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Preliminary Validation of the Pediatric Rating of Chronic Illness Self-Efficacy

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Preliminary Validation of the Pediatric Rating of Chronic Illness Self-Efficacy

by

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Each person whose signature appears below certifies that this thesis in his/her opinion is adequate, in scope and quality, as a thesis for the degree Doctor of Philosophy.

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ABBREVIATIONS

PRCISE	Pediatric Rating of Chronic Illness Self-Efficacy
CI	Chronic Illness
PHQ-A	Patient Health Questionnaire for Adolescents
CDSES	Chronic Disease Self-Efficacy Scales
LLU	Loma Linda University
ER	Emergency Room
PHQ	Patient Health Questionnaire
ICD	Informed Consent Document
EM	Expectation Maximization
EFA	Exploratory Factor Analysis
MCAR	Missing Completely at Random
PAF	Principal Axis Factoring
MLR	Multiple Linear Regression
KMO	Kaiser-Meyer-Olkin
ANOVA	Analyses of Variance

ABSTRACT OF THE DISSERTATION

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Dr. Brian Distelberg / Dr. Cameron Neece: Co-Chairpersons

Introduction: Tracking self-efficacy may be useful for identifying children at risk for medical noncompliance. We created the Pediatric Rating of Chronic Illness Self-Efficacy (PRCISE) to measure self-efficacy in children and adolescents dealing with a chronic illness (CI). **Method:** Data were collected from 217 families where one child aged 7-20 (M_{age} = 13.62, SD_{age} = 2.92; 62.7% Latino, 58.1% female) had a CI. Parent participants provided demographic information. Youth completed a depression measure, the Patient Health Questionnaire for Adolescents (PHQ-A), and the PRCISE. To determine the underlying latent structure of the scale, an exploratory factor analysis was conducted using parallel analysis. We also carried out three multiple linear regressions to explore the data and establish preliminary predictive validity. **Results:** The measure was reduced to 15 items, demonstrating a one-factor solution with strong reliability. Predictors of lower self-efficacy included having parents who had not attended college, being African American, and having higher PHQ-A scores (R^2 = .23, F[11, 174] = 5.62, p < .001.) Main effects were qualified by a two-way interaction, such that the decrease in PRCISE scores associated with depressive symptoms was attenuated in children with less educated parents. In terms of predictive validity, higher PRCISE scores unexpectedly predicted more number of ER visits (R^2 = .12, F[9, 113] = 2.73, p < .01). **Discussion:** The PRCISE

appears to be a reliable measure of a single self-efficacy construct. Secondary analyses revealed important health disparities in pediatric CI self-efficacy. Next steps may include validation of the PRCISE using confirmatory factor analysis.

Key Words: self-efficacy; chronic illness; health disparities; pediatrics

CHAPTER ONE

INTRODUCTION

Self-efficacy can be defined as the belief in one's ability to succeed. In regards to health, self-efficacy can predict, moderate, and mediate health behavior change (Bandura, 2004). Self-efficacy may be particularly important to study in pediatric chronic illness (CI), given the high rate of medical nonadherence in this population. In fact, as children mature into adolescents, developmentally expected drops in self-efficacy may explain the increase in non-adherence to medical regimens during this period (Wigfield & Wagner, 2005). Increasing patient self-efficacy has been associated with a number of health improvements, including medical adherence and health knowledge, reduced illness activity, and increased positive health behaviors across different patient populations and illness types (Armstrong, Mackey, & Streisand, 2011; Bandura, 2004; Dunbar-Jacob & Mortimer-Stephens, 2001).

Despite the importance of this construct to the management of pediatric CI, only disease specific self-efficacy scales have been developed, rendering the study of childhood and adolescent self-efficacy across multiple disease types difficult. To address this limitation, we developed a measure of self-efficacy in pediatric CI. The aim of the current study is to develop and evaluate the psychometric properties of the Pediatric Rating of Chronic Illness Self-Efficacy Scale (PRCISE, pronounced ‘precise’) in children ages 7 to 20 with a CI. Participants were recruited from patient populations being served by the Loma Linda University Health System.

Self-Efficacy

Bandura (1997) defined self-efficacy as being composed of "beliefs in one's capabilities to organize and execute the courses of action required to produce given attainments" (p. 3). Self-efficacy refers to the belief that outcomes can be achieved through the performance of actions related to one's unique abilities and attributes (Riggio, 2012). While self-efficacy can be described as a general attribute, it may also differ based on circumstance. For instance, an individual may have high self-efficacy globally, but have low self-efficacy in regards to a specific task. To this end, self-efficacy may also depend on the situation, environment, and degree of similarity with prior experiences (MacKinnon, 2015; Riggio, 2012).

When embarking on a discussion about self-efficacy, the construct must first be distinguished from both self-esteem and self-concept. The underlying construct of self-efficacy is potency (MacKinnon, 2015). Self-efficacy answers the question: am I capable of? By contrast, self-esteem is a judgment of self-worth that is expressly related to evaluation (Bandura, 2006; MacKinnon, 2015). Similarly, self-concept differs from self-efficacy in that it relates to identity and individuality (MacKinnon, 2015). Self-concept refers to an auto-assessment of one's characteristics, qualities, and uniqueness (Ferro & Boyle, 2013; MacKinnon, 2015). It thus answers the question: who am I? Some researchers have argued that self-esteem is simply the evaluative component of self-concept (MacKinnon, 2015).

While all three constructs can be understood as falling under the umbrella of self-sentiment, defined as the overarching term for attitudes and opinions we hold of ourselves (MacKinnon, 2015), self-efficacy also differs from the other two in that it is

thought to significantly vary across situations (Riggio, 2012). Self-efficacy should also be differentiated from locus of control, a construct of outcome contingency that answers the question: who determines the outcome of this situation? Individuals high in locus of control hold the belief that they are responsible for outcomes (i.e., that their actions will have meaningful repercussions). While individuals high in self-efficacy tend to have a high locus of control, the reverse is not necessarily true. One can feel responsible for an outcome yet incapable of meeting its demands (Bandura, 2006).

Authors like MacKinnon (2015) have argued that self-efficacy is in fact a motivational construct. Personality theorists propose that identity develops as a response to external reactions to our behaviors. If reactions are displeasing, we subsequently modify our behaviors, values, and attitudes in order to make sense of the world (MacKinnon, 2015). If by contrast reactions are as expected, we generalize this success to other behaviors, thereby increasing our sense of potency (MacKinnon, 2015). As our ability to gauge these reactions correctly increases, so does our self-efficacy, further promoting agency and the pursuit of new achievements (MacKinnon, 2015). For instance, a diabetic child learning to undertake his own blood sugar measurement may be naturally reinforced by feeling proud that he has correctly identified the physiological signs of hypoglycemia. This success and new aptitude may then promote more careful and informed monitoring.

Self-efficacy influences behavior and motivation through four processes: cognitive, affective, motivational, and selection (Bandura, 2014). By affecting our belief in our ability to accomplish certain goals, self-efficacy operates through *cognitive processes* that help us construe the world and predict future behaviors (Riggio, 2012). As

aforementioned, self-efficacy is also important to *motivational processes*. Studies have shown that people high in self-efficacy pursue goals more ambitiously and achieve more than their counterparts who are low in self-efficacy with the same skill level (Riggio, 2012). Self-efficacy also impacts *emotional processes* by leading us to make evaluative statements about our abilities. If we repeatedly experience fear and anxiety in response to failure, we may abandon and/or modify our pursuits (Riggio, 2012). Accordingly, self-efficacy also affects *selection* of activities by expanding or minimizing our pursuits. Those high in self-efficacy consistently choose more challenging goals, leading to important repercussions for both career and life trajectories (Riggio, 2012).

Self-Efficacy in Childhood

While self-efficacy continues to change throughout the lifespan, the development of self-efficacy begins in infancy (Schunk & Pajares, 2005). Children's self-efficacy is first and foremost influenced by their parents, though the relationship between child and family is bidirectional. While parents can provide a home that fosters exploration and promotes self-efficacy, parents are also influenced by the degree to which their children are curious and motivated (Schunk & Pajares, 2005). This relationship is also moderated by resources in the home and community (having access to books, parks, libraries, child care), as well as by parents' own qualities. In regards to the latter, parents who are more attuned to their children's temperamental needs and are consistently accepting, responsive, and warm encourage cognitive development (Schunk & Pajares, 2005). Children also learn about self-efficacy vicariously by seeing parents and other adults in

the community competently handle challenges and problem solve (Schunk & Pajares, 2005).

Once of school age, children also learn about self-efficacy from their peers and teachers (Schunk & Pajares, 2005). Self-efficacy development may depend on a number of factors, including type of peer network (i.e., having high-achieving versus low-achieving friends), relatedness to the school involvement (i.e., the degree to which children feel they fit in and participate in school activities), and natural academic transitions. With respect to the latter, self-efficacy is thought to decline as children move through school, due to increases in academic demands, better metacognition and peer comparison skills, and less teacher attention and individual feedback (Schunk & Pajares, 2005). However, given the natural improvement in cognitive skills as children age, self-efficacy is thought to generally become more accurate over time (Schunk & Pajares, 2005).

Self-Efficacy in Adolescence

Much of the research on adolescence and beliefs of competence has focused on the impact of self-efficacy on academic achievement (Wigfield & Wagner, 2005). Broadly, adolescents who have a higher sense of self-efficacy have a stronger sense that they control achievement outcomes and are thus likelier to put forth more effort to optimize these outcomes, leading to higher academic achievement (Wigfield & Wagner, 2005). Researchers also note that while children's motivation becomes more stable over time, including perceptions of competence, valuing of achievement, and intrinsic motivation, it takes a significant hit during early adolescence (Wigfield & Wagner, 2005). Specifically,

while general self-efficacy beliefs remain stable, perceptions of competence decrease. In other words, adolescents who are high in intrinsic motivation and self-efficacy will remain relatively high from year to year, but may exhibit a relative decline during the teenage years (Wigfield & Wagner, 2005).

Self-Efficacy and Physical Health

In regards to health, self-efficacy can predict, moderate, and mediate health behavior change (Schwarzer, 2008). Self-efficacy directly influences health behaviors through both stress appraisal and stress response (Jerusalem & Schwarzer, 2014), and via attributions of locus of causality, stability, and control (Kok et al., 2014). To begin, self-efficacy is a determinant of stress appraisal (Jerusalem & Schwarzer, 2014). Stress appraisal theorists propose that we assess environmental stressors using a two-step process. When faced with a potential threat, we use primary appraisal to determine whether danger is imminent and secondary appraisal to assess our capacity to deal with said threat (Jerusalem & Schwarzer, 2014). Self-efficacy can moderate appraisal of stressful situations by helping individuals both accurately identify the nature and degree of the stressor, and bolster motivation and resources to resolve the issue. As such, high self-efficacy has been associated with more tempered reactions to stressful situations (Jerusalem & Schwarzer, 2014). Once stress has been appraised, self-efficacy also dictates the course of threat response. Bandura (2014) summarized this conclusion by explaining that self-efficacy mediates the intention to change, the effort expended towards this change, and the persistence we show in light of the barriers we face.

Attribution mechanisms may further explain the effect of self-efficacy on health

behaviors (Kok et al., 2014). Individuals act in accordance to three attributional constructs: locus of causality (i.e., is the cause internal or external?), stability (i.e., is this likely to change?), and controllability (i.e., can my behaviors affect change?). Individuals with high self-efficacy are more likely to feel as though they can exert influence on the outcome of a given situation, which directly impacts goal setting and attainment (Kok et al., 2014). Consequently, in order to empower patients to change, interventions must go beyond psychoeducation about the benefits of a particular behavior (Kok et al., 2014). Interventionists must boost self-efficacy by both addressing a patient's incorrect attributions about health behaviors and increasing coping skill repertoires (Kok et al., 2014). Interventions for patients with CI that target self-efficacy have been associated with improved medical adherence and health knowledge, reduced illness activity, and increased positive health behaviors across different patient populations and illness types (Bandura, 2004; Dunbar-Jacob & Mortimer-Stephens, 2001; Griva, Myers, & Newman, 2000). Self-efficacy interventions may also modify maladaptive biological responses to stress. Perceived self-efficacy has been shown to affect immune function, blood pressure, heart rate, and serum catecholamine levels in challenging situations (Schwarzer, 2014).

Self-Efficacy and Chronic Illness

Self-efficacy may be particularly important when it comes to chronic medical conditions. In contrast to acute diseases and their treatment, chronic conditions almost always require some degree of self-management (Holman & Lorig, 2014). CI is also unique in that the patient often becomes the most knowledgeable person about the illness in terms of day-to-day manifestations and the impact of lifestyle factors and treatments

on health status (Holman & Lorig, 2014). As such, not only is a trustworthy partnership between patient and professional necessary to optimize outcomes, patients must also have enough self-efficacy to undertake the responsibility of self-management (Holman & Lorig, 2014). Otherwise, patients who have little knowledge about their CI and little confidence in their ability to manage it may be paralyzed by fear and anxiety and unable to self-manage. Holman and Lorig (2014) identified seven basic skills necessary for the proper management of a chronic condition, most of which are primarily determined by the patient rather than by the physician: "[1] minimizing or overcoming physical debility, [2] establishing realistic expectations and emotional responses to the vicissitudes of the illness, [3] interpreting and managing symptoms, [4] learning how to judge the effects of medications and manage their use, [5] becoming adept at ways to solve problems as they arise, [6] communication with health professionals and [7] using community resources to advantage" (p. 311). Researchers have established that self-efficacy directly contributes to all seven skills by influencing health choices, health behavior change motivation, and perseverance in the face of medical difficulty; the impact of negative thoughts associated with the CI; and comorbid stress and depression (Holman & Lorig, 2014).

Bandura (1986) proposed four ways to build self-efficacy in patients with CI. First, patients can achieve a sense of mastery over health behaviors through the chunking or chaining of complicated health behaviors (such as measuring blood sugar and administering insulin). This effectively helps patients feel progressively capable and builds coping skills that may be generalized to other complex or unpleasant management behaviors (Holman & Lorig, 2014). Second, patients can learn management techniques through social modeling by peers (e.g., seeing a fellow patient demonstrate difficult

physical therapy exercises rather than a practitioner). Third, social persuasion may be an important step in convincing patients that they can perform the suggested behavior. This may involve urging patients to set and reach easy goals rather than the final objective (e.g., encouraging a patient to lose five pounds rather than the ultimate forty). Finally, professionals can teach patients to reduce adverse physiological reactions to the illness or its treatments by gaining awareness about the antecedents of symptoms and the required behaviors to minimize their effects (Holman & Lorig, 2014).

To conclude, chronic illnesses are often incurable conditions that require lifelong management, most of which depends on actions taken by patients themselves. Given that the belief in one's capacity to alter outcomes is key to performing required management behaviors, self-efficacy interventions may help patients build the confidence and coping skills necessary to undertake the many responsibilities of CI management. Likewise, being able to identify patients with low self-efficacy can help providers address the incorrect assumptions and attributions that sustain avoidance of self-management and nonadherence behaviors.

Self-Efficacy and Chronic Illness in Adolescents

Prevalence of CI among children has risen since the 1990s due to continued scientific advances and improvements in diagnoses and treatments (Burns et al., 2010; Van Cleave, Gortmaker, & Perrin, 2010). In the United States, 13 to 27% of adolescents have a chronic medical condition (Anderson, 2010; Modi et al., 2012). Nearly half of these youths are considered noncompliant with their treatment regimen, which increases risk for complications, hospitalizations, and disability (Brown, Daly, & Rickel, 2007).

Moreover, noncompliance costs the United States 100 billion dollars every year (Nichols-English & Poirier, 2000).

Adolescence itself has been identified as a predictor of increased medical nonadherence, independent of childhood adherence and family climate (Fiese & Everhart, 2006). Besides entering the teenage years, other factors may explain nonadherence, including forgetfulness, oppositional behaviors, time management problems, and resistance related to denial of the disease and to peer conformity (Brown et al., 2007). As is the case with CI management in adulthood, self-efficacy has been identified as an important predictor of management success for adolescents (Dunbar-Jacob & Mortimer-Stephens, 2001). For instance, Griva et al. (2000) found that 30% of the variance in HbA1c levels for adolescents with Type I diabetes could be explained by participants' self-efficacy and illness perceptions. Other researchers have observed similar findings among adolescents with asthma (Bursch, Schwankovsky, Gilbert, & Zeiger, 1999), chronic pain (Bursch, Tsao, Meldrum, & Zeltzer, 2006), epilepsy (Caplin, Austin, Dunn, Shen, & Perkins, 2002), and other forms of pediatric CI (Anderson, 2010; Armstrong et al., 2011; Barlow & Ellard, 2006), highlighting the importance of self-efficacy in the management of pediatric CI.

Self-Efficacy and Mental Health

There is also ample evidence that self-efficacy is related to depression. Kavanagh (2014) summarizes the complex relationship between the two variables: "…lower self-efficacy may be making people depressed, the depression may be undermining their self-efficacy, or depression may be indirectly affecting self-efficacy through an impact on

performance attainments" (p. 177). In other words, the relationship between depression and self-efficacy is bidirectional. Low self-efficacy can contribute to the feelings of helplessness and hopelessness that can both incite and sustain depression (Kavanagh, 2014). Depression can also further reduce a person's self-efficacy by making their self-sentiment more negative and by lowering performance attainments through avolition, anhedonia, and behavioral inertia (Kavanagh, 2014). One of the most influential theories of depression, Seligman's (1975) learned helplessness theory, highlights this interplay (Miller & Seligman, 1975). People who experience negative outcomes regardless of their actions become depressed subsequent to a realization of disempowerment (Kavanagh, 2014).

Depression is particularly important to study in pediatric settings given that youth dealing with a CI are significantly more likely to suffer from depression than healthy peers (Pinquart & Shen, 2011), perhaps partly due to the likelihood of having felt hopeless and/or helpless in light of their medical condition. The relationship between CI and depression is thought to be bidirectional. On one hand, depression often predates, and in some cases precipitates, the onset of illness (Chapman, Perry, & Strine, 2005). On the other hand, CI may predispose children towards depression, which then puts the patients at significantly higher risk for medical noncompliance and maladjustment (DiMatteo, Lepper, & Croghan, 2000). Depression can also mediate the relationship between environmental or family factors and self-efficacy (Armstrong et al., 2011). Unfortunately, depression in pediatric CI often remains untreated because it is not reliably screened for (Chapman et al., 2005). Moreover, many patients may have subthreshold levels of

depression that, despite not meeting diagnostic criteria, may nonetheless have deleterious effects on adjustment and adherence (Barlow & Ellard, 2006).

Measuring Self-Efficacy

In order to intervene with children who have low self-efficacy, it becomes crucial to identify the construct in a reliable manner. Bandura (2006) outlined specifications for constructing successful self-efficacy scales. Given that self-efficacy is concerned with perceived capability, Bandura (2006) suggests wording items in the scale in terms of "can do" as opposed to "will do." Bandura (2006) also suggests that scale creation should include all relevant domains of functioning involved in the chosen sphere. That is, a self-efficacy scale for weight loss should not only tap into perceived capacity to control dietary choices, but also include other related behaviors that require discipline such as the ability to exercise, purchase healthy foods, and so forth. Bandura (2006) also notes that items should be phrased to address the capacity to perform a given task regularly. For instance, one may answer the question: "How confident are you that you can exercise for 30 minutes?" differently than "How confident are you that you can exercise for 30 minutes daily?" The latter sentence is more concerned with self-efficacy because it asks about capacity on a regular basis, which implies the ability to meet demands in light of impediments (Bandura, 2006).

One of the current limitations in the measurement of self-efficacy in pediatric CI has been the focus on creating scales specific to one disease type. While several successful measures of self-efficacy in pediatric populations have been validated, these measures rely on items that reflect symptoms unique to certain disease categories. For

instance, Caplin et al.'s (2002) scale of pediatric self-efficacy in epilepsy has fear items not meaningful to children who do not have seizures such as: "I can keep from being afraid after a seizure in order to manage the situation" (p. 304). The chronic pain self-efficacy scale by Bursch et al. (2006) focuses on ability to perform daily activities despite pain symptoms, which targets perceived competence when symptoms are active rather than self-efficacy in general. Given that many children with CI do not have symptoms consistently, such a focus on active symptomatology would limit the conclusions drawn from this measure.

Given the importance of self-efficacy to the successful management of pediatric CI and the lack of a valid measure that works across patients with different conditions, we constructed the Pediatric Rating of Chronic Illness Self-Efficacy (PRCISE), a 22-item self-report measure for self-efficacy in pediatric CI. The PRCISE was inspired by two previously validated disease-specific childhood self-efficacy scales (Bursch et al., 2006; Caplin et al., 2002) and an adult CI self-efficacy scale (Lorig et al., 1996).

Particularly, the 32-item adult measure by Lorig et al. (1996), the Chronic Disease Self-Efficacy Scales (CDSES), was a source of inspiration since this is the closest existing scale in regards to measuring multiple domains of functioning across illness types. In their validation study, Lorig et al. (1996) found that all subscales within the CDSES demonstrated relatively high reliability (internal consistency α = 77-.92; test-retest r = 0.89-0.89). The CDSES contains the following eight scales and two single items: Exercise Regularly Scale; Get Information About Disease Item; Obtain Help from Community, Family, Friends Scale; Communicate with Physician Scale; Manage Disease in General Scale; Do Chores Scale; Social/Recreational Activities Scale; Manage

Symptoms Scale; Manage Shortness of Breath Item; and Control/Manage Depression Scale.

The 32 items of the CDSES were pared down to 22 on the PRCISE to ensure all items were developmentally appropriate, fit across multiple pediatric conditions, and were understandable and applicable to children 7 to 20 years of age. Specifically, we did not include the single item on shortness of breath since we did not believe it would be meaningful across all pediatric conditions. We also left out the single item about obtaining information from community resources since this is not something minors are likely to do on their own. We combined two items on the exercise scale referring to strength training and aerobic exercise into a broader exercise question, since children are unlikely to differentiate between different types of physical activity. We collapsed the subscale on obtaining help from family and doctors into one scale, since this addresses help-seeking competence in general. Likewise, we grouped questions about chores and recreational activities into the same category because these items all relate to general quality of life. In the latter category, we also included perceived capacity to meet school demands, since educational self-efficacy was not addressed in the CDSES. In regards to the depression scale, we renamed it the mood scale to destigmatize feelings of sadness, and removed questions about loneliness as we believed this would be either under endorsed in children living in a family setting or unlikely to be admitted. We also replaced phrasing such as "down in the dumps" with terms such as "sad" and "worried" that may be better understood by younger children. Following recommendations by Bandura (2006), we phrased all items in the PRCISE using the same phrase used by Bursch et al. (2006) "How sure are you that you can?" this being a more developmentally

appropriate way to target perceived capacity than the phrase "How confident are you that?" used by Lorig et al. (1996). Following illness-specific pediatric self-efficacy scales by Bursch et al. (2006) and Caplin et al. (2002), we also included items relating to perceived academic and recreational functioning (i.e. chores, hobbies, homework, and play). For the purpose of data collection, we titled the scale "Chronic Illness Appraisal Inventory for Children," following guidelines by Bandura (2006) to stay away from the term self-efficacy to avoid socially desirable responding (See Appendix C for the PRCISE).

Development of the Pediatric Rating of Chronic Illness Self-Efficacy (PRCISE)

Family cohesion, which can be described as "togetherness" or the emotional bond of a family, has been related to greater autonomy development and more identity exploration, such that adolescents who feel accepted and loved are consequently more capable of "finding themselves" (Fullwider-Bush & Jacobvitz, 1993). Family cohesion has also been linked to better general adjustment to CI and greater wellbeing (Baer, 2002; Kazak, Rourke, & Nasvaria, 2009; Mullis et al., 2003).

In parallel, adjustment to illness will also depend on the rest of the family's ability to adapt to the new stressor (Fiese & Everhart, 2006; Thompson & Gustafson, 1996). Family flexibility refers to "the quality and expression of leadership and organization, role relationship, and relationship rules and negotiations" (Olson, 2011, p. 2). Families that are flexible are structured and democratic and tend to have established rules and approaches to decision-making and problem solving (Olson, 2000). Given that adjustment to illness depends on the family's ability to adapt to the new stressor (Fiese &

Everhart, 2006; Thompson & Gustafson, 1996), family flexibility may result in more adaptive reactions to major changes (Olson, 2000; 2011).

Current Study

The lack of a self-efficacy measure that works across pediatric conditions must be addressed. To this end, we constructed the Pediatric Rating of Chronic Illness Self-Efficacy (PRCISE) and tested its factor structure and psychometric properties in a sample of 217 children with a CI receiving healthcare within the Loma Linda University (LLU) Health System. Given the strong relationship between self-efficacy and depression, we also collected the PHQ-A (Johnson, Harris, Spitzer, & Williams, 2002), a screening tool for adolescent depression. Parents provided demographic information as well as information about their child's health.

In order to determine the factor structure of the PRCISE, we first ran a parallel analysis. We also ran reliability analyses to measure the scale's internal consistency. We also conducted exploratory analyses to investigate demographic and clinical predictors of self-efficacy. First and foremost, we expected that depression and self-efficacy would be strongly correlated. Although the relationship between the two is thought to be bidirectional (Chapman et al., 2005; DiMatteo, Lepper, & Croghan, 2000; Armstrong et al., 2011), we reasoned that, because depression often predates and/or exacerbates feelings of low efficacy related to health behaviors, PHQ-A scores would negatively predict PRCISE scores. Given established health disparities in CI management, treatment, and outcomes (Alegria et al., 2002; Osborn, Paasche-Orlow, Bailey, & Wolf, 2011; Paasche-Orlow & Wolf, 2007; Pascoe & Smart Richman, 2009), we also

hypothesized that the PRCISE total score would be predicted by socioeconomic factors. As such, our first multiple linear regressions (MLR) examined predictors of the PRCISE by determining the degree to which depression symptoms and demographic covariates (namely race/ethnicity and parental education) predicted self-efficacy scores.

Given the link between self-efficacy and health behaviors (Barlow & Ellard, 2006; Bursch et al., 1999, Bursch et al., 2006; Caplin et al., 2002; Dunbar-Jacob & Mortimer-Stephens, 2001; Griva et al., 2000), we also wished to test the scale's predictive validity by determining whether the PRCISE predicted health status variables. More specifically, since children with lower SE tend to have adherence problems and lower health-related quality of life, we hypothesized that the PRCISE would be able to demonstrate this known relationship.

However, two caveats influenced our hypothesis and moderated our expectations. Firstly, we did not measure self-reported adherence, thus limiting our analyses to variables related to or affected by adherence. Secondly, while the link between self-efficacy and health maintenance behaviors is well-established, the relationship between self-efficacy and health status may be less straightforward due to the influence of variables outside a family's control. In other words, prognosis and severity of CI may be influenced by factors unrelated to self-efficacy or adherence. For instance, a child's cancer may spread aggressively regardless of her chemotherapy attendance or follow-through on lifestyle recommendations. As such, while we felt it was important to test the predictive validity of the PRCISE on the health status variables we did collect (ER visits and missed schooldays), we were hesitant to hypothesize that the PRCISE would directly predict these variables. In other words, while we know self-efficacy and health status to

be related, we expected that the relationship between these variables would likely be mediated by illness covariates not measured in the current study. We thus cautiously expected that the PRCISE would be negatively related to both ER visits and missed schooldays.

CHAPTER TWO

METHODS

Participants

Data were collected from 217 families who have a child with a CI. Youths ranged in age from 7 to 20 (M_{age} = 13.62, SD_{age} = 2.92; 62.7% Latino; 58.1% female). Children were recruited from medical providers within the Loma Linda University Health System. Demographic variables and other study variables are detailed in Tables 1 and 2. Criteria for study inclusion included being able to read and complete the survey in English and having a CI, defined as a health problem lasting three or more months that impacts a person's daily activities and requires frequent medical intervention and/or management (Compas, 2012).

Of note, while we originally sought to recruit children through age 18, four older participants completed the surveys (two 19-years-olds and two 20-years-old). Given that most pediatric clinics serve transitional-age-youths (typically until 21 or 24 years of age), we decided to keep these participants in the sample. Additionally, given that self-efficacy proves crucial in the successful transition of pediatric patients to adult healthcare (Treadwell et al., 2016), we felt that the inclusion of these four participants increased the generalizability and clinical utility of our scale.

Measures

Demographic Survey

Parent participants completed a demographic questionnaire that provided information about their child's age, gender, ethnicity/race, primary health condition,

number of emergency room visits in the past 12 months (hereafter referred to as "ER visits"), and number of missed schooldays in the last month (hereafter referred to as "missed schooldays"). Parents also provided information about their level of education (see Appendix A).

The Patient Health Questionnaire for Adolescents (PHQ-A)

Child participants completed the PHQ-A (Johnson et al., 2002), a modified version of the widely used self-report tool for depression, the Patient Health Questionnaire (PHQ; Spitzer, Kroenke, Williams, & Patient Health Questionnaire Primary Care Study Group, 1999). The PHQ-A includes nine Likert scale items that ask participants to state how often they have been bothered by each of the following symptoms in the past two weeks on a scale from zero for "not at all" to three for "nearly every day." Examples of symptoms are: "feeling down, depressed, irritable, or hopeless" and "[having] little interest or pleasure in doing things."

The nine questions are followed by four additional items that ask: (1) whether the adolescent has felt depressed on more days than not in the past year (a yes/no question to identify dysthymia); (2) about difficulty functioning due to the symptoms endorsed in the first nine questions (answered on a four point scale from not at all difficult to very difficult); (3) a yes/no question about suicidal ideation in the past month; and (4) a yes/no question about lifetime suicide attempts (see Appendix B). The PHQ-A has demonstrated satisfactory sensitivity, specificity, diagnostic agreement, and overall diagnostic accuracy compared to clinical interviews of depression (Johnson et al., 2002). Its specificity (i.e., the percentage of correctly identified controls) and sensitivity (i.e., the percentage of

correctly identified cases with psychiatric disorders) were comparable to the PHQ (Johnson et al., 2002).

Scale score totals are derived by summing scores across the first nine items of the scale. As recommended by the authors, cases with one or two missing responses received a prorated score, which is calculated by summing the answered items for a partial raw score, then multiplying this score by nine and dividing it by the number of items answered (i.e., a partial raw score of six for seven completed items would receive a total score of 7.71; Johnson et al., 2002).

The Pediatric Rating of Chronic Illness Self-Efficacy (PRCISE)

The PRCISE is a 22-item self-report questionnaire designed for this study to assess children and adolescents' perceived ability to manage their illness and to thrive despite symptoms, complications, and management issues. The survey begins with the following phrase: "Even though you have a health condition…" Each item then proceeds with the stem: "How sure are you that you can," followed by different perceived abilities relating to exercise; obtaining help from family, friends, and doctors; illness management; chores, hobbies, and recreation; symptoms; and mood. All items are answered on a Likert scale from zero to ten, ranging from 0 for "not at all sure" to 10 for "very sure." Total scaled scores are then derived by summing across all item scores. Using SPSS listwise deletion, total scaled scores were only calculated for items with no missing responses. A Microsoft Word reading-level analysis was also performed, revealing that the scale requires a seventh grade reading level. Given the discrepancy between the scale's reading level and

the minimum age of inclusion, the informed consent document instructed parents to help their child understand the questions as needed. See Appendix C for a copy of the scale.

Procedure

The study received approval from the Loma Linda University Institutional Review Board (Certification # 5150165). Families were approached in clinics by a clinic staff member (receptionist, social worker, nurse, or physician assistant) or by a member of the research staff in designated outpatient or inpatient pediatric clinics within the Loma Linda University Health System. Parents considered participation by reading through an informed consent document (ICD), and were asked to provide assent for their children using an embedded assent summary in the ICD. Since no personal health information was collected, no signed informed consent was required. Although a majority of families completed the survey on printed paper copies, a subset of families participated in the study by completing the survey electronically on the Qualtrics website using an iPad. As aforementioned, parents completed the demographic questionnaire while their child completed the PRCISE and the PHQ-A. Once parties finished the survey measures, they were asked to seal their responses in a designated envelope and to return the envelope to the clinic or research staff member. Families also had the option of completing the paper survey at home and mailing it back, though very few families chose this option (n = 4). Participants who completed the survey on an iPad simply returned the device to the team member. These data were subsequently sent to an online server (e.g., Qualtrics), and exported into SPSS 21.0 (IBM, 2012) by a member of the research team.

Statistical Analysis

Factor Analysis

Using the guidelines listed in Tabachnick and Fidell (2013), we first inspected univariate descriptive statistics for accuracy of input. We followed by evaluating the amount and distribution of missing data and outliers and using the Expectation Maximization (EM) procedure in SPSS to impute missing data. Of note, we used imputed values only in the exploratory factor analysis (EFA), given that the EM procedure underestimates standard errors that are important for inferential tests such as multiple linear regression (Von Hippel, 2004).

After preliminary screening of the data, we tested the assumption that the missing data were "missing completely at random" (MCAR) using Little's MCAR test. While Little's MCAR test resulted in a chi-square of 297.81 (df = 147; $p < .001$), indicating that the data were not missing completely at random, Little's MCAR test is considered very conservative (Van Ness, Murphy, Araujo, Pisani, & Allore, 2007) and SPSS's EM method is capable of handling data that may violate the MCAR assumption without significantly affecting parameters (Dong & Peng, 2013). Moreover, although a significant Little's MCAR test suggests that there is an identifiable pattern to the missing data, the pattern in our dataset is likely due to the fact that some participants missed whole groups of questions.

Before discussing factor extraction, we must also address power and reliability. Although there are variations in power estimates for exploratory factor analysis, Furr and Bacharach (2014) recommend having at least ten participants per survey item, which would require roughly 220 participants for a final scale of 22 items. The current study

collected data from 217 participants (including 195 scales with no missing items), proving sufficient for the final fifteen-item measure described below. In terms of reliability, inter-item correlations informed us that four of the 22 variables were significantly correlated ($r > .8$), suggesting that they were likely measuring the same aspect of self-efficacy. We thus removed these four items as well as three others that showed either little decrements in the *reliability if item deleted* estimates (two items) or unusually high kurtosis (one item had kurtosis > 3). A parallel analysis was then conducted on the 15 item scale using principal axis factoring (PAF) with oblique rotation (Direct Oblimin).

Multiple Linear Regressions (MLR)

To establish whether comorbid depressive symptoms, health and demographic variables predicted or were predicted by the PRCISE total score, we carried out three MLR analyses, one with the PRCISE as the dependent variable; and two using the PRCISE to predict ER visits and missed schooldays. To narrow down potential control variables, bivariate correlations were calculated to examine the relationship between our main variables of interest (PRCISE, PHQ-A total scores, ER visits, and missed schooldays) and possible demographic covariates (child age, gender, ethnicity, illness type, and parents' education level). Covariates that significantly correlated with the main study variables were included as controls in the three MLRs.

Prior to running each MLR, we also checked for and removed two outliers, deriving a final sample of 215 before case wise deletion. We also verified the assumptions of linearity, normality, and multicollinearity necessary for MLR. While the

assumptions of linearity and multicollinearity were not violated, the data were relatively heteroscedastic and the distribution of errors was non-normal. Attempts to normalize the data through log linear, square root, and reciprocal transformations of each outcome variable did not improve the shape of our distribution. As such, we maintained each dependent variable in its original form. Of note, we reiterate the fact that all inferential analyses were conducted on non-imputed data since the EM method described above is not appropriate for deductive statistical tests that rely on standard errors (Von Hippel, 2004).

Variables were recoded as follows. The highest level of education of either parent or guardian was chosen to estimate the effect of parental education using four categories: "less than high school," "high school," "some college," and "college graduate or higher." The variable was subsequently dummy coded, using the most common educational level as the reference group: some college. Child ethnicity was also dummy coded using the following categories: Caucasian, African American, Asian, Latino and 'other,' with Caucasian serving as the reference group. The PHQ-A was scored and summed according to the authors' instructions, using pro-rated total scores for cases with fewer than three items missing (Johnson et al., 2002).

For our exploratory analyses of self-efficacy predictors, a hierarchical multiple linear regression analysis was used to examine the relative contributions of depression (as measured by the PHQ-A), ethnicity, and parental education on the PRCISE total score; these three variables having had the most significant correlations with the PRCISE. We also examined all two-way interactions between parental education and depression on the PRCISE.

Using the same process and same variable coding schemes, we conducted two other MLRs to establish the scale's preliminary predictive validity. The second MLR was used to determine whether the PRCISE predicted ER visits; the third sought to see if the PRCISE total score predicted missed schooldays. Given high intercorrelations among the PHQ-A and both health proxy variables, the PHQ-A and ER visits were included as predictors of missed schooldays, and the PHQ-A and missed schooldays were used as independent variables for the MLR predicting ER visits.

CHAPTER THREE

RESULTS

Demographic variables and other participant characteristics are summarized in Table 1 and 2. PRCISE total scores varied according to certain study variables, detailed in Table 3 and described below. Inter-item correlations among PRCISE items are presented in Table 4; inter-variable correlations are presented in Table 5. Youth had a mean self-efficacy score of 114.34 (*SD* = 31.74) out of a possible 150, and a mean PHQ-A score of 4.55 (*SD* = 4.95) out of a possible score of 27. The sample was categorized into the following illness categories: endocrinology (Type 1 diabetes), nephrology (kidney disease or transplant), cardiology (heart disease or transplant), hematology/oncology (vasculitis, cancer), rheumatology (rheumatoid arthritis, lupus), gastroenterology (Crohn's disease, irritable bowel syndrome, or ulcerative colitis), and other illnesses (asthma, cystic fibrosis, dermatitis, spina bifida, seizures, etc.). Of note, although all participants were pre-identified as having a chronic condition by their healthcare providers through the recruitment process noted above, a significant number of families skipped the item on the survey asking them to identify the child's chronic condition (*N* = 56, 26%).

Table 1. T-Tests Measuring Differences in Continuous Study Variables by Illness Types

	Self-Efficacy (PRCISE)		Depression (PHQ-A)		Age		Number of ER Visits		Number of Missed Schooldays	
Illness Type	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Endocrinology (*N* = 25)	123.41*	28.78	5.60	5.91	12.56	3.22	1.00	3.16	1.90	4.60
Nephrology (*N* = 30)	119.86	23.77	5.32	5.79	14.43	2.58	1.28	1.69	5.11	8.77
Cardiology (*N* = 18)	110.63	36.59	4.57	4.25	13.81	3.08	0.73	1.94	4.57	8.44
Hematology/Oncology (*N* = 17)	111.23	24.31	6.85	5.94	13.59	2.40	1.00	1.59	6.38	10.71
Rheumatology (*N* = 44)	97.59*	41.22	3.32	4.49	13.59	2.91	0.69	1.44	3.06	5.48
Gastroenterology (*N* = 7)	127.80	15.16	6.16	3.56	13.00	1.29	0.67	1.03	10.00	10.95
Other (*N* = 26)	113.50	32.73	5.60	5.06	13.38	2.59	1.29	2.48	6.20	9.40
Missing (*N* = 48)	122.04	23.99	2.94	3.61	13.67	3.25	0.29	0.84	1.28	2.26

*$p < .05$. PRCISE = Pediatric Rating of Chronic Illness Self-Efficacy; PHQ-A = Patient Health Questionnaire for Adolescents

Table 2. Categorical Study Variables by Illness Types

	Gender (%)		Race (%)					Highest Parent Education (%)			
Illness Type	Female	Male	Black	Asian or Pacific Islander	Hispanic	Caucasian	Other	Less than High School	High School	Some College	College Graduate or Higher
Endocrinology (*N* = 25)	56.0	44	7.7	0.0	12.5	13.8	42.9	0.0	8.9	13.3	10.0
Nephrology (*N* = 30)	50.0	50	7.7	14.3	14.0	13.8	0.0	9.8	4.4	20.0	20.0
Cardiology (*N* = 18)	50.0	50	0.0	0.0	9.6	6.9	0.0	3.3	4.4	11.7	15.0
Hematology/Oncology (*N* = 17)	41.2	58.8	15.4	0.0	8.1	3.4	0.0	9.8	11.1	5.0	7.5
Rheumatology (*N* = 44)	63.6	36.4	30.8	28.6	20.6	10.3	14.3	24.6	22.2	16.7	12.5
Gastroenterology (*N* = 7)	71.4	28.6	11.5	0.0	1.5	3.4	14.3	0.0	4.4	3.3	7.5
Other (*N* = 26)	73.1	26.9	11.5	14.3	11.0	24.1	0.0	8.2	8.9	18.3	15.0
Missing (*N* = 48)	58.3	41.7	15.4	42.9	22.8	24.1	28.6	29.5	35.6	11.7	12.5

Table 3. Analyses of Variance (ANOVAs) Examining Mean Differences in PRCISE Total Scores (n = 215)

Independent Variable	*F*	*p*	Partial η^2
Illness	2.20	<.05	0.09
Gender	2.80	>.05	0.02
Ethnicity	3.14	<.05	0.07
Parent Education	5.96	<.01	0.09
Age	1.03	>.05	0.02
Depression (PHQ-A)	7.99	<.001	0.08
Missed School Days (in past 30 days)	1.23	>.05	0.03
ER Visits (in past 12 months)	0.04	>.05	0.00

Note. PRCISE = Pediatric Rating of Chronic Illness Self-Efficacy; PHQ-A = Patient Health Questionnaire for Adolescents

Table 4. Correlations Among the Final 15 PRCISE Items

Item	*N*	SE2	SE3	SE4	SE5	SE6	SE7	SE9	SE11	SE12	SE13	SE15	SE16	SE17	SE18	SE20
SE2	212	6.85 (3.18)														
SE3	208	0.45	7.96 (2.73)													
SE4	208	0.41	0.73	7.70 (3.01)												
SE5	209	0.48	0.52	0.59	7.31 (3.20)											
SE6	210	0.42	0.56	0.58	0.51	8.20 (2.64)										
SE7	210	0.42	0.53	0.46	0.45	0.66	7.98 (2.41)									
SE9	210	0.40	0.45	0.41	0.41	0.57	0.57	8.03 (2.48)								
SE11	205	0.46	0.52	0.58	0.51	0.62	0.61	0.66	7.98 (2.60)							
SE12	209	0.56	0.49	0.46	0.39	0.56	0.54	0.51	0.55	7.58 (2.81)						
SE13	210	0.57	0.62	0.54	0.50	0.51	0.53	0.52	0.62	0.66	8.20 (2.52)					
SE15	209	0.47	0.52	0.51	0.37	0.47	0.55	0.43	0.54	0.61	0.69	7.38 (3.01)				
SE16	205	0.55	0.50	0.45	0.54	0.55	0.51	0.56	0.57	0.53	0.63	0.55	7.05 (2.70)			
SE17	205	0.47	0.42	0.37	0.50	0.43	0.46	0.53	0.54	0.49	0.56	0.53	0.76	7.11 (2.73)		
SE18	206	0.49	0.47	0.49	0.44	0.44	0.50	0.46	0.56	0.55	0.65	0.69	0.64	0.70	7.26 (2.77)	
SE20	207	0.45	0.46	0.46	0.44	0.56	0.52	0.47	0.62	0.54	0.60	0.66	0.63	0.61	0.70	7.10 (2.99)

All correlations are significant at $p < .001$. *Note.* See Table 6 for the item descriptions. Means and standard deviations are displayed on the diagonal with means on top and standard deviations below, in parentheses.

Table 5. Spearman's Rho Correlations

	Age	Gender	Ethnicity	Illness Type	Parent Education	ER visits	Missed Days of School	PRCISE	PHQ-A
Age	1								
Gender	-0.088	1							
Ethnicity	-0.013	0.01	1						
Illness Type	-0.023	-0.153	-0.082	1					
Parent Education	-0.05	0.1	-0.012	-0.009	1				
ER visits	0.03	-.155*	0.039	0.026	.149*	1			
Missed Days of School	0.117	0.034	0.048	.169*	0.127	.376**	1		
Self-Efficacy (PRCISE)	-0.019	.152*	.252**	-0.144	.203**	-0.014	-0.051	1	
Depression (PHQ-A)	.258**	-0.133	-0.034	-0.015	0.066	.274**	.299**	-.369**	1

*$p < .05$. **$p < .001$. *Note.* PRCISE = Pediatric Rating of Chronic Illness Self-Efficacy; PHQ-A = Patient Health Questionnaire for Adolescents.

Factor Analysis

A parallel analysis was conducted on the 15-item PRCISE scale using principal axis factoring (PAF) with oblique rotation (Direct Oblimin). Using the Kaiser-Meyer-Olkin measure, we verified the sampling adequacy for the analysis (KMO = .93, considered 'superb' according to Field, 2009). All KMO values for individual were .87 or greater, which is well above the acceptable limit of .5 (Field, 2009). We also used Bartlett's test of sphericity χ^2 (105) = 2178.33, $p < .001$ to confirm that correlations between items were sufficient for PAF.

The results of the parallel analysis initially supported a two-factor solution, returning two eigenvalues over Kaiser's criterion of 1 and explaining 62.83% of the variance. However, given that these two factors were highly correlated (r = .74), that items cross-loaded on both factors, and that the scree plot was ambiguous (in that it did not clearly differentiate between a one or two factor solution), we chose to examine the fit of the data by running a secondary analysis with a fixed extraction of one factor. Of note, while not theoretically problematic (Field, 2009), significant intercorrelations between factors suggests a shared construct, justifying the fixed extraction of one factor. The single factor structure explained 55.52% of the variance. The determinant had a value of 3.143E-005, which is significantly smaller than the necessary 0.0001. Table 6 demonstrates the factor loadings of our final one-factor matrix, selected as the best solution for the data.

Table 6. Results of Exploratory Factor Analysis for the PRCISE Based on Final, Single-Factor Solution (n = 195)

Item	Factor Loading
How sure are you that you can continue to do your hobbies and things you enjoy? (Item 13)	0.81
How sure are you that you can reduce your physical discomfort or pain? (Item 16)	0.78
How sure are you that you stay away from things that make you feel bad? (Item 11)	0.77
How sure are you that you can keep your health problems from getting in the way of what you want to do? (Item 18)	0.77
How sure are you that you can keep from feeling sad about your health? (Item 20)	0.76
How sure are you that you can go to school without having your health get in the way of your learning? (Item 15)	0.75
How sure are you that you can ask your doctor questions when you are worried or unsure about your health? (Item 6)	0.73
How sure are you that you can complete your household chores? (Item 12)	0.72
How sure are you that you can make yourself better when you feel sick? (Item 17)	0.72
How sure are you that you can follow your doctor's advice every day? (Item 7)	0.71
*How sure are you that you can get help from family with tasks and activities such as homework or chores? (*Item 3)	0.70
How sure are you that you can tell when feelings in your body mean that you should see a doctor again? (Item 9)	0.69
How sure are you that you can get family to help you when you are feeling sad or worried (such as listening or talking about problems)? (Item 4)	0.68
How sure are you that you can get friends to help you when you are feeling sad or worried (such as listening or talking about problems)? (Item 5)	0.64
How sure are you that you can exercise regularly? (Item 2)	0.64
Eingenvalue	8.33
% of variance	55.52
Cronbach's α	0.94

Overall the PRCISE demonstrated high reliability (α = .94). Moreover, all fifteen items had corrected item-total correlations greater than .6, suggesting that all variables correlated significantly with the total scale. Likewise, none of the scale items had *Cronbach's Alpha if Item Deleted* values above our total scale α of .94, which suggests that removing any of the fifteen items would not significantly improve the scale.

Analyses of Variance (ANOVA)

Before running our MLRs, we sought to explore differences in self-efficacy using simple exploratory analyses. We conducted one-way ANOVAs to determine whether self-efficacy differed across demographic, and mental and physical health variables, using illness type, gender, ethnicity, parent education, age, PHQ-A scores, ER visits, and missed schooldays as predictors of the PRCISE total score (Table 3). Firstly, self-efficacy scores were significantly different based on illness type, $F(6,147) = 2.20$, $p < .05$, $\eta_p^2 = .09$. Post hoc pairwise comparisons using the Tukey correction for familywise Type I error demonstrated that PRCISE score differences between children with rheumatologic illnesses ($M = 97.59$, $SD = 41.22$) and those with diabetes ($M = 123.41$, $SD = 28.78$) approached significance ($p = .054$), with diabetic children having higher self-efficacy scores. Secondly, self-efficacy scores differed based on ethnicity, $F(4,184) = 3.14$, $p < .05$, $\eta_p^2 = .07$. Post hoc pairwise comparisons using the Tukey correction for familywise Type I error indicated that Caucasian children ($M = 131.52$, $SD = 17.93$) had significantly higher PRCISE scores than African American ($M = 103.46$, $SD = 38.46$; $p < .05$) and Latino ($M = 111.41$, $SD = 32.40$; $p < .05$) children. Thirdly, PRCISE scores differed based on parent education, $F(3,185) = 5.96$, $p < .01$, $\eta_p^2 = .09$. Post hoc pairwise

comparisons using the Tukey correction for familywise Type I error revealed that participants with parents with less than a high school education (M = 100.58, SD = 40.50) had lower PRCISE scores than children with parents with some college education (M = 123.27, SD = 22.62; $p < .01$) and those with college graduated parents (M = 120.77, SD = 22.80; $p < .01$). Finally, self-efficacy scores were significantly different based on depression scores, $F(6,147) = 2.20$, $p < .05$, $\eta_p^2 = .09$. For the purposes of this analysis, PHQ-A scores were categorized according to mild, moderate, and severe depression, in accordance with cutoffs described by the authors of the PHQ (Spitzer et al., 1999). Post hoc pairwise comparisons using the Tukey correction for familywise Type I error demonstrated that children with no or mild depression (M = 117.61, SD = 31.47) had higher PRCISE scores than both those with moderate depression (M = 95.85, SD = 24.50; $p < .01$) and those with severe depression (M = 74.67, SD = 51.19; $p < .05$). PRCISE scores did not significantly differ by gender, age, missed schooldays, or ER visits, $p > .05$ (Table 3).

Multiple Linear Regressions (MLR)

As aforementioned, the objective of the three MLR were two-fold. The first MLR was used to further explore ways in which demographic and clinical correlates predicted self-efficacy. We thus hypothesized that the PHQ-A would be negatively associated with the PRCISE, in hopes of confirming prior authors' conclusion that depression and self-efficacy are highly related, albeit distinct, constructs. The second and third MLRs were used to determine the PRCISE's utility in predicting health outcomes, which may be more distantly related to self-efficacy.

Predicting the PRCISE Total Score

As expected, self-reported depressive symptoms strongly predicted the PRCISE total score (b = -3.54, 95% CI [-5.26, -1.82], sr^2 = .09, p < .001). Having parents with less than a high school education (b = -37.73, 95% CI [-53.38, -22.08], sr^2 = .12, p < .001) or a high school education (b = -19.48, 95% CI [-35.96, -3.00], sr^2 = .03, p < .05) and being African American (b = -20.25, 95% CI [-36.91, -3.59], sr^2 = .03, p < .05) were also associated with lower self-efficacy. Other ethnicities and education levels were not significantly predictive of the PRCISE (see Table 7). Overall, the optimal linear combination of these three predictor variables accounted for 23% of the variance in PRCISE total scores, adjusted R^2 = .23, F(12, 174) = 4.52, p < .001.

Table 7. Results of Multiple Regression Analysis Predicting the PRCISE Total Score from Depression (PHQ-9) and Covariates

Variables	*b*	SE	β	*t*	*p*	95% CI	sr^2
Depression (PHQ-A)	**-3.54**	**0.87**	**-0.53**	**-4.07**	**<.001**	**[-5.26, 1.82]**	**0.09**
Black/African American	**-20.25**	**8.44**	**-0.21**	**-2.40**	**<.05**	**[-36.91, -3.59]**	**0.03**
Asian/Asian American	-22.81	12.13	-0.14	-1.88	>.05	[-46.75, 1.14]	0.02
Latino/Hispanic American	-9.58	6.63	-0.14	-1.45	>.05	[-22.68, 3.52]	0.01
Other Race/Ethnicity	5.66	14.10	0.03	0.40	>.05	[-22.18, 33.50]	0.00
Less Than High School (HS)	**-37.73**	**7.92**	**-0.53**	**-4.76**	**<.001**	**[-53.38, -22.08]**	**0.12**
HS Graduate	**-19.48**	**8.35**	**-0.25**	**-2.33**	**<.05**	**[-35.96, -3.00]**	**0.03**
College Graduate or Higher	-5.41	8.57	-0.07	-0.63	>.05	[-22.32, 11.51]	0.00
PHQ-A x Less Than HS	**2.80**	**1.17**	**0.29**	**2.39**	**<.05**	**[0.49, 5.10]**	**0.03**
PHQ-A x HS	2.06	1.26	0.19	1.63	>.05	[-0.44, 4.55]	0.02
PHQ x College Graduate of Higher	0.17	1.40	0.01	0.12	>.05	[-2.60, 2.93]	0.00

Bolded values are significant at $p < .05$. *Note.* Race/ethnicity reference group = Caucasian; Parent education reference group = some college; PRCISE = Pediatric Rating of Chronic Illness Self-Efficacy; PHQ-A = Patient Health Questionnaire for Adolescents.

Having established a potential link between the PHQ-A and the PRCISE, we also tested interaction effects between the PHQ-A and parental education, adding all two-way interaction terms in the next step of the hierarchical MLR. We found that the effect of depression on the PRCISE total score significantly depended on parent education. Specifically, having parents with less than a high school education attenuated the effect of depression ($t[1] = 2.39$ 95% CI [0.49, 5.10], $p < .05$). While higher depression scores were consistently associated with lower scores on the PRCISE, this effect was stronger for children with parents of higher education. In other words, self-efficacy scores were less impacted by depressive symptoms in children with less educated parents (Figure 1).

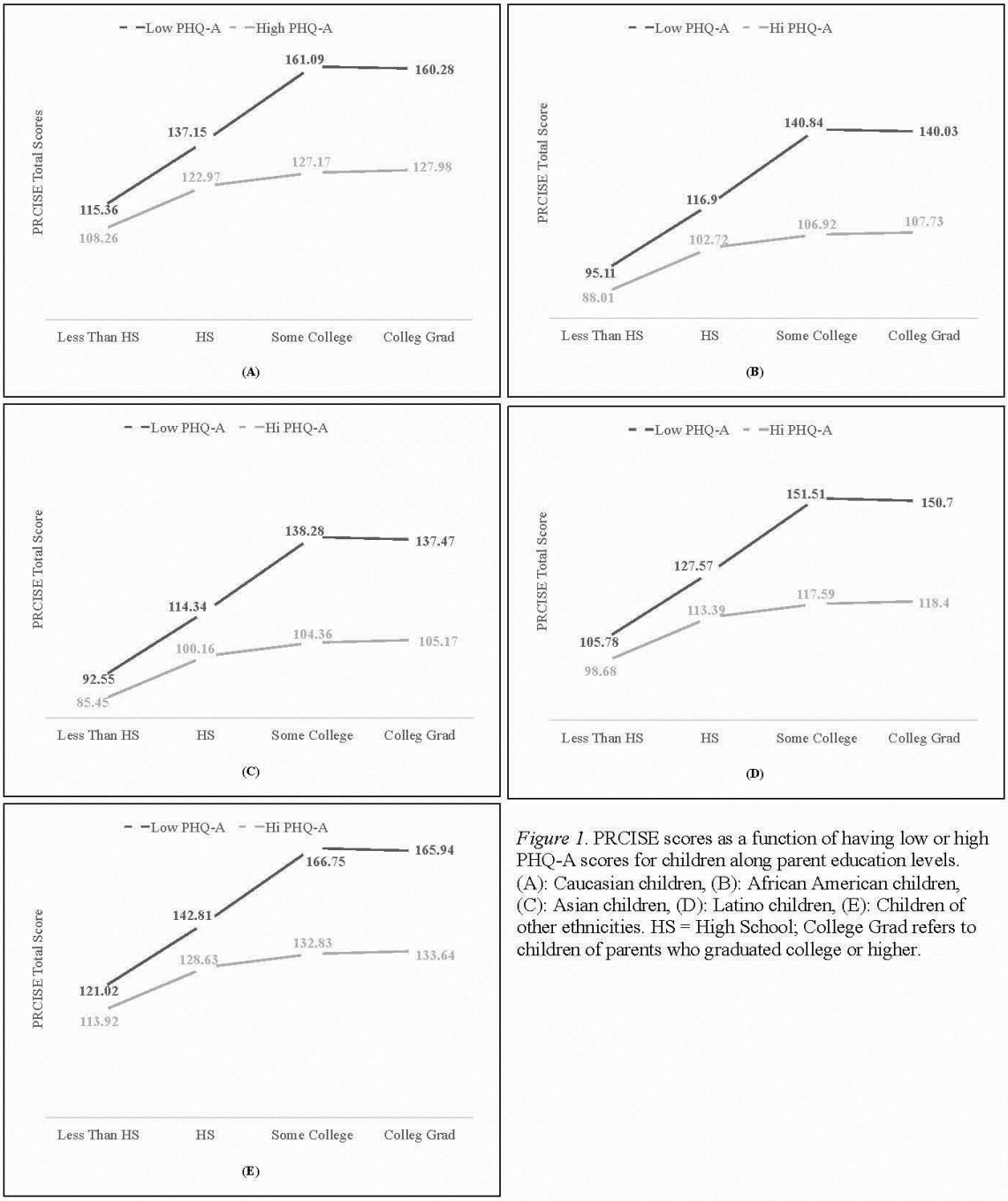

Figure 1. PRCISE scores as a function of having low or high PHQ-A scores for children along parent education levels. (A): Caucasian children, (B): African American children, (C): Asian children, (D): Latino children, (E): Children of other ethnicities. HS = High School; College Grad refers to children of parents who graduated college or higher.

Predicting Number of ER Visits

A second MLR analysis was used to examine predictors of number of ER visits. The optimal linear combination of missed schooldays, illness type, PHQ-A, and PRCISE total scores accounted for 12% of the variance in number of ER visits, adjusted $R^2 = .12$, $F(9, 113) = 2.73$, $p < .01$. As anticipated, missed days of school ($b = 0.04$, 95% CI [0.01, 0.08], $p < .05$) and PHQ-A scores ($b = 0.07$, 95% CI [0.01, 0.13], $p < .05$) were positively associated with ER visits. Unexpectedly, higher PRCISE scores (i.e., better self-reported self-efficacy) were associated with more ER visits ($b = 0.01$, 95% CI [0.001, 0.02], $p < .05$). Of note, we also tested models without covariates to determine if the direction of the relationship changed; it did not. Results of the multiple regression model are presented in Table 8.

Table 8. Results of Multiple Regression Analysis Predicting Number of ER Visits in Last Year from Self-Efficacy and Covariates

Variables	*b*	SE	β	*t*	*p*	95% CI	sr^2
Self-efficacy (PRCISE)	**0.01**	**0.01**	**0.22**	**2.17**	**<.05**	**[0.001, 0.02]**	**0.04**
Depression (PHQ-A)	**0.07**	**0.03**	**0.23**	**2.28**	**<.05**	**[0.01, 0.13]**	**0.04**
Number of Missed Schooldays	**0.04**	**0.02**	**0.22**	**2.30**	**<.05**	**[0.01, 0.08]**	**0.04**
Illness: Endocrinology	-0.49	0.48	-0.11	-1.02	>.05	[-1.43, 0.46]	0.01
Illness: Nephrology	0.41	0.39	0.12	1.04	>.05	[-0.37, 1.19]	0.01
Illness: Cardiology	0.14	0.51	0.03	0.27	>.05	[-0.87, 1.14]	0.00
Illness: Hematology/Oncology	0.41	0.52	0.08	0.78	>.05	[-0.62, 1.43]	0.00
Illness: Gastroenterology	-0.14	0.77	-0.02	-0.18	>.05	[-1.66, 1.39]	0.00
Illness: Other	-0.05	0.43	-0.01	-0.11	>.05	[-0.89, 0.80]	0.00

Bolded values are significant at $p < .05$. *Note.* Illness reference group = rheumatology. PRCISE = Pediatric Rating of Chronic Illness Self-Efficacy; PHQ-A = Patient Health Questionnaire for Adolescents.

Predicting Number of Missed Schooldays

A final MLR analysis was used to examine predictors of number of missed schooldays. The optimal linear combination of ER visits, illness type, PHQ-A, and PRCISE total scores accounted for 10% of the variance in number of missed schooldays, adjusted $R^2 = .10$, $F(9, 113) = 2.36$, $p < .05$. Number of ER visits was the only significant predictor of missed days of school ($b = 1.16$, 95% CI [0.16, 2.16], $p < .05$). Reducing number of predictors in the model did not significantly impact results. Results of this multiple regression model are presented in Table 9.

Table 9. Results of Multiple Regression Analysis Predicting Number of Missed Schooldays from Self-Efficacy and Covariates

Variables	*b*	SE	β	*t*	*p*	95% CI	sr^2
Self-Efficacy (PRCISE)	0.03	0.03	0.09	0.91	>.05	[-0.03, 0.08]	0.01
Depression (PHQ-A)	0.29	0.16	0.19	1.79	>.05	[-0.03, 0.62]	0.03
Number of ER Visits	**1.16**	**0.51**	**0.22**	**2.30**	**<.05**	**[0.16, 2.16]**	**0.04**
Illness: Endocrinology	-2.32	2.51	-0.10	-0.92	>.05	[-7.30, 2.66]	0.01
Illness: Nephrology	1.26	2.09	0.07	0.60	>.05	[-2.88, 5.39]	0.00
Illness: Cardiology	0.76	2.68	0.03	0.28	>.05	[-4.54, 6.07]	0.00
Illness: Hematology/Oncology	3.13	2.73	0.12	1.15	>.05	[-2.28, 8.53]	0.01
Illness: Gastroenterology	0.95	4.06	0.02	0.23	>.05	[-7.10, 8.99]	0.00
Illness: Other	2.53	2.24	0.12	1.13	>.05	[-1.90, 6.97]	0.01

Bolded values are significant at $p < .05$. *Note.* Illness reference group = rheumatology. PRCISE = Pediatric Rating of Chronic Illness Self-Efficacy; PHQ-A = Patient Health Questionnaire for Adolescents.

CHAPTER FOUR

DISCUSSION

Factor Structure of the PRCISE

The current study explored the preliminary reliability and validity of the PRCISE, a 15-item self-report measure of pediatric chronic illness self-efficacy. The exploratory factor analysis revealed a one-factor structure with high reliability, and the scale explained a significant amount of variance. While the scale initially showed a two-factor structure, the strong inter-correlation between factors and the cross-loading of items on both factors led us to believe that these two constructs measured overlapping aspects of self-efficacy. We thus retained the single factor structure and concluded that the PRCISE appears to measure general health self-efficacy.

Mean Differences in Reported Self-Efficacy

The ANOVAs revealed several significant group differences in PRCISE total scores, namely discrepancies in illness type, ethnicity, and depression levels. With regard to illness type, children with rheumatologic diseases had the lowest PRCISE scores; those with diabetes had the highest. Several possibilities may explain this disparity. To begin, children in the rheumatology group are likely to have co-occurring pain, as this is a primary symptom of both arthritis (Ravelli, & Martini, 2007) and lupus (Houghton, Tucker, Potts, & Mckenzie, 2008), the two most common diagnoses in this subsample. Research has shown that self-efficacy is predicted by the extent to which people believe they can effectively manage pain (Schwarzer, 2014). Efficacious beliefs about the ability to cope with pain also predict greater efforts toward reducing the pain (Schwarzer, 2014).

Patients who believe they can achieve pain control also interpret it as less harmful, less permanent, and more tolerable. The reverse is also true; those who tend to focus on the uncontrollable aspects of pain report more pain (Schwarzer, 2014). Moreover, chronic pain management may require more individualized assessment of coping strategies and may be less straightforward and concrete than daily management of other diseases, such as blood sugar monitoring in diabetes. Differences in self-efficacy along illness type may also be attributable to the quarter of families who did not list a diagnosis on the demographic form. To reiterate, while all participants were pre-identified as having a chronic condition by their healthcare providers, a significant amount of families left illness type blank, thus limiting inferences drawn about differences based on diagnosis.

PRCISE total scores were also different based on children's ethnicity and parents' educational levels, with Caucasian children and those with parents with at least some college education demonstrating significantly higher self-efficacy than African or Hispanic American children or those with parents with a high school education or less, respectively. These findings confirm the link between socioeconomic variables and self-efficacy (Alegria et al., 2002). Potential reasons for these disparities and implications for clinical care are discussed in more detail below.

Finally, PRCISE scores differed based on depression level, such that children with no or mild depressive symptoms reported significantly higher levels of self-efficacy than those with moderate or severe depressive symptoms. This supports the assumed predictive validity of the PRCISE, as it mirrors the known negative relationship between the depression and self-efficacy (Kavanagh, 2014). As aforementioned, depression may lead to feelings of hopelessness and helplessness that undermine feelings of efficacy.

Likewise, feeling incompetent or ineffective is also linked to depressive symptoms (Kavanagh, 2014).

Exploratory Analyses Predicting Self-Efficacy and Health Status Variables

Predicting the PRCISE Total Score

In the first MLR, we aimed to explore demographic and clinical predictors of self-efficacy, focusing on socioeconomic factors and depressive symptoms. Given the strong negative relationship between depression and self-efficacy (Kavanagh, 2014), we anticipated that the PHQ-A would predict a significant amount of variance in the PRCISE. Our findings confirm this hypothesis. Compared to children who reported no depression symptoms, those with higher PHQ-A scores showed significant decrements in self-efficacy, confirming prior authors' assertion that the two constructs are inextricably linked (Kavanagh, 2014). Nevertheless, depression did not explain all of the variance in the PRCISE, suggesting that depression and self-efficacy are related but not the same construct.

Some of the variance was also explained by ethnicity. While being of minority racial status was predictive of lower self-efficacy scores, this disparity was not consistent across ethnicities. While African American children demonstrated lower self-efficacy, Latino, Asian, and those in the "other" ethnic category did not. This inter-minority discrepancy may be explained by both system-level and patient-level variables. On one hand, differences in the health beliefs and behaviors of African Americans are well documented. African Americans have been shown to be less adherent to dietary recommendations, more likely to report side-effects of medications, and less likely to

engage in physical activity (Warren-Findlow, Seymour, & Huber, 2012), all of which contribute to lower adherence. On the other hand, most research on health disparities indicates that minorities are negatively affected in a similar way, such that both Latino and African Americans share common disparities. For instance, minority patients are less likely to have had a recent physician visit (Flores & Lin, 2013), to have a coordinated medical home (Raphael, Guadagnolo, Beal, & Giardino, 2009), and are more frequently prescribed a complex drug regimen than their White counterparts (Warren-Findlow et al., 2012).

The fact that our results identified only African Americans as having significantly lower self-efficacy than Caucasian peers may be explained in part by socioeconomic confounds. Researchers have argued that health disparities among Latino patients are more tied to language and socioeconomic variables than those among African Americans (Alegria et al., 2002). For instance, while both Latino and African American patients have significantly lower odds of receiving specialty care than Caucasian patients (Alegria et al., 2002), the disparity between Latino and Caucasian patients ceases to be significant when socioeconomic and diagnostic variables are accounted for. By contrast, the disparity in use of care remained statistically significant for African Americans. In other words, African Americans receive less specialty care even when illness type, income, and neighborhood are controlled for (Alegria et al., 2002).

Such results suggest that health disparities are not purely socioeconomic in nature for African Americans, but likely related to implicit and institutionalized racism. Alegria and colleagues (2002) have proposed that the difference between the two minority groups may be explained by reactions to discrimination. African Americans may be more

mistrustful of medical and mental health practitioners due to the multi-generational racism and trauma that they have endured. Their lower rate of treatment seeking may thus reflect a deep-seated belief that they will not receive the care they need or deserve (Alegria et al., 2002). This hypothesis would also explain why our ANOVA identified Latinos as having lower self-efficacy but our MLR did not; the former did not account for the socioeconomic variable of education, but the latter did.

This same explanation could account for the significant difference in self-efficacy observed in our African American participants. As three of the fifteen items in our final PRCISE scale involve questions about seeking help from doctors, African American patients may simply rank this particular aspect of self-efficacy as lower if they hold the belief that reaching out to providers will not positively affect their health. Meta-analytic researchers confirm the notion that perceived discrimination leads to poor physical health and nonparticipation in healthy behaviors via the chronic stress associated with racism (Pascoe & Smart Richman, 2009). More research is needed to determine if attitudes towards medical personnel impact self-efficacy scores in pediatric chronic illness.

Parent education level was also a significant predictor of self-efficacy in that children of parents with no college education report lower self-efficacy than their counterparts. The association between lower education and worse health outcomes is well established (Osborn, Paasche-Orlow, Bailey, & Wolf, 2011; Paasche-Orlow & Wolf, 2007). Three mechanisms are thought to contribute to this relationship. One, patients of lower education have less access to and lower use of healthcare care due to differences in income and health literacy (Paasche-Orlow & Wolf, 2007). Two, uneducated patients are likely to be less comfortable in their interactions with medical providers for fear that

"their limited literacy will be exposed," thereby increasing feelings of shame and perpetuating the discomfort in medical settings (Orlow & Wolf, 2007, p. S20). Three, lower health literacy is associated with reduced compliance with necessary self-care behaviors (Paasche-Orlow & Wolf, 2007). Finally, self-efficacy may mediate the relationship between education and health. Osborn and colleagues (2011) proposed that lower education contributes to reduced treatment seeking and adherence to medical recommendations because patients feel ineffectual in knowing when and how to advocate for care and how to follow medical recommendations.

Parent education also influenced the relationship between self-efficacy and depression, as observed in the significant interaction between these three variables. Although higher PHQ-A scores were consistently predictive of lower PRCISE scores, the effect of depression was more substantial for children of parents with higher education. By contrast, the difference between children with below average versus above average PHQ-A scores was attenuated in participants whose parents had less than a high school education (Figure 1). Specifically, while we observed a thirty-point self-efficacy difference between low versus high PHQ-A scores in children with college educated parents, there was just a seven-point discrepancy for participants with parents who did not complete high school. The difference in slopes may reflect the possibility that lower self-efficacy related to education may depreciate scores to such a degree that depression does not exacerbate health motivation or confidence to the same degree as it does in children who would otherwise feel competent and efficacious in regards to health management.

While educational and racial disparities may explain much of the variance in self-efficacy and depression of children with a CI, we also suspect that both financial resources and access to healthcare further complicate the clinical picture. To begin, minority families are more likely to have a lower household income yet more dependents (Flores & Tomany-Korman, 2008). We are also aware that health insurance, as an important determinant of health care use, likely contributed to the observed disparities. Although we are limited in our ability to infer about the contribution of health insurance because this was not measured in our dataset, research has shown that uninsured children are less likely to have a seen a physician recently and more likely to have unmet healthcare needs (Cummings, Lavarreda, Rice, & Brown, 2009; DeVoe, Tillotson, & Wallace, 2009). As such, under the assumption that some of our participants were either uninsured or underinsured, we may posit that financial strain related to underinsurance may account for some of the unexplained variance in self-efficacy.

Predicting ER Visits and Missed Schooldays

The second and third MLRs were designed to explore the scale's predictive utility. As aforementioned, self-efficacy has been identified as an important predictor of management success in adolescents (Dunbar-Jacob & Mortimer-Stephens, 2001). As such, we sought to determine whether PRCISE scores predicted variables considered to be proxies of health status: number of ER visits in the last year, and the number of missed schooldays in the last thirty days. While the PRCISE did not predict number of missed schooldays, it did predict the number of ER visits. However, this relationship was unexpectedly, though marginally positive. Otherwise said, having higher self-efficacy

predicted more ER visits. This finding, though initially perplexing, may be explained by the fact that children who report greater self-efficacy may be more confident in their ability to perceive significant changes in their health status. As such, when health unexpectedly worsens, these children may be better able to advocate for an emergency visit. As Holman and Lorig (2014) explain, chronic conditions require the patient to become his or her own specialist in order to accurately manage and monitor symptoms. It is also possible that the construct is multiply realized such that youth with higher self-efficacy scores may have been part of systems that promoted seeking urgent medical care while those of low self-efficacy were in environments less attuned to acute health changes.

With regards to the nonsignificant school attendance variable, we believe that the discrepant timeframe between our health proxy variables may explain this difference. Specifically, while number of ER visits was reported for the past year, missed schooldays only reflected the last month. The lack of significance between PRCISE scores and missed schooldays may thus be due to two factors. Firstly, the thirty-day timeframe may have failed to capture significant health declines in the months preceding. Secondly, variations in school attendance may simply reflect breaks in the academic calendar. Since nearly a fifth of the surveys were collected during summer or early fall, participants may have denied missing school in the last month due to the fact that many of them were on summer break.

Conclusion

The aim of the study was to create and then validate the PRCISE. We demonstrated

that the PRCISE is a highly reliable scale with one factor. We found important predictors of pediatric CI self-efficacy through our exploratory analyses and established preliminary predictive validity by confirming the link between self-efficacy and ER visits. While this study replicates others in underscoring the importance of depression to self-efficacy and adjustment to chronic illness, it is unique in its finding that less-modifiable risk factors such as minority status and parent education significantly influence children's belief in their ability to succeed in personal health management. In future research, we may endeavor to explore whether health status and family variables moderate the relationship between clinical and demographic variables and self-efficacy scores. One of the principal strengths of this study is that data was collected from a particularly diverse group of patients, thus exposing important racial disparities in the self-efficacy of youth with pediatric chronic illness.

The study must also be considered in terms of its limitations. To begin, the survey did not collect information about adherence, limiting our ability to explore whether the PRCISE can be used to track compliance with medical regimens. Additionally, as we mentioned above, a large number of respondents failed to list their child's principal medical diagnosis, restricting the inferences we are able to make about differences based on diagnostic group. Moreover, the lack of information about health insurance reduces our ability to understand how socioeconomic factors influence education and depression in this sample. Lastly, the cross-sectional nature of this study limits our ability to make causal or directional inferences.

Despite these limitations, we believe that the reliability and predictive validity of the PRCISE make it a promising measure. Since biological measurement of adherence

across pediatric CI is not possible due to differences in biomarkers, treatments, and disease courses, an accurate self-efficacy scale would permit the active monitoring of patients who are likely to be noncompliant with medical recommendations. Next steps may include confirming the scale's structure through a confirmatory factor analysis, and furthering predictive and discriminant validity by testing whether the PRCISE predicts or is predicted by other clinical and health variables. Moreover, it would prove worthwhile to establish the PRCISE's clinical utility by having medical practitioners test the measure as a tool for identifying patients at risk of non-compliance.

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APPENDIX A

DEMOGRAPHIC SURVEY

For office use only, study ID:_____

Parent Fills Out

Demographic Information

What is your relationship to this child?

☐ Mother, Step Mother, Foster Mother ☐ Grandmother ☐ Guardian
☐ Father, Step Father, Foster Father ☐ Grandfather ☐ Other _____

INFORMATION ABOUT THE CHILD

Age of child : _____ *Current grade*: _____ *Child is:* ☐ male ☐ female

IS YOUR CHILD CURRENTLY IN SCHOOL? ☐ **YES** ☐ **NO** **IF YES, CURRENT OR MOST RECENT GPA:** _____

Ethnic Group or Race: ☐ Black, Non-Hispanic ☐ Hispanic ☐ Native American or Alaskan Native ☐ Asian or Pacific Islander ☐ White, Non-Hispanic ☐ Other_____

INFORMATION ABOUT MOTHER	INFORMATION ABOUT FATHER
Marital Status: ☐ Single ☐ Living with someone ☐ Married ☐ Divorced ☐ Separated ☐ Widowed	*Marital Status*: ☐ Single ☐ Living with someone ☐ Married ☐ Divorced ☐ Separated ☐ Widowed
Highest Level of Education: ☐ 6th grade or less ☐ 7th-9th grade or less ☐ 9th-12th grade or less ☐ High school graduate ☐ Some college or certification course ☐ College Graduate ☐ Graduate or Professional Degree	*Highest Level of Education*: ☐ 6th grade or less ☐ 7th-9th grade or less ☐ 9th-12th grade or less ☐ High school graduate ☐ Some college or certification course ☐ College Graduate ☐ Graduate or Professional Degree
Occupation Or Job Title: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐	*Occupation Or Job Title:* ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐
Yearly Income: ☐ $0-$14,999 ☐ $15,000-$24,999 ☐ $25,000-$39,999 ☐ $40,000-$59,999 ☐ $60,000-$79,999 ☐ $80,000-$100,000 ☐ More than $100,000	*Yearly Income:* ☐ $0-$14,999 ☐ $15,000-$24,999 ☐ $25,000-$39,999 ☐ $40,000-$59,999 ☐ $60,000-$79,999 ☐ $80,000-$100,000 ☐ More than $100,000

IMPACT SCALE

*In the past **6 months**, has your child…*

Had a chronic health condition such as <u>Type I diabetes, kidney disease, organ transplant, asthma, epilepsy</u>, etc. ?
A chronic condition is defined as a physical or mental health condition that has lasted or is expected to last at least 6 months, and interferes with your child's activities. ☐ NO ☐ YES

IF YES, What is the name of your child's chronic health condition? _____

*In the past **12 months**, has your child had…*

Any **OVERNIGHT VISITS** to the hospital? ☐ NO ☐ YES **IF YES,** … How many times? ☐☐ What was wrong? _____	Any **EMERGENCY ROOM/URGENT CARE** visits? ☐ NO ☐ YES **IF YES,** … How many times? ☐☐ What was wrong? _____

*In the past **30 days**…*

How many days did your child miss from school due to physical or mental health? ☐☐
How many days was your child sick in bed or too ill to play? ☐☐
How many days did your child need someone to care for him/her due to physical or mental health? ☐☐

*In the past **30 days**,* how many days have you or your spouse missed from work due to your child's health? ☐☐

*In the past **30 days**, has your child's health interfered with…*	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
Your or your spouse's daily routine at work	0	1	2	3	4
Your or your spouse's ability to concentrate at work	0	1	2	3	4

APPENDIX B

THE PATIENT HEALTH QUESTIONNAIRE FOR ADOLESCENTS (PHQ-A)

Child Fills Out

PHQ-9 modified for Adolescents (PHQ-A)

Instructions: How often have you been bothered by each of the following symptoms during the past **two weeks**? For each symptom put an **"X"** in the box beneath the answer that best describes how you have been feeling.				
	(0) Not at all	**(1) Several days**	**(2) More than half the days**	**(3) Nearly every day**
1. Feeling down, depressed, irritable, or hopeless?				
2. Little interest or pleasure in doing things?				
3. Trouble falling asleep, staying asleep, or sleeping too much?				
4. Poor appetite, weight loss, or overeating?				
5. Feeling tired, or having little energy?				
6. Feeling bad about yourself – or feeling that you are a failure, or that you have let yourself or your family down?				
7. Trouble concentrating on things like school work, reading, or watching TV?				
8. Moving or speaking so slowly that other people could have noticed? Or the opposite – being so fidgety or restless that you were moving around a lot more than usual?				
9. Thoughts that you would be better off dead, or of hurting yourself in some way?				

In the **past year** have you felt depressed or sad most days, even if you felt okay sometimes?

☐Yes ☐No

If you are experiencing any of the problems on this form, how **difficult** have these problems made it for you to do your work, take care of things at home or get along with other people?

☐Not difficult at all ☐Somewhat difficult ☐Very difficult ☐Extremely difficult

Has there been a time in the **past month** when you have had serious thoughts about ending your life?

☐Yes ☐No

Have you **EVER**, in your WHOLE LIFE, tried to kill yourself or made a suicide attempt?

☐Yes ☐No

***If you have had thoughts that you would be better off dead or of hurting yourself in some way, please discuss this with your Health Care Clinician, go to a hospital emergency room or call 911.*

Office use only: **Severity score: _____**

Modified with permission from the PHQ (Spitzer, Williams & Kroenke, 1999) by J. Johnson (Johnson, 2002)

The Pediatric Rating of Chronic Illness Self-Efficacy (PRCISE)

Child Fills Out

Chronic Illness Appraisal Inventory for Children

Even though you have a health condition…

Exercise	Circle the number that best describes how sure you are:
1. How sure are you that you can exercise without making your health worse?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
2. How sure are you that you can exercise regularly?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure

Obtain Help from Family, Friends and Doctors	Circle the number that best describes how sure you are:
3. How sure are you that you can get help from family with tasks and activities such as homework or chores?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
4. How sure are you that you can get family to help you when you are feeling sad or worried (such as listening or talking about problems)?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
5. How sure are you that you can get friends to help you when you are feeling sad or worried (such as listening or talking about problems)?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
6. How sure are you that you can ask your doctor questions when you are worried or unsure about your health?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure

Illness Management	Circle the number that best describes how sure you are:
7. How sure are you that you can follow your doctor's advice everyday?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
8. How sure are you that you can take your medications correctly every day?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
9. How sure are you that you can tell when feelings in your body mean that you should see a doctor again?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
10. How sure are you that you can do everything you need to do to stay healthy?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
11. How sure are you that you stay away from things that make you feel bad?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure

Chores, Hobbies and Recreation	Circle the number that best describes how sure you are:
12. How sure are you that you can complete your household chores?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
13. How sure are you that you can continue to do your hobbies and things you enjoy?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
14. How sure are you that you can continue to do the things you like to do with friends and family?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
15. How sure are you that you can go to school without having your health get in the way of your learning?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure

For office use only *Study ID:*

Symptoms	Circle the number that best describes how sure you are:
16. How sure are you that you can reduce your physical discomfort or pain?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
17. How sure are you that you can make yourself better when you feel sick?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
18. How sure are you that you can keep your health problems from getting in the way of what you want to do?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure

Mood	Circle the number that best describes how sure you are:
19. How sure are you that you can keep from getting worried when nothing you do seems to make any difference?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
20. How sure are you that you can keep from feeling sad about your health?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
21. How sure are you that you can do something to make yourself feel better when you are feeling worried?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure
22. How sure are you that you can do something to make yourself feel better when you are feeling sad?	not at all sure 0 1 2 3 4 5 6 7 8 9 10 very sure

For office use only *Total Score:* _____ *Study ID:* _____