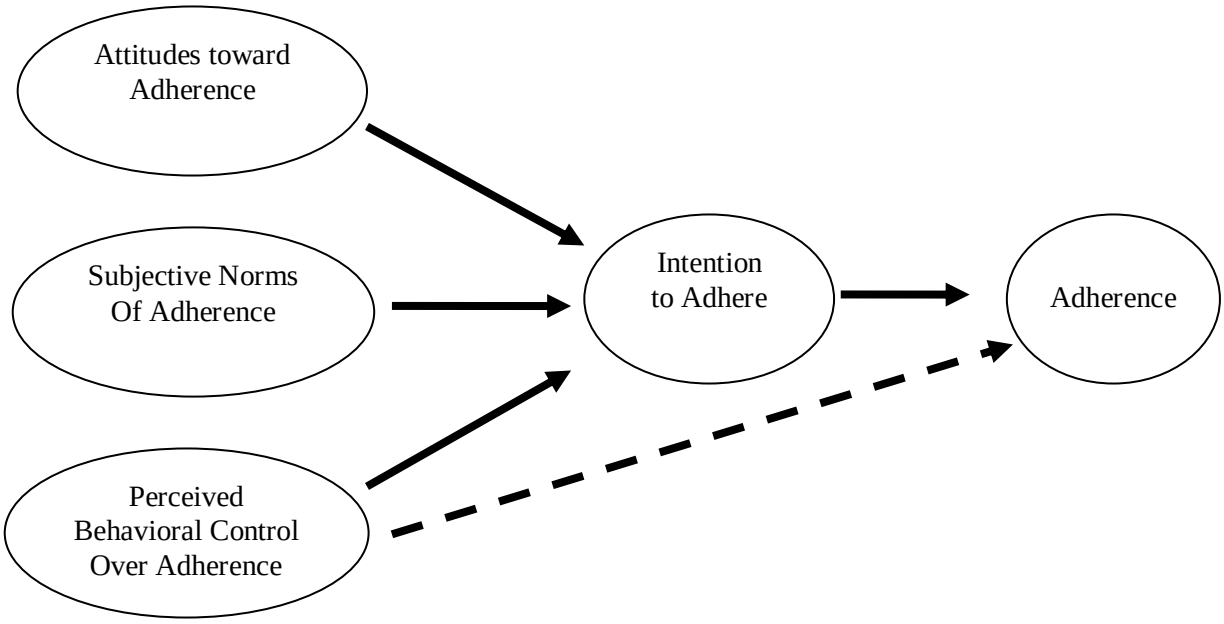

Figure 3.1

Theory of Planned Behavior Model

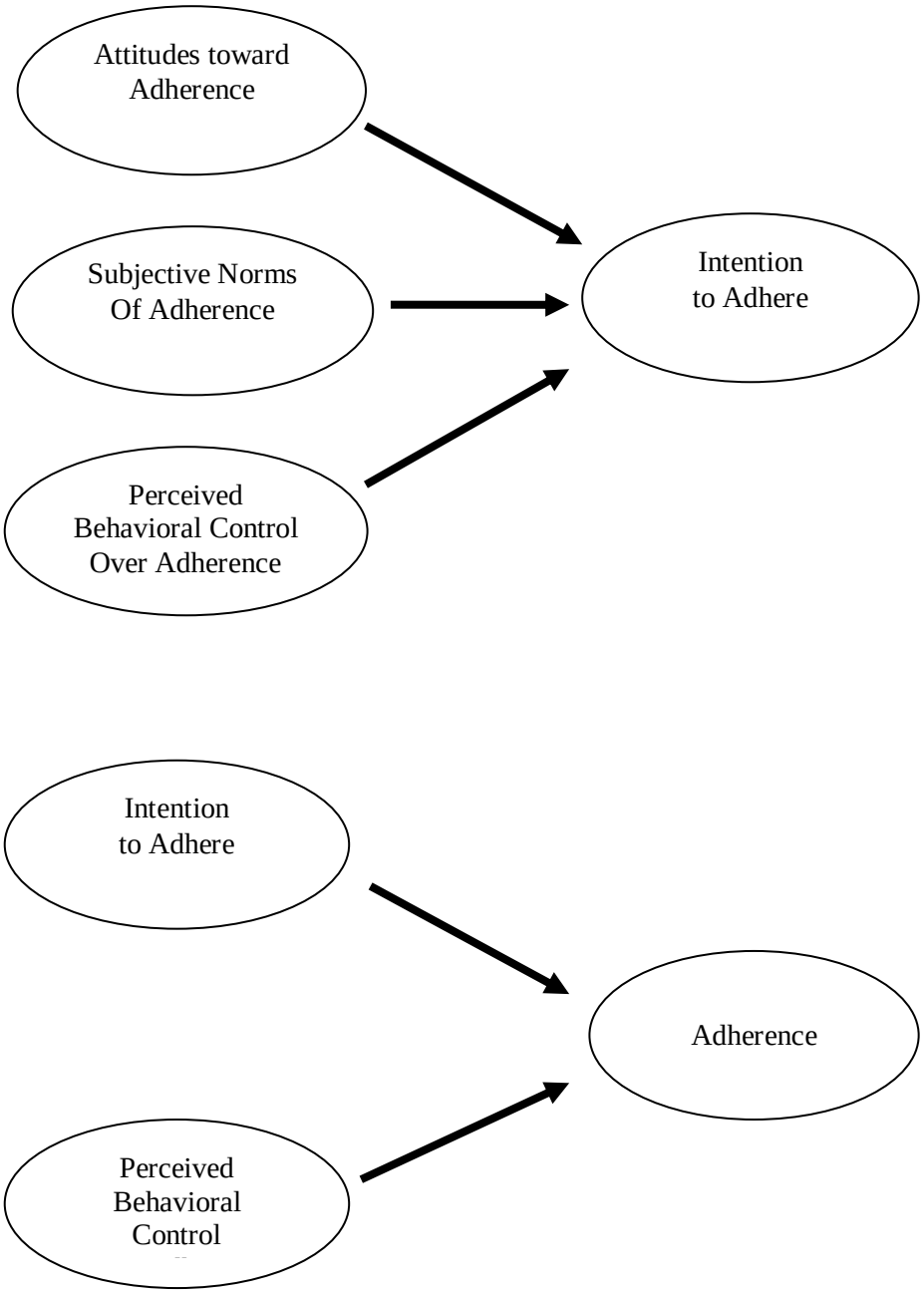

Figure 3.2

Representation of TPB Components Arranged by Multiple Regression Variables

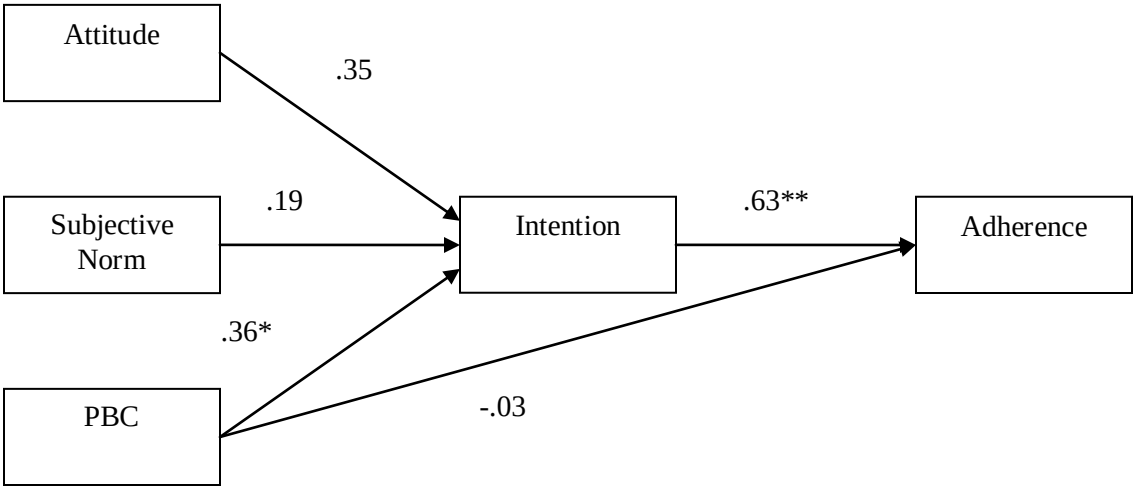

Figure 3.3

Path Diagram for Results of Multiple Regression Analyses

Note. PBC = Perceived Behavioral Control. *p < .05; **p <.01

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CHAPTER 4

DISSERTATION SUMMARY AND CONCLUSIONS

Great strides have been made in the policy, science, and technology of healthcare. In recent years, the policy initiatives in the United States have resulted in increased access to healthcare services through low-cost and no-cost public health insurance programs for children. Treatment guidelines for various chronic illnesses have been published and promoted in many nations (for review of various national asthma guidelines, see Cope, Ungar, & Glazier, 2008). Medications to manage chronic illness are more effective, result in fewer side effects, and can be delivered through less complex regimens (e.g., reduced frequency of administration due to long-acting and combined formulations) than ever before. Scientists have even devised more palatable formulations of medications for children (e.g., Hames, Seabrook, Matsui, Rieder, & Joubert, 2008). Monitoring of medication maintenance has also become more sophisticated through the widespread use electronic medical records, availability of device technologies (e.g., MEMS caps), internet data transmission (e.g., Chan et al., 2007; Jan et al., 2007), and healthcare professionals' increased attention to/awareness of adherence issues. Despite these advances in policy, science, and technology, non-adherence and resultant poor management of chronic illness in children continues to occur at alarming rates.

In an effort to advance the understanding of non-adherence in children, this dissertation was undertaken with two primary aims. The first of these aims was to examine the current status of adherence research in children with chronic illness, with particular attention to promising theoretical frameworks around which a science of pediatric adherence could be built through empirical means. An extensive review of adherence literature revealed several themes. First, and

perhaps least surprising, pediatric adherence research lags behind that of adult adherence research. Second, no well-researched, child-specific models of adherence were found. Third, each of the models with potential utility in the study of pediatric adherence (Transtheoretical Model, Health Behavior Model, Social Cognitive Theory, and Theory of Planned Behavior) demonstrated strengths and weaknesses. Finally, of the models examined, the Theory of Planned Behavior has demonstrated the most promise as a potential framework for medical treatment adherence in children, based on an extensive literature and explicit research guidance (e.g., Ajzen, 2002; Francis et al., 2004; Hankins et al., 2000), amount of variance explained in previous studies (for a meta-analytic review of studies, see Armitage & Conner, 2001), and parsimony of design.

The second aim of this dissertation was to empirically test the Theory of Planned Behavior (TPB) as a framework for pediatric adherence. More specifically, 29 children with asthma completed measures assessing the constructs of the TPB (Attitudes, Subjective Norms, Perceived Behavioral Control, intentions, and behavior) specific to adherence behavior for daily controller medication. Relationships between variables were analyzed using two multiple regression models aligned with TPB theoretical predictions. Multiple regression analyses provided general support for the overall model; however, PBC was the only significant independent predictor of Intention, and Intention was the only significant independent predictor of self-rated adherence behavior. Overall, results suggest that the TPB provides a useful groundwork on which to build a theoretical framework to explain and predict adherence in children with asthma. The TPB alone, however, appears insufficient to explain/predict child adherence behavior. The constructs of Subjective Norm and PBC, in particular, may require

developmentally-tailored operationalization and/or differing methods of assessment (e.g., measures of perspective-taking, parent variables, perceived responsibility) with children.

Perhaps more important than evidence supporting the TPB's potential utility in the study of pediatric asthma adherence are the questions that remain. There is a substantial body of TPB research literature and commendable attention paid to methodological integrity of TPB research (e.g., Ajzen, 2002; Francis et al., 2004; Hankins et al., 2000); however, whether studied in adults or children, the TPB offers only partial explanation of adherence behavior. Recent attempts to expand, revise, and account for child-relevant variables (e.g., parents and parenting) are encouraging (e.g., Cha, Kim, & Doswell, 2007; de Bruijn et al., 2007; Desrichard, Roche, & Begue, 2007; O'Callaghan & Nausbaum, 2006; White et al., 2008). Though continued study of the TPB in children is certainly warranted, research regarding more fundamental aspects of TPB model testing are critical. That is, research of TPB measurement practices, implicit assumptions in method of measurement, cultural differences, among others, is likely to provide clues regarding discrepant findings and less than optimal prediction. Indeed, measurement integrity should be the first order of business in the validation of any model, but particularly so when applied to outcomes of health and mortality. Further, the importance of true multi-disciplinary efforts cannot be overstated. Researchers must be willing to think creatively and to challenge dominant paradigms, while focusing on foundational efforts of theory building. It is understandable and even commendable that many researchers bypass theory and measurement in an effort to quickly solve the alarming problem of non-adherence through intervention protocols and treatment studies; however, these efforts may be enhanced through alignment with theory and careful measurement.

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APPENDIX A

DQ

Caregiver Information

1. Your Age: _____

2. Your gender (circle): Male Female

3. Your relationship to child (circle):
   - Parent
   - Grandparent
   - Foster Parent
   - Other (please list)_____

4. Your Race/Ethnicity (circle):
   - Asian
   - Black/African American
   - Hispanic
   - Native American/ Pacific Islander
   - White/Caucasian
   - Other (please list) _____

5. Marital Status (circle):
   - Single
   - Married
   - Divorced
   - Separated
   - Widowed
   - Other (please list) ___

6. Please list, by relationship to you, each person living in the home (include age).

Example: Son, 7 years old; Boyfriend 42 years old; Mother, 79 years old.

_____
_____
_____
_____

7. If the child here with you today does not live in your household, please indicate where he/she lives: _____

8. Annual Household Income (circle): less than $20,000

$20,000 - $39,999

$40,00 - $59,999

More than $60,000

9. Employment Status (circle): Full-time

Part-time

Not employed

10. What type of payment do you use for your child's doctor visits? (circle)

Medicaid/Peach Care

Self-pay

Private Insurance

Other: _____

11. Has anyone else in this child's immediate family (including parents) ever been diagnosed with asthma? (circle)

No

Yes (please list all) _____
_____
_____

12. Has anyone else in this child's immediate family ever been diagnosed with another major health condition? If yes, who and what?
_____
_____
_____

Child Information (Please provide the following information about your child who is visiting the clinic today)

1. Child Age: _____

2. Child Race/Ethnicity (circle): Asian

Black/African American

Hispanic

Native American/ Pacific Islander

White/Caucasian

Other (please list) _____

3. Does your child have difficulty reading or writing? Y or N

If yes, Please describe: _____
_____

4. Does your child have any other major health conditions besides asthma? Please describe.
_____
_____
_____

5. Has your child received allergy shots at this clinic in the past 6 months? Y or N

6. Do you take vitamins on a regular basis? Y or N

7. Does your child take vitamins on a regular basis? Y or N

8. Do you use any natural, herbal, or homeopathic remedies? Y or N

9. Does your child use any natural, herbal, or homeopathic remedies? Y or N

If yes, please describe: _____
_____
_____
_____

APPENDIX B

MAQ – Child

Interviewer reads: *Your doctor prescribes* [interviewer fill in name of med] _____ *for asthma. Tell me what that medicine looks like?* [If correct, continue. If incorrect, describe the medicine, then continue with instructions]. *The following questions ask about how you take that medicine and only that medicine. Kids sometimes have trouble taking their medicine, sometimes take less or more than is prescribed, and sometimes miss doses of their medicine. Remember, there are no right or wrong answers. Your answers won't be shared with your parents or your doctors, so please be honest. Always ask me if you don't understand something or if you need help reading the words.*

1. How many times per day does your doctor say to take this medicine? _____

2. Over the past three days, how many days have you taken the medication listed in #2 EXACTLY AS YOUR DOCTOR SAYS? (circle one)

0 days 1 day 2 days 3 days

3a. Did you miss ANY doses of this medicine over the past three days? Y or N

3b. Did you take ANY extra doses of this medicine over the past three days? Y or N

4. There are many reasons kids miss doses of medicine. Some common reasons are listed below. Please put a check next to any of the reasons that have caused you to miss taking your medicine. You can check more than one.

__ Medicine is too expensive or sometimes can't afford it.*
__Can't always get to the pharmacy.*
__I don't like something about the medicine (such as how it tastes, smells, the way I take it, or how it makes me feel).
__I forget to take the medicine.
__I don't always need the medicine.
__Not enough time (before school, before bed, etc.).
__Forget medicine at home when going somewhere.*
__I have trouble opening the bottle or making medicine come out of the inhaler.*
__My parents forget to give it to me.
__We ran out of the medicine.

5. Please list any other reasons why you have missed doses of medicine:

_____

_____

_____

6. What do you LIKE about taking your medicine exactly as your doctor prescribes it:

_____

_____

_____

7. What do you DISLIKE about taking your medicine exactly as your doctor prescribes it?

_____

_____

_____

8. Who is MOST in charge of making sure you take your medicine? (circle one)

You

Your mom or dad

Someone else (like the school nurse or babysitter)

9. Check which things your parents do almost all the time: (you can check more than one)

___Remind you to take your medicine.
___Give you your medicine (hand you your pill or inhaler when you're supposed to take it)
___Ask you if you've taken your medicine.
___Watch you take your medicine.

APPENDIX C

MAQ – Parent

1. Please list the medications your child takes, along with the dosage, scheduling, and the length of time your child has been prescribed this medication:

Medication	Dose (mg)	Times per day	How long on this med?

2. Your child takes a daily controller medication for asthma or allergies. Please name this medication here (ask the researcher if you're not sure). _____

3. Over the past three days, how many days has your child taken the medication listed in #2 EXACTLY AS IT WAS PRESCRIBED? (circle one)

0 1 2 3

4a. Did your child miss ANY of the prescribed doses of the medication listed in #2 over the past three days? (circle)

Y or N

4b. Did your child take ANY extra doses of the medication listed in #2 over the past three days?

Y or N

5. There are many reasons children miss doses of the medication listed in #2. Some common reasons are listed below. Please put a check next to any of the reasons that affect the way your child takes his or her medication (check all that apply).

__ Medication is too expensive or sometimes can't afford it.*
__Don't always have transportation to the pharmacy.*
__My child refuses because he or she does not like something about the medication (such as how it tastes, smells, the procedure, or how it makes them feel).
__My child forgets to take the medication.
__My child doesn't always need the medication.
__Not enough time (before school, before bed, etc.).
__Forgets medication at home when going somewhere.*
__I or my child have difficulty opening the bottle/ actuating the inhaler.*
__I forget to give my child the medication.
__We ran out of the medication.

6. Please list any reasons your child has missed doses of medication that were not listed above:

_____

_____

_____

7. What do you think are the ADVANTAGES of your child taking this medication exactly as it is prescribed by the doctor?

_____

_____

_____

8. What do you think are the DISADVANTAGES of your child taking this medication exactly as it is prescribed by the doctor?

_____

_____

_____

9. Who assumes the MAIN responsibility for administering your child's doses of THIS medication (check one only)?

___Child
___Parent
___Other. If you check "Other", please list that person's role. For example, school nurse, babysitter, other caregiver, etc. (please list) _____

10. Which of the following do you or another caregiver do on a REGULAR basis (check all that apply):

___Remind your child to take his/her medicine.
___Watch your child take his/her medicine.
___Give your child his/her medicine (hand them the inhaler or pill).
___Ask your child if he/she remembered to take their medicine.

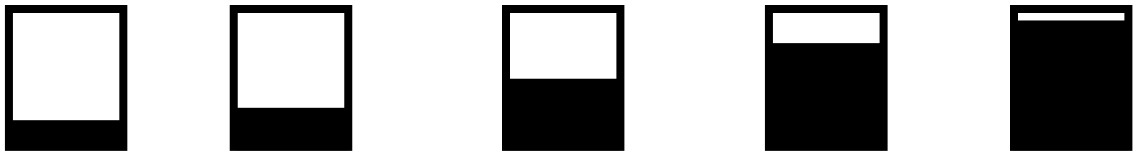
APPENDIX D

TPBQ

Examiner reads: *These questions ask about how you think and feel about taking your _____(fill in w/ appropriate med) exactly as your doctor says, or like you should. Kids have lots of different feelings about taking their medicine. Your answers will not be shared with your parents or your doctors, so please be honest.*

These questions are answered a little differently. Let's do an example.

A. I like puppies.



Almost Never Not very often Sometimes Often Almost Always

1. **It's good to take my medicine like I should.**

Almost Never Not very often Sometimes Often Almost Always

2. **My friends take THEIR medicine like they should.**

Almost Never Not very often Sometimes Often Almost Always

3. **It's hard to take my medicine like I should.**

Almost Never Not very often Sometimes Often Almost Always

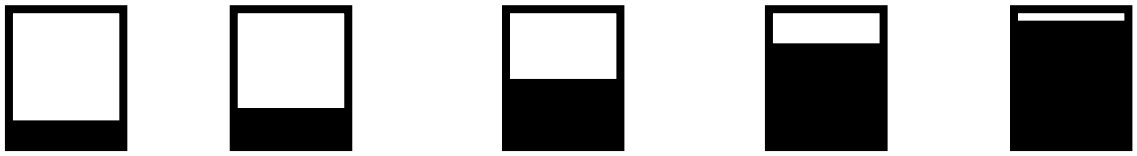
4. **I'm going to take my medicine like I should.**

Almost Never Not very often Sometimes Often Almost Always

5. **It's a waste of time to take my medicine like I should.**

Almost Never Not very often Sometimes Often Almost Always

Remember,



Almost Never Not very often Sometimes Often Almost Always

6. My parents think it's good to take my medicine like I should.

Almost Never Not very often Sometimes Often Almost Always

7. If I want to, I can take my medicine like I should.

Almost Never Not very often Sometimes Often Almost Always

8. I want to take my medicine like I should.

Almost Never Not very often Sometimes Often Almost Always

9. It's frustrating to take my medicine like I should.

Almost Never Not very often Sometimes Often Almost Always

10. People I like want me to take my medicine like I should.

Almost Never Not very often Sometimes Often Almost Always

11. It's up to me to take my medicine like I should.

Almost Never Not very often Sometimes Often Almost Always

12. I mean to take my medicine like I should.

Almost Never Not very often Sometimes Often Almost Always

Remember,

Almost Never Not very often Sometimes Often Almost Always

13. I like taking my medicine like I should.

Almost Never Not very often Sometimes Often Almost Always

14. Kids at school want me to take my medicine like I should.

Almost Never Not very often Sometimes Often Almost Always

15. Other people decide whether I take my medicine like I should.

Almost Never Not very often Sometimes Often Almost Always

16. I plan to take my medicine like I should.

Almost Never Not very often Sometimes Often Almost Always

17. It's bad to take my medicine like I should.

Almost Never Not very often Sometimes Often Almost Always

18. My family members take THEIR medicine like they should.

Almost Never Not very often Sometimes Often Almost Always

19. I don't know if I can take my medicine like I should.

Almost Never Not very often Sometimes Often Almost Always

Remember,

Almost Never Not very often Sometimes Often Almost Always

20. I try to take my medicine like I should.

Almost Never Not very often Sometimes Often Almost Always

21. I hate taking my medicine like I should.

Almost Never Not very often Sometimes Often Almost Always

22. My friends think it's bad to take my medicine like I should.

Almost Never Not very often Sometimes Often Almost Always

23. It's easy to take my medicine like I should.

Almost Never Not very often Sometimes Often Almost Always

24. I will take my medicine like I should.

Almost Never Not very often Sometimes Often Almost Always

25. It's useful to take my medicine like I should.

Almost Never Not very often Sometimes Often Almost Always

26. My parents don't want me to take my medicine like I should.

Almost Never Not very often Sometimes Often Almost Always

Remember,

Almost Never Not very often Sometimes Often Almost Always

27. I can't take my medicine like I should.

Almost Never Not very often Sometimes Often Almost Always

28. I won't take my medicine like I should.

Almost Never Not very often Sometimes Often Almost Always