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ASSESSING PEDIATRIC CHRONIC PAIN TREATMENT ENGAGEMENT: DEVELOPMENT AND INITIAL VALIDATION OF THE PEDIATRIC PAIN PERCEIVED BEHAVIORAL CONTROL MEASURE

by

Nina G. Linneman

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ABSTRACT

ASSESSING PEDIATRIC CHRONIC PAIN TREATMENT ENGAGEMENT: DEVELOPMENT AND INITIAL VALIDATION OF THE PEDIATRIC PAIN PERCEIVED BEHAVIORAL CONTROL MEASURE

by

Nina G. Linneman

The University of Wisconsin—Milwaukee, 2022
Under the Supervision of Professor Nadya A. Fouad

Pediatric chronic pain significantly impacts functioning across all domains of life and often carries forward into adulthood. Chronic pain is often complex to treat and pediatric non-adherence to treatment recommendations has been indicated to be upwards of 55%. Using the Theory of Planned Behavior as a framework, the aim of the present study was to develop and validate two measures of *perceived behavioral control* for chronic pain treatment recommendations with a clinical adolescent patient sample (patient and parent proxy versions). The measures underwent development, data from a pediatric chronic pain clinical sample were collected, and an exploratory factor analysis was conducted on both a patient and parent proxy versions of the pediatric pain perceived behavioral control measure. The resulting measures included a 2-factor patient measure that accounted for approximately 65% of the variance, and a 3-factor parent proxy measure that accounted for approximately 72% of the variance. The resulting measures demonstrated reliability, content validity, and emerging construct validity. Implications for future directions include further validation of the study measures as well as further analysis into reasons why certain hypothesized recommendations did not emerge or appear as relevant factors including lifestyle modifications and psychotherapy. Future development of the measures should include collecting data from a new clinical sample to determine if the factor structure holds through use of a confirmatory factor analysis.

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Chapter 1: Introduction

It is estimated that a quarter of children and adolescents will experience chronic pain at some point in their development, Pain prevalence estimates vary widely though across various pediatric medical diagnostic categories (Fuss, Page, & Katz, 2011; King et al., 2011; Perquin et al., 2000). To characterize the prevalence of pediatric chronic pain, King et al. (2011) completed a systematic review in which they analyzed 41 studies that described chronic pain rates in children and adolescents. From this review, it was determined that pediatric lifetime pain prevalence rates vary considerably and range from 8-83% of children experiencing chronic headaches, 4-53% experiencing abdominal pain, 14-24% experiencing back pain, 4-40% experiencing musculoskeletal pain, 4-49% experiencing pain in more than one area, and 5-88% experiencing “other” pains. Community samples have yielded similar overall prevalence rates. In a sample of Canadian children and adolescents, it was found that 27% of the 1,006 child and adolescent participants reported experiencing chronic pain at least once during the course of their development (Fuss et al., 2011). Further, Tumin et al. (2018) analyzed responses from the 2016 National Survey of Children’s Health in order to characterize the percentage of children and adolescents who experience pain at any given time. From their analyses of the responses, the authors determined that 6% of children and adolescents experience a chronic pain condition at any given time.

Chronic pain is defined as “ persistent or recurrent pain lasting longer than 3 months” (International Association for the Study of Pain (IASP) Terminology Working Group, 2011; Scholz et al., 2019; Smith B. et al., 2019; Treede et al., 2015). The effects of experiencing chronic pain as a child or adolescent are not isolated to childhood, as chronic pain concerns have been shown to carry forward into adulthood as well. At a tertiary-level pain clinic servicing adult chronic pain patients, a sample of 1,045 new patients completed questionnaires about their pain history. From this sample, 17% of the respondents indicated that they experienced chronic pain either in childhood or adolescence. Further, 80% of those who endorsed having a chronic pain condition in childhood or adolescence reported that they still struggled with that same chronic pain condition as an adult (Hassett et al., 2013).

In addition to the longitudinal health impacts related to chronic pain, treatment costs and health care utilization are also very high. In a study analyzing the financial impacts of chronic pain treatment, Groenewald et al. (2014) surveyed 149 treatment-seeking adolescents at a tertiary-level pain clinic to better understand the financial burden of specialty pain treatment for moderate to severe chronic pain. The authors found that on average, patients paid almost $12,000 to treat their chronic pain condition. To extrapolate health care costs, the authors calculated reported healthcare usage by average unit cost. From this calculation, the authors determined that the cost to treat moderate to severe chronic pediatric pain totaled $19.5 billion annually in the United States. While the economic figure is startling, the impacts and costs of chronic pain in adults in the United States is upwards of $635 billion annually (Gaskin & Richard, 2012). These figures speak to the need to address chronic pain appropriately and swiftly during childhood and adolescence.

Pediatric chronic pain patients often experience other related psychosocial concerns that co-occur with the chronic pain including anxiety, depression, school functioning concerns, and peer and family functioning concerns (Anderson Khan et al., 2015; King et al., 2011; R. J. Ladwig & Khan, 2007; Sato et al., 2007). Many studies have indicated a strong linkage between markers of emotional distress, including depression and anxiety, and chronic pain occurrence and recurrence

(King et al., 2011; Stanford et al., 2008). School functioning and school attendance concerns have also been linked to pediatric chronic pain, with those who have chronic pain having an increased risk of missing school due to pain and associated psychosocial symptoms (Anderson Khan et al., 2015; Gorodzinsky et al., 2011; Ladwig, 2007; Sato et al., 2007). Additionally, those with chronic pain are also at an increased risk for peer and family functioning concerns, including reduced contact with peers as well as reduced participation in social activities (Palermo, 2000).

Given the chronic pain prevalence rates, frequency with which chronic pain in childhood and adolescence advance into adulthood, and prevalence of co-occurring emotional distress, multidisciplinary chronic pain treatment has been indicated as the gold standard of care (Odell & Logan, 2013). Multidisciplinary care teams provide a comprehensive, biopsychosocial approach to chronic pain treatment. Within the context of this multidisciplinary approach, providers from various backgrounds come together to develop a treatment plan to address the chronic pain condition or conditions. Oftentimes, these specialists include medical providers from disciplines such as anesthesiology or neurology, psychology, physical therapy, and occupational therapy, among others. Generally, comprehensive recommendations for pain management may include medication management, modifications to activity level or lifestyle, use of cognitive and behavioral strategies in order to manage pain symptoms, as well as related therapeutic interventions such as physical or occupational therapy (Jenson, Nielson, & Kerns, 2003). While a team approach has been proven to both reduce the impact of pain symptoms as well as the overall cost of health care utilization, (Turk, 2002) very few studies have analyzed adherence to multidisciplinary treatment team recommendations for pediatric chronic pain. Further, the author is aware of no studies that have measured perceived behavioral control regarding chronic pain treatment recommendations in a pediatric sample.

While multidisciplinary care has been deemed to be the gold standard approach to chronic pain, there is presently no single measure of adherence that has been deemed to be a “gold standard” in terms of ability to accurately measure multidisciplinary chronic pain treatment progress (Quittner, Modi, Lemanek, Ievers-Landis, & Rapoff, 2008). In Rapoff’s review of the pediatric adherence literature, 111 studies focused on adherence across different health conditions and regimens. In general, nonadherence has been shown to occur in 50-55% of pediatric patients with a chronic health condition (as cited in Rapoff, 2010). Given this level pediatric non-adherence, the high cost of healthcare utilization known to exist for chronic pain patients, as well as the strong likelihood of chronic pain conditions lasting into adulthood, it is critical to accurately and appropriately measure whether patients will be willing to fully engage with comprehensive treatment recommendations.

Perceived Behavioral Control

Perceived Behavioral Control is a construct that is central to the Theory of Planned Behavior (Azjen, 1991). Perceived behavioral control refers to “people’s perception of the ease or difficulty of performing a behavior of interest” (Azjen, 1991, p. 183). The model posits that constructs including attitudes, subjective norm, and perceived behavioral control predict behavioral intentions which then predict behaviors. While various other models, including the Health Belief Model (Strecher, Champion, & Rosenstock, 1997), The Protection Motivation Theory (Prentice-Dunn & Rogers, 1986), and Social Cognitive Theory (Bandura, 1986) also aim to understand behavior, these theories tend to focus more on the construct of perceived self-efficacy or self-efficacy, which is similar, though distinct, from the construct of perceived behavioral control. Bandura defined perceived self-efficacy as “beliefs in one’s capabilities to organize and execute the courses of action required to produce given attainments” (Bandura, 1997, p. 3). While there is certainly a component of cognitive appraisal present in both constructs, Azjen’s perceived behavioral control construct hinges on the notion that individuals perceive behaviors to be on a spectrum of difficulty to perform.

The Theory of Planned Behavior has been widely used in various fields including adult health behavior research (Brooks et al., 2017; Jiang, Lu, Hou, & Yue, 2013; Montanaro & Bryan, 2014; Pineles & Parente, 2013) as well as the field of business (Van Breukelen, Van Der Vlist, & Steensma, 2004; Yoon, 2011). While the Theory of Planned Behavior has been commonly used to understand adherent and non-adherent behaviors in the adult health literature, the theory has not been commonly used in the pediatric health literature to understand adherent and non-adherent behaviors. Despite its lack of use in the pediatric literature, the construct of perceived behavioral control adds a unique element to the understanding of adherent and non-adherent behavior because it aims to measure the level of perceived behavioral control that one believes is present across various specific behaviors. Further, the Theory of Planned Behavior model aims to characterize how perceived behavioral control as a construct can be used as a predictor for behavioral performance.

Research Aims

To date, there exists very little theoretically grounded research on perceived behavioral control with pediatric populations. Further, the author was not aware of any studies that examined the construct of perceived behavioral control in the context of pediatric chronic pain management prior to the execution of this study. As such, this study aimed to develop and validate a measure of perceived behavioral control (both pediatric patient and parent/guardian proxy versions) for use in an adolescent clinical chronic pain population for patients aged 10-17 years old. Following scale development, the measure underwent exploratory factor analysis (EFA) and initial validation. It was hypothesized that both versions of the measure would be positively correlated with constructs including self-efficacy and quality of life and negatively correlated with reports of depressive and anxiety symptoms. It was further hypothesized that the study measures would load on similar factors (See Tables 2 and 3 for hypothesized factor loadings).

Definitions

Adherence. “The extent to which a person’s behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice” (Haynes, 1979, pp. 1-2).

Chronic Pain. “Persistent or recurrent pain lasting longer than 3 months” (International Association for the Study of Pain (IASP) Terminology Working Group, 2011; Scholz J. et al., 2019; Smith B. et al., 2019; Treede et al., 2015).

Multidisciplinary Pain Treatment Team. Treatment team composed of various sub-specialties including, but not limited to, medical providers such as medical doctors, advanced practice providers (advanced practice nurses, physician assistants), behavioral health providers (psychologists, therapists), physical therapists, occupational therapists, and dieticians.

Perceived Behavioral Control. “People’s perception of the ease or difficulty of performing a behavior of interest” (Azjen, 1991; Azjen & Madden, 1986).

Quality of Life. “An individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (World Health Organization, 1999, p.3)

Self-efficacy. “Beliefs in one’s capabilities to organize and execute the courses of action required to produce given attainments” (Bandura, 1997, p. 3).

Tertiary level pain clinic. Specialty pain clinic servicing patients with both acute and chronic pain concerns.

Chapter 2: Literature Review

To establish the need for a perceived behavioral control measure for the pediatric chronic pain population, the following review will serve to assess and critique the foundational literature base in the area of perceived behavioral control. Additionally, the review will cover broad pediatric chronic condition adherence and self-management literature as well as current adherence and self-management measures. Due to the paucity of literature in the area of pediatric chronic pain treatment adherence, the literature review will also evaluate the applications of the related constructs such as *self-efficacy*, and *perceived barriers* and *perceived benefits* from associated models of behavioral change including the Health Belief Model. Additionally, a more concentrated effort will focus on research in pediatric chronic pain and pediatric chronic pain adherence specifically. Finally, an analysis of the best practice recommendations for measurement development will round out the literature review.

Theory of Planned Behavior

The Theory of Planned Behavior was developed and refined from The Theory of Reasoned Action (Azjen & Fishbein, 1980; Fishbein & Azjen, 1975) which posited that behavior could be predicted from constructs including *attitude* toward the behavior, the *subjective norm* (i.e., the degree to which one believes others want them to engage in the behavior), and *behavioral intention*. While this theory accounted for the influences of others (*subjective norm*) as well as one's attitudes and viewpoints regarding a target behavior, the component of cognitive appraisal associated with the *behavioral intention* was not accounted for in the original model. Thus, the theory was updated and refined by Azjen in 1991 to include the construct of *perceived behavioral control*, which then became a key element to understanding and predicting behavioral intentions and ultimately behavior execution. The new theory was called the Theory of Planned

Behavior (Azjen & Madden, 1986). The addition of the construct of *perceived behavioral control*, added to the constructs of *attitudes* and *subjective norm* in the prediction of *behavioral intentions* and eventual behavioral engagement.

Related Constructs and Models

To explain the construct of *perceived behavioral control*, it is important to understand constructs and other theories that are very similar to *perceived behavioral control*. The most closely related construct is the concept of *self-efficacy*. In Bandura's model, the Social Cognitive Theory's (Bandura, 1977, 1986, 1997) concept of *self-efficacy* fits within the construct of *personal factors* and works together with the two other constructs of *behavioral factors* and *environmental factors* to explain that learning and acquisition of knowledge occurs in a social context. *Behavioral factors* include *outcome expectations*, which refers to one's beliefs about achieving a specific outcome. *Environmental factors* relate to the various social supports and barriers that are present in the environment. Sources of self-efficacy stem from four areas including past performance accomplishments, vicarious experiences, verbal persuasion of others, and factors related to one's physiological arousal. While the constructs of *perceived behavioral control* and *self-efficacy* are closely related and both incorporate beliefs and perceptions about one's performance, *perceived behavioral control* adds the element of the perception of difficulty, which adds to the cognitive appraisal of control regarding implementing a specific behavior.

Another related model that has been used more in pediatric adherence literature is the Health Belief Model. This framework originally developed in the 1950s by social scientists at the United States Public Health Service aimed to describe disease prevention strategies and early screening behavior from a population-level perspective. The Health Belief Model posits that *perceived susceptibility*, *perceived severity of the illness*, *perceived benefits* of the treatment, and *perceived barriers* to the treatment, comprise a person's health motivation to engage in specific health promoting behaviors. While this model is useful for broad population-level research, one limitation of its application to the present study was that the sample for this scale development already had chronic pain. Thus, the utility of the perceived susceptibility and perceived threat of developing illness were not applicable because this clinical population already had reported ongoing pain concerns.

Theory of Planned Behavior in Healthcare

In a review of the Theory of Planned Behavior in healthcare applications, (Godin & Kok, 1996) were one of the earliest groups of researchers to evaluate the healthcare literature base in order to understand both the breadth and depth of the application of the Theory of Planned Behavior. While somewhat dated at this point, it serves as a basis to understand the breadth of the healthcare literature base that aimed to use this behavioral model. All of the 56 included articles were those that included at least basic information on all aspects of the Theory of Planned Behavior model, including *attitudes, subjective norm, perceived behavioral control,* and *behavioral intentions*. The healthcare categories and behaviors were broad and included addiction concerns, clinical screening efforts, driving behaviors, eating, exercising, HIV/AIDs protective behaviors, and oral hygiene. Results from the review indicated that moderate to strong positive correlations (range of .32 to .67) between *intention* and *behavioral control* emerged from the data. Overall, *perceived behavioral control* was found to be significantly correlated with *behavioral intentions* in 85.5% of the studies included in the review. Interestingly, of the other two constructs theorized to predict *behavioral intentions,* the construct of *attitudes* was significantly positively correlated in 81.6% of the studies, but *subjective norm* was only significantly correlated in 47.4% of the studies. While the predictive nature of the constructs was not robustly analyzed, *perceived behavioral control* emerged as the construct with the strongest association to subsequent behavioral performance constructs in the model.

Theory of Planned Behavior: Applications with Children

More recently, the Theory of Planned Behavior has been utilized within the child literature base in a variety of contexts. The following section will aim to describe the breadth of literature, as well as to provide a critique of the applications to date.

Several studies aimed to understand exercise behaviors among groups of racially under-represented children. In one study completed by Martin et al. (2005), the researchers aimed to understand the moderate to vigorous exercise behaviors, as well as cardiovascular fitness of 548 African American children, aged 9–12 years old. The participants completed measures of the various constructs of Theory of Planned Behavior and a structural equation model was utilized to understand the paths of the various constructs. The researchers found that, in fact, the model did not tend to hold up in this sample of children. *Perceived behavioral control* was found to be non-significant in its association with *behavioral intention*. Rather, *perceived behavioral control* emerged as a mediator between *attitudes* and *intention* as opposed to a distinctive path. Several methodological issues existed in this study however, including the use of non-validated measures. The authors note that the measures were created using guidelines from the theory's creator, Icek Azjen. However, these measures were not robustly validated prior to their use (Martin et al., 2005). In particular, only two non-validated *perceived behavioral control* items were utilized and as such the study's conclusions should be interpreted with caution. One strength of the study is that it included a large, typically underrepresented sample. In another study completed by the same group of researchers with Mexican American children, the researchers found that while the variance in *behavioral intentions* was captured by the combination of the first three constructs in the model, *perceived behavioral control* did not add significantly to the variance in *intentions*, and accounted only for 2.4% of the variance (Martin, Oliver, & McCaughtry, 2007). Again, however, it appears as though the authors utilized the same two items from the previous study (Martin et al., 2005) to measure perceived behavioral control, and these were not robustly validated.

In the area of child nutrition, a group of researchers (Lien, Lytle, & Komro, 2002) aimed to explore how well the Theory of Planned Behavior could be applied to a sample of adolescents in order to understand their behaviors around eating fruits and vegetables. In general, the construct of "barriers" accounted for the greatest variance in predicting the behavior, however, it is unclear whether the authors of this study fully understood the theoretically grounded variables of the model because they utilized the construct of "barriers" in place of *perceived behavioral control*. From a theoretical standpoint, it is not appropriate to substitute "barriers" for *perceived behavioral control* in the model. Unfortunately, barriers to behavioral engagement do not truly capture the cognitive appraisal element of ones' perceptions of their ability to do the behavior. Additionally, the authors created their own measures of the constructs, and although they used focus groups in the initial phases of the scale development, there was not a clear robust effort to establish other forms of validity. Thus, this study is limited in its ability to draw conclusions about *perceived behavioral control*.

Pediatric Adherence

Pediatric adherence to complex medical regimens and routines is critical for overall functioning, but when non-adherence occurs, it can have dangerous medical effects as well as increased healthcare utilization. When patients do not adhere to treatment recommendations, the medical impacts can be immediate and harmful. In a study completed by Modi, Wu, Rausch, Peugh, & Glauser, 2014, the researchers analyzed a group of pediatric patients (n=109) with epilepsy over two years in order to understand their adherence patterns and risk of seizures. Four adherence groups emerged from the data, including three non-adherent groups (n=66) and one highly adherent group (n=43). Additionally, patients were classified as having either high or low seizure probability. Through latent growth modeling, the researchers were able to significantly predict the seizure risk group based upon the adherence groups. Thus, the team identified that those with adherence problems were significantly more likely to have higher seizure activity than those who had high adherence rates.

In another study conducted by Bhatia and colleagues, the research team analyzed treatment adherence in a population of Hispanic (n=169) and non-Hispanic (n=158) pediatric patients with Acute Lymphoblastic Leukemia. The researchers found that adherence issues related to oral chemotherapy was associated with higher risk of disease relapse across the entire sample (Bhatia et al., 2012).

In a study completed by Hommel et al. (2017), the team analyzed the medical utilization of patients aged 2-21 years over a two-year period with Inflammatory Bowel Disease. The results of the study indicated that for those with declining adherence over time, as calculated by medication refills and disease activity ratings, they had a 3-fold increase in healthcare utilization as calculated by physician and hospital charges, when compared to those who had stable adherence over time. The results from this study demonstrate the cost of nonadherence in a sample of complex pediatric patients over time, and points to the need to study pediatric nonadherence more closely.

Pediatric Chronic Condition Adherence and Self-Management Measures

Because very little research exists in the area of pediatric chronic pain treatment adherence, it is necessary to look at adherence and self-management within related pediatric chronic health conditions for guidance regarding adherence concerns broadly, as well as to understand adherence measures presently in use in clinical settings. Pediatric chronic conditions require an array of treatment tasks and self-management behaviors to manage symptoms and disease progression. Pediatric patients are often required to take daily medications, engage in a variety of therapies (e.g., psychotherapy, occupational therapy, speech therapy, physical therapy, etc.), perform daily cares (e.g., glucose monitoring, nebulizer treatments, etc.), and engage in a host of lifestyle behaviors including increased physical activity, increased fluid intake, sleep regulation, and specific food choices in order to manage their chronic health condition (Modi & Driscoll, 2020).

In 2003, a task force through the Society of Pediatric Psychology (American Psychological Association (APA) Division 54) formed in order to analyze the evidence-based assessment measures that were currently in use by pediatric psychologists in the field (as cited in Quittner et al., 2008). Specifically, the Adherence Workgroup was tasked to investigate the present adherence measures and accompanying psychometric data to provide recommendations about which measures clinicians should consider using in their practice. The workgroup discovered five primary methods of assessment including self-report questionnaires and structured interviews, diary measures, electronic monitors, prescription refill histories, and biochemical assays. From here, the workgroup then utilized Evidence Based Assessment guidelines endorsed by the APA to categorize the assessment measures as either "well-established," "approaching established assessment," or "promising assessment." Some specific pediatric chronic health conditions that have a more robust literature base in the areas of adherence and self-management include the areas of diabetes, solid organ transplant, cystic fibrosis, asthma, HIV/AIDS, and spina bifida. For the purposes of this review, only those self-report or structured interviews of adherence deemed to be "well-established" (at least two separate research teams have published articles both on the evaluation of the measure as well as the establishment of strong psychometric properties) by Quittner et al., 2008 will be further discussed below.

Within the area of pediatric diabetes management, La Greca, et al. (1988) developed the Self Care Inventory (SCI) which has been deemed as a "well established" assessment for self-care, or self-management behaviors. The original measure consisted of 13 self-report items on a 1-5 Likert scale and assessed the frequency that patients engaged in self-care behaviors for their diabetes. The structure of the assessment is a 30-day lookback of behavioral adherence with items assessing glucose monitoring, insulin administration, appointment adherence, dietary, and exercise recommendations. The SCI was revised in 1992 (La Greca, 1992) to include one additional item. Soon after this addition, it was utilized by several researchers who established both test-retest reliability of .77 over a 2-4 week period as well as internal consistencies of .80 and above in several studies with adolescents (Davis et al., 2001; Delamater et al., 1997; La Greca, 2004). This measure was further extended for use within the adult diabetes population, and a revised version is available for use with adults. The Self Care Inventory-Revised (SCI-R) (Weinger et al. 2005) yielded results suggesting good reliability and validity. Validation efforts in the adult population have yielded internal consistency of Cronbach's alpha at 0.87, concurrent validity of r=0.63 between the SCI-R and the Summary of Diabetes Self-Care Activities (Toobert, Hampson, & Glasgow, 2000), which measures frequency of diabetes cares. The authors also assert that the SCI-R correlates negatively with diabetes related stress, depression, anxiety, and elevated HBA1C, and positively correlates with self-esteem and self-efficacy. Although the SCI had been in use for many years, Lewin et al. (2009) noted the gap in the validation for this measure and decided to test the psychometric properties of both the pediatric patient and parent SCI forms. It was found that the measure had construct validity in that it was moderately associated with the Diabetes Self-Management Profile (Harris et al., 2000), moderately negatively associated with elevated HBA1C, and moderately positively associated with blood glucose monitoring frequency.

Although the SCI has somewhat limited psychometric data, it nonetheless has had its use extended to other pediatric conditions. Bourdeau et al. (2007) modified portions of the SCI to adapt the measure to a sample of pediatric patients with cystic fibrosis and asthma. The purpose of this study was to analyze the relationship between various parent variables and the self-care behaviors of children with either diabetes, cystic fibrosis, or asthma. Several limitations exist within this study including the lack of theoretical grounding and a sample composed of majority White, college-educated, higher income families, which limits the generalizability of the findings. One of the most significant limitations of the study was that the researchers did not describe the measurement development process for the SCI's adapted use with either the cystic fibrosis or asthma samples. The authors noted that "for the purposes of the current study, the original SCI was adapted to reflect specific self-care behaviors associated with each of the other two illness groups" (Bourdeau et al., 2007, p. 129). The authors noted Cronbach's alpha=.68, and .66 (parents' ratings of their child's self-care behaviors and child ratings, respectively). This level of reliability is considered to be somewhat questionable (Nunnally, 1978). This same measurement tool was then utilized by Dempster et al. (2018) in order to understand treatment adherence in another pediatric cystic fibrosis sample. While this study was more concretely theoretically grounded in the Health Belief Model, it too did not provide robust information about the validation of the instrument for use with this sample. Instead, the authors cited Bordeau et al. (2007) and relied upon information that it had "...been used in other empirical studies with patients with cystic fibrosis" (Dempster et al., 2018, p. 437). Unfortunately, Bourdeau and colleagues' original study only describes how they adapted the measure to self-care behaviors necessary for cystic fibrosis management without other information regarding the validation of this tool after the items were modified to fit their sample. Additionally, the small sample size in Dempster et al. study (n=33) and the subsequent bootstrapping methodology point to potential issues related to power as well as to concerns related to generalizability and risk of error.

Another "well established" measure is the Diabetes Regimen Adherence Questionnaire (DRAQ). This 15-item adolescent self-report measure was created by Brownlee-Duffeck et al. (1987) in order to assess adolescents' adherence to diabetes management behaviors from the Health Belief Model. This longitudinal study consisted of two separate groups of participants that were classified as either "young" or "old." The range for the younger group was 13-26 years old (M=18 years old). Participants completed health belief questionnaires at the first timepoint, and the DRAQ (dependent variable) at the later time-point. While the authors noted internal consistency as measured by Cronbach's alpha of .79, validation of this author-created measure was not referenced in the study. It was noted that correlations between adherence and the Health Belief Model construct of "costs" were the only correlated items.

Pediatric Chronic Pain

Related Measures

While not measuring adherence specifically, the Pain Stages of Change Questionnaire-Adolescent and Parent versions (Guite et al. (2011) are tools that were adopted and modified from the Pain Stages of Change Questionnaire (Kerns et al., 1997). This modified measure was developed for use with adult chronic pain patients. The PSOCQ-A and PSOCQ-P measure both pediatric patient and parent perceptions of their readiness to adopt pain self-management strategies, which is based upon the stages of the Transtheoretical Model (Prochaska & DiClemente, 1984). The Transtheoretical Model is essentially a stages of change model that provides definition of behavioral change and is based upon the cognitive and behavioral factors associated with four phases of change behavior: precontemplation, contemplation, action, and maintenance. Confirmatory Factor Analysis indicated that the measure had adequate construct validity for a four-factor model for parent report (RMSEA value of 0.064 and CFI=0.840), and a 3-factor model for child report (RMSEA value of 0.068 and CFI=0.836). In both of these instances though, CFI values did not meet the recommended threshold of at least .95 for adequacy (Bentler, 1990; Hu & Bentler, 1999). While the parent report mapped onto the four phases of the Transtheoretical Model, the child measure indicated high correlation between the action and maintenance phases. The measure poses a series of self-management strategies for patients and parents to consider. Ultimately scores should help clinicians to understand which phase of the transtheoretical model the patient is in at the beginning of treatment. However, given that the measure items are on a continuous scale, it is difficult to categorize children into one discrete phase of the model, thus potentially limiting its utility.

Pediatric Adherence in Chronic Pain

The first, and presently, only study to the author's knowledge, to analyze multi-faceted adherence in a tertiary-level pediatric chronic pain clinic in the United States was completed by Simons et al. (2010) at Boston Children's Hospital. The purpose of this study was multifaceted and aimed to understand adherence to multidisciplinary chronic pain treatment recommendations, collect longitudinal data to examine changes in functioning over a three-month period, and analyze factors that influenced adherence such as familiarity with recommendations, expectations, barriers, and perceived benefits. The sample comprised 70 parents and 57 pediatric patients, aged 10-17 years old, who had a chronic pain diagnosis. Demographic data were collected for the patients, who were majority White (88.8%) and female (79.2%). Unfortunately, demographic data were not collected for the parent respondents, aside from education level and marital status, of which 56.9% of mothers and 62.4% of fathers had a college degree or higher. Additionally, 71.9% of the parent sample indicated that they were married.

The authors opted to conceptualize the study from the Health Belief Model. Using this theory, the researchers conducted a study in which they had patients seeking services at a tertiary-level chronic pain clinic complete child and parent measures immediately following their initial multidisciplinary pain treatment intake appointment, as well as measures approximately 3 months post intake. While some of the theory-specific measurements do not exactly fit with the proposed present study, the results offer valuable insight into which types of recommendations this particular pediatric population was adherent to. Adherence varied from 47% to 100% adherence to the team recommendations, which were grouped into three categories: medical, physical therapy, and psychological. Of those recommendations, physical therapy recommendations were completed most frequently. In contrast, less than 50% of families followed through with recommendations to begin cognitive behavioral therapy for pain management. The authors conceptualized this difference in adherence to the notion that it is more challenging for families to commit to and follow through with new psychological therapy. Overall, the authors noted modest functional improvements in those who reported higher levels of adherence to the recommendations.

Qualitative responses from the study also shed light on reasons why families were unable to completely adhere to specific treatment recommendations. The reasons generally fell into four primary categories including access issues, financial problems, scheduling demands, and negative attitudes or beliefs. Interestingly, negative attitudes or beliefs comprised the largest categories related to non-adherence in all three domains. Examples of negative attitudes included "Did not want to do it; Did not feel like it made a difference; Did not provide relief; Not interested." Regarding medical non-adherence, 73% of those who did not follow through with recommendations cited negativistic attitudes or beliefs about treatment as compared with 65% who did not follow through with physical therapy recommendations, and 50% of respondents who did not follow through the psychotherapy recommendations.

In a separate publication, Claar & Simons (2011) analyzed the same data collected in Simons et al. (2010) to better understand the particular non-adherence to the team's psychological treatment recommendations. For this study, the researchers analyzed data collected for participants aged 13-17 years old in order to apply a coping typology framework and assess initial and follow-up data. From that age subsample, a total of 85 parent and child dyads completed initial data. The child responses were then coded according to their typology of coping, a method outlined by Walker et al. (2008). Patients were classified into six pain coping typologies including: self-reliant copers, engaged copers, avoidant copers, dependent copers, infrequent copers, and inconsistent copers. Due to the small sample size in the study, the coping types were collapsed broadly into adaptive copers (n=23) and nonadaptive copers (n=34), based upon findings in Walker et al. (2008) that self-reliant and engaged copers generally engaged in more “adaptive” coping overall as compared to avoidant and dependent copers, which fell under the category of “non-adaptive.” Adaptive copers tended to report lower levels of emotional distress and functional disability whereas nonadaptive copers tended to report higher levels of disability, somatic concerns, and emotional distress (Claar & Simons, 2011; Walker et al., 2008). Due to this methodology, Clarr and Simons did not analyze the remaining 28 “infrequent” or “inconsistent” copers, due to the assertion that “...previous research using these coping profiles has not yet yielded any significant clinical findings” (Claar & Simons, 2011, p. 194). Thus, the team was left with 57 responses after the initial data collection. Parents of the adaptive copers reported higher expectations regarding general psychological treatment as well as hypnosis as compared to the nonadaptive copers. There were no group differences regarding parent expectations about biofeedback or relaxation training.

At the follow-up data collection timepoint, the team was able to collect responses from 28 child-parent dyads that had previously been coded as either “adaptive” or “nonadaptive.” Interestingly, results from the study indicate that there were no group differences between the adaptive and nonadaptive copers in initiating psychological treatment intervention. It was noted that at the 3-month follow-up time point, 7 of the 12 adaptive copers and 9 of the 16 nonadaptive copers had sought out psychotherapy, which was not significantly different. However, the small sample size may have been to blame for the lack of detection of significant differences between groups at the follow-up time point regarding follow through on psychotherapy recommendations.

Additionally, the authors noted a high attrition rate (approximately 50%), which impacts the generalizability of the study and limits the general understanding of how adolescent patients and their parents engage with the psychological recommendations from their treatment team. Though several methodological concerns exist, the authors highlight the importance of this work for clinical applications, including how treatment teams present psychotherapy recommendations and provide education around the necessity of such interventions while simultaneously reducing barriers to access, including providing all families with appropriate, pain-specific, community clinician referrals.

In addition to Simons et al. (2010) and Clarr and Simons (2011), a study completed by researchers in Germany analyzed adherence to treatment recommendations in a sample of 416 children and adolescents in an outpatient chronic pain clinic. The study utilized semi-structured interviews that were completed approximately 12 months after their pain clinic appointments. The semi-structured interviews aimed to better understand the family's perceptions of the pain-related recommendations and their effectiveness in reducing their child's pain. Overall, the researchers noted that lifestyle recommendations were followed in 93.5% of cases, physical therapy in 83% of cases, and medication adherence in 91.6% of cases. Recommendations around active relaxation as well as psychotherapy recommendations were followed less often, with less than half of respondents indicating adherence to therapy recommendations. The article is written in German, so unfortunately the investigator is unable to provide a more robust critique of the study (Barth, Wager, Hoebner-Moehler, & Zernikow, 2016; as cited in Modi & Driscoll, 2020, Chapter 6).

In conclusion, due to the paucity of literature in pediatric chronic pain adherence, coupled with the limited number of robustly validated measures, the present study aims not only to fill these gaps, but to develop a measure that will be clinically useful for multidisciplinary pediatric chronic pain providers to use prior to the delivery of pain treatment recommendations.

Best Practices in Measurement Development

Boateng et al. (2018) put forth recommendations for best practices related to the development and validation of scales for health and other behavioral research. The process consists of several phases including item development, scale development, and scale evaluation. The following section will aim to describe the various processes. During the process of item development, the team suggests that researchers identify the specific domain of assessment as well as the item generation to fit the suggested domain. Following item creation, it is recommended that the items undergo the process of content validation whereby the initial item pool is analyzed by a group of experts including assessment of formalized scaling efforts as well as conducting cognitive interviews to evaluate the face validity of the items.

The second phase of the process is scale development. During the first part of scale development, questions are pre-tested with interviews, and verbal feedback about the experience of answering the questions is collected. Next, researchers enter the data collection phase whereby they administer the survey to approximately 200-300 participants to establish emerging construct validity through exploratory factor analysis. After data collection efforts, researchers engage in item reduction efforts to retain the most parsimonious items. Additional analyses include determining correlations between items and the degree to which the items measure the construct. The final step of this phase is to extract factors by analyzing scree plots and factor loadings through exploratory factor analysis.

During the scale development phase, the researcher conducts a confirmatory factor analysis with a new sample and aims to understand the presence of latent constructs. Additionally, item invariance and scale scores are calculated. The final steps include tests of reliability as well as validity to determine if the target construct indeed is measured (Boateng et al., 2018).

In pediatric psychology literature specifically, Holmbeck & Devine (2009) outline a checklist of nine necessary steps for measurement development. While many of the recommendations overlap with the previous components outlined by Boateng et al. (2018), Holmbeck & Devine (2009) outline several other necessary areas including justification and grounding within a theory, justification for the measure's clinical utility and cost-effectiveness, as well as clearly defined guidelines and occasions for using the measure.

Chapter 3 Methodology

The purpose of this study is to develop and provide initial validation for a measure of perceived behavioral control for pediatric patients (aged 10-17 years) and their parents regarding multidisciplinary recommendations for the treatment of chronic pain. The methodology related to the development and analysis of this measure is detailed within this chapter.

Procedure

Phase 1: Item Development

Guided by the recommendations put forth regarding the development and validation of scales for health and behavioral research (Boateng et al., 2018), the author will engage in the preliminary phases of scale development (including the item development and scale development phases). During the first phase of item development, the author will review the relevant literature and determine the various domains of perceived behavioral control that are relevant for pediatric chronic pain, as well as potential multidisciplinary pain treatment recommendations for the treatment of chronic pain. Following a review of the literature, an initial item pool will be developed to measure perceived difficulty regarding implementation of the target behaviors for pain treatment. These items, for example, will include perceptions of behavioral control in the domains of medication usage, engagement with further medical tests, psychotherapy recommendations, physical therapy, and lifestyle modifications such as changes to diet, exercise, sleep, etc. The items will be measured on a Likert scale (1=very difficult, 2=somewhat difficult, 3=neither easy nor difficult, 4=somewhat easy, 5=very easy).

Following the initial creation of the item pool, the items will be assessed for content validity. The author will solicit feedback from content experts who regularly treat pediatric chronic pain (e.g., anesthesiologists, chronic pain nurse practitioners, pediatric psychologists) about the content and scope of the item pool. Further, the author will welcome any other potential recommendations about items that the reviewers feel would be relevant for the treatment of pediatric chronic pain.

Phase 2: Scale Development

Following item development, the author will recruit for the scale development phase of the project. Because the author will have completed expert reviews of the item pool, the next phase outlined by Boateng et al. (2018) regarding conducting pre-testing of questions through a cognitive interview process, will not be completed. After the content validation is complete, the author will recruit participants as outlined below.

Sample Size

Little consensus exists on the best way to conduct an a priori power analysis for an exploratory factor analysis (EFA). In particular, there is a split in the literature regarding whether researchers should use a minimum number of respondents or whether there is a preferred ratio of responses to items. Regarding minimums, a large range exists with Barrett & Kline (1981) referencing that a sample size of at least 50 respondents is needed, whereas Aleamoni (1976) suggests a minimum sample size of 400 respondents. Others believe that sample sizes should be determined using a specific ratio of participants to items. In a review of psychological studies published between 2002-2003 involving the use of EFA (Osborne, 2014) it was found that 63% of studies had participants to item ratio of 10:1 or less. It is advised to use a ratio of at least 5-10 responses per item (Costello & Osborne, 2005). Thus, the target recruitment for the study will utilize the recommendation of 5-10 responses per item for both the patient and parent-proxy versions.

Participants

Participants will be recruited from the Chronic Pain and Headache Clinics (CPHC) at Children's Wisconsin (CW). Both patients (aged 10-17 years) and their parents/guardians will complete the study measures as a part of a larger clinic registry project, the CW Collaborative Health Outcomes Information Registry (CHOIR). This survey comprises many psychosocial measures as well as demographic measures. All patients and parents/guardians will complete the CHOIR measures prior to their initial multidisciplinary pain team intake appointments. The CHOIR project is approved through the Institutional Review Board (IRB) at the Medical College of Wisconsin (MCW). All participants complete the CHOIR measures as a part of their clinic visit, and they have the option of opting in to allow their data to be used for research purposes. Only those participants who have opted-in to research will have their data extracted for use in this project. Patients and parents/guardians will not be compensated or provided an incentive to complete the CHOIR measures due to the clinical use of the measures. It was determined that this clinical sample will be sufficient as the CPHC conducts approximately 1,500 patient visits annually, the bulk of which meet inclusion criteria for the study.

Inclusion Criteria: All participants will be 1) New patients (aged 10-17 years old) seeking intake appointments at the CPHC and their parents/guardians; 2) Patients experiencing chronic pain (all diagnoses) for at least 3 months; 3) Proficient in reading and responding to items written in English; and 4) Only have their data extracted if they complete the pain clinic intake appointment and receive a pain diagnosis.

Exclusion Criteria: Participants will be excluded from the study if they are 1) Established CPHC patients and families; 2) Non-English proficient patients and/or parents or guardians; or 3) Endorsing pain lasting for less than 3 months.

Measures

Patient Measures

Demographics. Demographic information will include patient biological sex, race, ethnicity, and age, as well as pain diagnoses at the intake appointment.

Study Measure. The perceived behavioral control measures for the patient and parent/guardian proxy versions will be included in the data collection, in addition to the measures described below, which will be used to establish validity.

Pain Measure. Pain frequency, severity, and duration (PFSD) (Salamon et al. (2014) as well as pain diagnosis/diagnoses at the time of the appointment will be collected in order to confirm the presence of chronic pain. The PFSD is a 6-item measure that prompts participants to report how many days in the past two weeks they have been in pain, their usual and worst levels of pain within the last two-week timeframe, and the number of months they have experienced pain. The PFSD has been shown to be valid in a population of pediatric chronic pain patients (n=278) and has demonstrated adequate reliability with Cronbach's alpha determined to be 0.87 (Salamon et al., 2014). Regarding initial convergent validity of the instrument, the measure was significantly correlated with activity limitations. Regarding discriminant validity, the measure was negatively correlated with quality-of-life measures.

Self-efficacy. To establish convergent validity in the pediatric measure, the Pain Self-Efficacy Questionnaire (PSEQ) (Nicholas, 2007) will be used. The PSEQ is an 8-item measure that prompts participants to indicate on a 7-point Likert scale (0=”not at all confident” to 6=”completely confident”) how confident they are about completing activities of daily living, despite their pain. This measure has been validated with patients reporting chronic pain in those aged 13-88 years and has demonstrated good internal consistency (Cronbach's alpha=0.92) as well as test-retest reliability over a 3-month time-period (*r*=.73). Further, it has demonstrated adequate construct and convergent validity (Nicholas, 2007). Regarding factor structure, the PSEQ has been demonstrated to yield a single-factor structure which accounted for approximately 59% of the variance in the study sample. It also has demonstrated adequate convergent validity when compared with measures of pain-related disability and coping strategies. Given the constraints of the clinical registry and need for brief measures, the PSEQ will be used with the full sample of participants, even though it has not been validated, to the author's knowledge, in a sample of participants as young as 10 years of age.

Pediatric Global Health. In addition to self-efficacy, the construct of quality of life will be used with the patient sample using the computerized adaptive test (CAT) version of the PROMIS Global Health (PGH-7). The PROMIS measures (Patient-Reported Outcomes Measurement Information System) are the result of a National Institutes of Health funded initiative to create a variety of robust, valid, and reliable self-report measures to be used with adults and children in both research and clinical settings. The measures are appropriate for both the general and clinical populations. The PHG-7 measures factors such as physical, psychological, and social health. The PGH-7 is a 7-item measure of child-reported global health that asks participants to respond to questions about their physical, mental, and social health, as well as quality of life on a 5-point Likert scale from (1=poor to 5=excellent). The measure has been validated with children aged 8-17 years. The development and validation process for the PGH-7 involved both qualitative and quantitative methodology to eventually derive 7 items that had an internal consistency of Cronbach's alpha=0.88. Test-retest reliability coefficients over a two-week period ranged from 0.66-0.75, depending on the age group. Validation information for the measure indicated construct validity with Confirmatory Factor Analysis results for the child measure being CFI=0.98; TLI=0.96; RMSEA=0.17. Differential item functioning also indicated that there were no differences in responses across demographic variables including age, sex, race, or ethnicity (Forrest et al., 2014).

To further establish convergent validity with the patient perceived behavioral control measure, the CAT PROMIS Pediatric Anxiety and Pediatric Depression measures will be used. As described above, The PROMIS measures have undergone robust development and validation efforts. For both the anxiety and depressive symptoms measures, researchers conducted a thorough psychometric evaluation of the measures and completed a Confirmatory Factor Analysis. They also completed differential item functioning and results for the anxiety scale were CFI=0.98, TLI=0.97, RMSEA=0.07. This 15-item measure asks participants to respond to questions about anxiety symptoms on a scale of (0=never to 5=almost always). The initial version of this measure was found to be reliable and valid with children aged 8-17 years and was robustly analyzed in a sample of 1,529 participants who were recruited from settings including public schools, hospital-based outpatient clinics, and subspecialty pediatric clinics (Irwin et al., 2010). On the pediatric depression scale, results yielded CFI=0.99, TLI=0.99, and RMSEA=0.04. This 14-item measure asks participants to respond to questions about depressive symptoms on a scale (0=never to 5=almost always). Again, the measures have been validated with children aged 8-17 years (Irwin et al., 2010).

Parent Measures

Self-efficacy Parent Proxy. To establish convergent validity on the parent proxy measure, the parents will complete the parent version of the Self-efficacy Scale for Child Functioning Despite

Chronic Pain (Bursch et al. 2006). This 7-item measure asks parents to rate on a 5-point Likert scale (1=very sure to 5=very unsure) “How sure are you that your child is able to do each of the following things when he or she is in pain?” The items measure activities of daily living including attending school, completing chores, and spending time with family. The measure was validated with a sample (n=67) of chronic pain patients (aged 8-18 years) in a tertiary-level chronic pain clinic. Reliability statistics for the parents’ measure of their perception of their child’s self-efficacy yielded a Cronbach’s alpha of .90. Additionally, construct validity was established for the measure insofar as the original authors confirmed 23 of their 27 hypothesized associations. When parents reported that their child was functioning well despite being in pain, it was significantly correlated with fewer physical, emotional, somatic, and behavioral symptoms.

The parent/guardian measures will also include the CAT PROMIS Parent Proxy Pediatric Global Health-7. This particular measure has been validated with a robust sample of children and adult dyads at two time points (Time point 1; n=1608; Time point 2; n=1001) (Forrest et al., 2016). Robust validation of the measure yielded test-retest reliability over a 9-month period of 0.74. The measures also demonstrated good convergent and discriminant validity. Convergent validity emerged as global health scores were positively associated with subjective well-being including positive affect, life satisfaction, and meaning and purpose. Global health was negatively correlated with physical stress experiences and psychological stress experiences.

Finally, the CAT PROMIS Parent Proxy measures for pediatric anxiety and PROMIS Parent Proxy measures for pediatric depression will be used to assess the association between the study measure and screening measures of emotional distress. Again, these measures have undergone robust development (Dewalt, Rothrock, Yount, & Stone, 2007) and have been validated with a sample of parent-child dyads. For each of these measures, 1,548 parent-child dyads completed pediatric proxy or self-report items. The fit analyses results yielded very good overall fit with 87% of the variance accounted for on the anxiety scale and 89% accounted for on the depressive symptoms scale (Varni et al., 2012).

Missing Data Treatment Plan

Guided by recommendations put forth by (Schlomer et al. (2010), there are several suggestions both for the reporting as well as analyzing quantitative data when there is inevitably missing data present to some extent. First, a summary of practices in reporting the pattern of missing data will be covered, followed by missing data techniques. First, the authors note that it is critical to characterize the extent of the missing data, as well as the pattern of missing data, including whether it is Missing Completely at Random, Missing at Random, or Missing Not at Random. The two primary ways to deal with missing data treatment include deletion and imputation. The two deletion methods include listwise and pairwise deletion. Listwise deletion can result in a drastic reduction of useable data, which then, in turn, can result in a reduction of power for the overall study, but it does ensure that only the cases that are complete are present in the analysis, and all measures of interest have complete data. Another method of missing data treatment includes pairwise deletion, whereby only cases with missing variables of interest are eliminated from analysis. One additional way to deal with missing data treatment is to do imputation. Mean imputation is not recommended generally, as it imputes the calculated mean of the non-missing data and can result in biased means overall in addition to reducing the variance of the study variables. Expectation maximization and multiple imputation are also options, though this process is considerably more complex, and may not be necessary for the dataset. Given the needs of this project and the nature of the clinical registry, listwise deletion will be used and only complete cases will be retained.

Factor Analysis

Construct Validity

To establish emerging construct validity, an Exploratory Factor Analysis (EFA) procedure will be used to analyze both the patient and parent measures. This procedure is appropriate because the aim of the study is to develop an initial factor structure from the pool of perceived behavioral control items. It is appropriate to use an EFA as opposed to a confirmatory factor analysis (CFA) because there is not a strong underlying theoretical basis for a particular factor structure, and thus, this effort was exploratory in nature. First, items will be analyzed descriptively for mean, frequency, skew, kurtosis, and item-total correlations to inform next appropriate steps for initial removal of any items as well as to determine the factor analysis method, which is described below. In particular, items with item-total correlations less than .3 will be removed from future analyses because this threshold value indicates that these items are not measuring an underlying construct (As cited in Cristobal et al., 2007; Nurosis, 1994). Next, the author will analyze initial reliability through a Chronbach's alpha analysis. Chronbach's alpha is recommended to be at least 0.7 (Kline, 1999; as cited in Field, 2009).

Following descriptive analyses and initial reliability statistics, the author will then check if the data meet the assumptions for factor analysis. Several test statistics are used to determine appropriateness to conduct an EFA including the Kaiser-Meyer-Olkin (KMO) Test for Sampling Adequacy (Kaiser, 1970; Kaiser & Rice, 1974), Bartlett's Test of Sphericity (Tobias & Carlson, 1969), and multicollinearity diagnostics. The KMO is a test of sampling adequacy, and it is recommended that the KMO value be greater than .6 to proceed with a factor analysis. Bartlett's Test of Sphericity identifies how different the correlation table is from the identity matrix, which would assume no correlation between items. If Bartlett's Test of Sphericity is significant, this indicates that it is appropriate to proceed with factor analysis, as there are correlations between items that can be factor analyzed. Multicollinearity issues emerge when factors are too highly correlated. As a result, multicollinearity diagnostics would be assessed prior to proceeding to detect for potential significant redundancy that may materialize in the factor structure. There are several ways to determine if multicollinearity may become an issue including analyzing the correlation matrix for any individual items that may be highly correlated (R>0.8), assessing the determinant value of the correlation matrix to ensure that the determinant is greater than .00001, or using regression analysis to regress individual items onto the total score of the measure so that VIF and tolerance scores can be determined and analyzed (Field, 2009).

Factor Extraction Method

Because the author aims to understand the underlying construct of perceived behavioral control within the items, an EFA, as opposed to a principal components analysis will be utilized. Regarding selecting the most appropriate factor extraction method, Costello and Osborne (2005) note that there is a paucity of robust data to support the selection of a particular extraction method. That being said, two of the most common factor analysis methods include Principal Axis Factoring (PAF) and Maximum Likelihood (ML) Analyses. Fabrigar, et al., 1999 provide the most comprehensive description of the benefits and drawbacks to utilizing each of these extraction methods. ML provides robust goodness-of-fit statistics for each of the respective factor solutions but assumes normally distributed data. While PAF does not provide as robust of goodness-of-fit statistics for the factor solution or solutions, it does not assume normally distributed data, and therefore is preferred for instances when data are non-normally distributed.

Factor Analysis Rotations

Following the selection of the appropriate factor extraction method, the researcher will then determine the most appropriate rotation method. The two types of rotation include orthogonal and oblique rotations. Orthogonal rotations assume that none of the factors are related, whereas an oblique rotation method allows for factors to correlate (Costello & Osborne, 2005; Field, 2009). To determine the most appropriate rotational method (if any), the author will analyze the factor correlation matrix after an initial oblique rotation method had been applied to assess the extent to which the factors are correlated.

Following appropriate extraction and rotation, the author will then determine the number of factors present by retaining only the number of factors that have eigenvalues greater than one, as advised by the Kaiser criterion (Kaiser, 1970). Then, an analysis of correlations will be completed to determine if any of the items were highly correlated and needed to be removed. Items that were too vague or redundant will also be addressed during this phase. Finally, any items that cross-loaded onto multiple factors will be removed to retain only those items that measured a particular factor.

Reliability

To establish reliability, Cronbach's alpha will be used to measure the level of internal consistency both in the patient and parent proxy measures. Cronbach's alpha is used to determine internal consistency following item reduction to characterize the reliability of the final study measures. An analysis of Chronbach's alpha will also be conducted with the other measures in the study to ensure reliability prior to proceeding with further analyses.

Validity

To establish convergent validity, the final patient and parent proxy measures will be correlated against the self-efficacy, global health, anxiety, and depressive symptom scales. For the patient measure, it is hypothesized that the perceived behavioral control measure will be positively correlated with scores on the PSEQ and PROMIS Global Health and will be negatively correlated with scores on the PROMIS anxiety and depressive symptom scales.

For the parent proxy measure, it is similarly hypothesized that the perceived behavioral control measure will be positively correlated with the Self-efficacy Scale for Child Functioning Despite Chronic Pain (Bursch, et al., 2006) and parent proxy global health measures. It is further hypothesized that the parent proxy study measure will be negatively correlated with scores on the PROMIS anxiety and depressive symptom scales.

Chapter 4: Results

Content Validation and Expert Reviews

The team of content experts reviewed the measures and did not have additional items or substantive feedback about the content of the items and the initial item pool was largely retained. The patient and parent scales were similar and only had slight modification to the stem of the question and Likert-options, which were modified to be accessible to reading levels of patients as young as 10 years of age. The patient stem read: “Pretend your doctors tell you to do some different things to help you with your chronic pain. Please show how easy or hard each of these things would be for you to do.” The patient measure included the following Likert-scale anchors: 1=very hard, 2=a little hard, 3=neither easy nor hard, 4=a little easy, 5=very easy. The parent stem read: “Imagine your child’s doctors tell your child to do several different things to help treat their chronic pain. Please show how easy or difficult each of these things would be for your child to do.” The parent measure included the following Likert-scale anchors: 1=very difficult, 2=somewhat difficult, 3=neither easy nor difficult, 4=somewhat easy, 5=very easy.

Data Cleaning Procedure

A total of 214 patient-parent/guardian dyads consented to allow their clinical CHOIR data to be used for research purposes. While the author considered conducting Missing Values Analysis (Little, 1988) through SPSS, it was ultimately determined that listwise deletion would be appropriate as complete measures were needed for analyses. Additionally, due to the clinical nature of the measures, patients were required to respond to all items and could not skip any. Thus, listwise deletion was also the most appropriate approach because data were generally only missing after the participant or the parent abandoned the survey entirely, thus resulting in whole measures being missed. The researcher maintained the recommended threshold of five to ten responses per item (100-200 total participants) by using this approach, and thus the threat to power was minimal. Of those, 26 patients endorsed having pain lasting less than three months and therefore did not qualify as having chronic pain. An additional 7 families completed CHOIR measures but did not attend the initial pain clinic appointment. Finally, 38 families either had incomplete data for either patient, parent, or both patient and parent on the study measure or related measures necessary for validation. This resulted in a total sample size of 143 complete patient and parent dyads for analysis.

Patient Perceived Behavioral Control Factor Structure

First, items were analyzed descriptively for mean, frequency, skewness, and item-total correlations, as well as initial reliability statistics to inform next appropriate steps for initial removal of any items as well as to determine the factor analysis method. Overall, each of the 19 study items measured were non-normally distributed. To assess normality, Z-Skewness was calculated by dividing the skewness value of each individual item by the standard error of the skewness for each item. Because the data were skewed, the most appropriate factor analysis strategy was determined to be PAF, which is recommended for non-normally distributed data (Costello & Osborne, 2005; Fabrigar et al., 1999). Item-total correlations were then analyzed and it was determined that two items did not meet the minimum recommended value of .3 (Nurosis, 1994, as cited in Cristobal et al., 2007), and thus were eliminated from further analyses. These items included “Sleep between 8-10 hours per night” and “Go to a therapist for talk therapy” which had inter-item correlations of .264 and .239 respectively. Initial reliability analyses for the remaining 17-item scale yielded Cronbach’s alpha of .878.

Next, the 17-item measure was analyzed to determine appropriateness to proceed with factor analysis. The remaining 17-item measure yielded Kaiser-Meyer-Olkin test of sampling adequacy to be KMO = .790. Bartlett's test of sphericity was determined to be χ^2 (136) = 1203.39, $p <$ .001. As such, an EFA using the PAF due to the non-normality of the data, was utilized with an oblique rotation (Direct Oblimin) due to the hypothesis that the factors were likely correlated. It was determined that the oblique rotation was the most appropriate rotation as there were several factors that were correlated greater than .32, which is indicative of at least a 10% overlap in variance between factors (Tabachnick & Fidell, 2013). The determinant of the matrix, which indicates possible issues of collinearity, did yield a value of p<.0001, which is not greater than the recommendation to proceed only if the determinant is p>.00001 (Field, 2009). As such, the correlation matrix was analyzed to identify and remove items that were highly correlated. None of the correlations between items rose about the .80 threshold, however. Thus, the initial pattern structure was analyzed to assess the initial eigenvalues and factor loadings. The initial solution yielded a 5-factor structure, though three factors comprised only two items each, which is insufficient for a robust factor. The three factors were analyzed, and it was determined that in each case, the items were highly similar. Thus, to avoid forming a testlet, the six items across the three incomplete factors were determined to be highly similar to one another and were all dropped. In addition to these items being highly similar from a qualitative perspective, they were also moderately correlated as well. These items included "Get more medical tests to help the doctors understand more about your pain" and "Go to more doctor appointments about your pain" which had a correlation of .72. The items "Drink more water every day" and "Double your water intake" had a correlation of .73. Finally, the items "Move your body more" and "Exercise 30 minutes per day" had a correlation of. 66.

A second factor analysis was conducted using PAF with Direct Oblimin rotation. This factor analysis yielded a three-factor solution, but again, one of the factors had only two items loading onto it including “Do relaxation exercises” as well as “Do breathing exercises.” These two items were removed in part due to the loading as well as the vague language in the items. Additionally, the item “Ask your school nurse or teacher for your medicine when you have pain” was loading below .4 on two separate factors and was removed from further analyses.

A third and final factor analysis was conducted on the remaining items using the same PAF method with Direct Oblimin rotation. The remaining 8-item measure yielded Kaiser-Meyer-Olkin test of sampling adequacy was determined to be KMO = .735. Bartlett’s test of sphericity was determined to be χ^2 (28) = 518.81, $p < .001$. The determinant was calculated to be .024, which is above the recommended value of .0001. This final factor analysis yielded a 2-factor solution which accounted for 64.56% of the variance and was determined to be the best fit for the data using eigenvalues greater than 1 (Kaiser, 1970). Factor 1, the Exercise and Therapies Factor, had an eigenvalue of 3.81 and accounted for 47.66% of the variance comprised five items including “Practice the exercises that your therapist tells you to do at home”; “Go to physical therapy for your pain”; “Practice physical therapy exercises for your pain at home”; “Go to occupational therapy for your pain”; and “Practice occupational therapy exercises for your pain at home.” The loadings of the five items had a range of .53-.82. Factor 2, the Medication factor, had an eigenvalue of 1.35 and accounted for 16.90% of the variance comprised items including “Start a new medicine that you take every day”; “Start a medicine and take only when you have pain”; and “Ask your parent for your medicine when you have pain.” The loadings of these three items had a range of .50-.80. The final reliability statistics for the 8-item measure yielded Cronbach’s alpha of .832. The mean of the responses was (M=3.75, SD=.77). (See Table 4).

Finally, initial convergent validity was assessed by comparing the Z-mean score of the study measure to the Z-mean scores of the self-efficacy measure (PSEQ) as well as T-Scores of the CAT PROMIS global health, anxiety, and depression measures. Results of Spearman correlations indicated significant positive associations between the study measure and self-efficacy (rs(143)=.195, *p*<.05) as well as the study measure and global health (rs(143)=.371, *p*<.01). Additionally, Spearman correlation analyses indicated significant negative associations between the study measure and anxiety (rs(143)= -.387, *p*<.01) as well as the study measure and depression (rs(143)= -.444, *p*<.01). (See Table 5).

Parent Proxy Perceived Behavioral Control Factor Structure

First, items were analyzed descriptively for mean, frequency, skewness, and inter-item correlations, as well as initial reliability statistics to inform next appropriate steps for initial removal of any items as well as to determine the factor analysis method. Overall, each of the 16 study items measured were largely non-normally distributed. To assess normality, Z-Skewness was again calculated by dividing the skewness value of each individual item by the standard error of the skewness for each item. Because the data were skewed, the most appropriate factor analysis strategy was determined to be PAF (Costello & Osborne, 2005; Fabrigar et al., 1999). Inter-item correlations were then analyzed and it was determined that four items did not meet the minimum recommended value of .3 (Nurosis, 1994, as cited in Cristobal et al., 2007), and thus were eliminated from further analyses. These items included “Sleep between 8-10 hours per night”; “Drink more water every day”; “Start to see a therapist for talk therapy”; and “Get more medical tests to help the doctors understand more about their pain.” These items had inter-item correlations of .275, .282, .200, and .287 respectively. Initial reliability analyses for the 12-item scale yielded Chronbach’s alpha of .871.

Next, the reduced 12-item measure was analyzed to determine appropriateness to proceed with factor analysis. The remaining 12-item measure yielded KMO = .782 and Bartlett's test of sphericity χ^2 (45) = 760.49, *p*< .001. As such, an EFA using the PAF due to the non-normality of the data was utilized with an oblique rotation (Direct Oblimin) due to the hypothesis that the factors were likely correlated. It was determined that the oblique rotation was the correct rotation as there was one set of factors that were correlated greater than .32, thus again indicating greater than 10% overlap in the variance of the factors (Tabachnick & Fidell, 2013). The determinant of the matrix did yield a value of *p*<.0001, which is not greater than the recommendation to proceed only if the determinant is p>.00001 (Field, 2009). As such, the correlation matrix was analyzed to identify and remove items that were highly correlated. It was determined that the items "Complete physical therapy exercises specifically for pain" and "Complete occupational therapy exercises specifically for pain" were highly correlated (*r*=.81), and thus both of those items were dropped from further analyses.

A second and final factor analysis was conducted using the same PAF method with Direct Oblimin rotation following removal of the above-mentioned items. This final factor analysis yielded a 3-factor solution which accounted for 71.60% of the variance and was determined to be the best fit for the data using eigenvalues greater than 1 (Kaiser, 1970). Factor 1, the Exercises factor, which had an eigenvalue of 3.97 and accounted for 39.67% of the variance, comprised four items including "Practice the exercises that their therapist tells them to do at home"; "Do relaxation exercises"; "Practice breathing exercises"; and "Exercise 30 minutes per day." The loadings of the four items had a range of .44-.90. Factor 2, the Therapy and Activity factor, which had an eigenvalue of 1.72 and accounted for 17.20% of the variance, comprised items including "Increase their physical activity level"; "Go to physical therapy for pain management";

and "Go to occupational therapy for pain management." The loadings of the three items had a range of .47-.97. Factor 3, the Medication/Medical factor, which had an eigenvalue of 1.47 and accounted for 14.73% of the variance, comprised three items including "Start a new medicine that they take every day"; "Start a medication and take only when they have pain"; and "Go to more doctor appointments about their pain." The loadings of the three items had a range of .42-.80. The final reliability statistics for the 10-item measure yielded Cronbach's alpha of .824. The mean of the responses was (M=3.81, SD=.68). (See Table 6).

Finally, initial convergent validity was assessed by comparing the Z-mean score of the study measure to Z-mean scores of the parent proxy self-efficacy measure as well as T-Scores of the CAT PROMIS global health, anxiety, and depression measures. Results of Spearman correlations indicated a nonsignificant association between the study measure and parent proxy self-efficacy (rs(143)= -.016, *ns*). When the study measure was correlated with the parent proxy global health measure, results of the Spearman correlation indicated a significant positive association (rs(143)=.456, *p*<.01). Additionally, Spearman correlation analyses indicated a significant negative association between the study measure and parent proxy anxiety (rs(143)= -.360, *p*<.01) as well as the study measure and parent proxy depression (rs(143)= -.408, *p*<.01). (See Table 7).

Chapter 5: Discussion

The aim of the present study was to develop and provide initial validation for a measure of perceived behavioral control from the Theory of Planned Behavior for pediatric patients seeking assessment for chronic pain concerns at a tertiary-level chronic pain clinic. This chapter will review the results of the project as well as discuss clinical and research implications, limitations of the study, and future directions.

The resulting patient and parent-proxy measures of perceived behavioral control resulted in a 2-item and 3-item factor structure respectively. As hypothesized, the perceived behavioral control measure was positively correlated with reports of global health both for the patient and parent proxy versions of the measure. Thus, for participants who perceived their ability to engage with treatment recommendations to be higher, it was much more likely that their overall sense of their physical and mental health would be higher too. Regarding anxiety and depression, both the patient and parent proxy versions of the measure were negatively associated with the study measure, thus confirming the hypothesis that the construct of perceived behavioral control would be negatively correlated with anxious and depressive symptomology. Finally, the construct of self-efficacy, which was expected to closely align with perceived behavioral control was positively and significantly correlated with the patient measure. However, the parent proxy for both perceived behavioral control and self-efficacy to function despite pain were essentially uncorrelated. Several potential reasons may explain this result including the COVID-19 pandemic and its associated impacts on social, emotional, and physical functioning. In particular, the parent proxy measure to assess self-efficacy was composed of seven total items, of which, two explicitly measured pain functioning at school and one item measured pain functioning with friends. Given both the inconsistent school circumstances during the data collection period as well as the diffuse nature of student, social, and family responsibilities, the parents' responses about these areas of functioning may have been impacted, in part, because of these unique times. Additionally, parents may have viewed these items as being unrelated to their child's self-efficacy and rather associated with their own ability, as parents, to support their child in completing these recommendations from the pain treatment team. As such, it may be important to assess parental self-efficacy to carry out treatment recommendations in support of their child's treatment plan to identify potential challenges and barriers to treatment adherence.

To better understand the impacts of the COVID-19 pandemic on pain functioning with a clinical sample, Law, Zhou, Seung, Perry, & Palermo, 2021 engaged in longitudinal data collection aimed at understanding and characterizing the impacts of the COVID-19 pandemic on a sample of pediatric pain patients. Their data collection, which occurred in four waves between April 2020 and July 2020, collected both quantitative and qualitative data on pain, functioning, sleep, and mental health during this timeframe as well as level of direct exposure to the virus and exposure to secondary stressors (such as economic or financial stress). Overall, these markers of functioning were stable, though clinically significant, over the time-period. Of note though, in cases of families who were not experiencing secondary impacts from the pandemic, such as financial strain or job loss, there were significant decreases in pain interference over the four-month timeframe. Qualitatively, patients and families remarked overwhelmingly that virtual school was a major contributor to either the alleviation or the exacerbation of pain related functioning. Some patients and families remarked about considerable improvements in functioning with virtual school, given that patients could be more flexible with their schedules and complete coursework when they felt well enough to do so. In contrast, other families commented how the lack of consistent routine, structure, and socialization led to an exacerbation of pain concerns since their usual outlet for distraction from pain was drastically different.

Given that the present study's data collection occurred very close to the Law and colleagues' study, it is possible that these factors were similarly impacted in the present sample. Additionally, the pandemic's impacts on parenting practices during such an unprecedented time may have influenced how patients and parents responded to the items across both the study measure and the related validation measures.

Clinical Implications

During the development of the perceived behavioral control measure, it was hypothesized that one of the factors would include lifestyle items or lifestyle modifications that might be important to increase functioning such as modifications to sleep, fluid consumption, exercise, etc. Interestingly, a large proportion of the lifestyle factors did not load adequately either during the initial item-total analysis phase, or the subsequent factor analysis stage. In addition, the item about attending psychotherapy, on both the patient and parent proxy measures, was eliminated even before the factor analysis because it had very low item-total correlations. While not assessed in the context of the present study, the pain clinic referral source of the patient may be pertinent for understanding how and why patients and parents potentially are not recognizing the impacts of behavioral health on pain functioning. This may account for the reason why the items did not correlate at the initial stages of item analysis. Tumin et al. (2018) analyzed sources of referrals for pain clinics and found in a pediatric sample that roughly half of referrals came from primary care pediatricians. The remaining half of referrals were placed by specialty care providers. In Tumin's study, it was found that participants had consulted an average of three providers, in addition to their primary care provider, before receiving specialized pain assessment. Future research should aim to understand the context and content of those referral explanations to patients and families to better understand what patients and families expect going into chronic pain multidisciplinary assessments. Based upon the resulting factor structure that emerged for both the patient and parent proxy in this study, it would seem that patients and parents have less awareness about the impact that behavioral health has on pain and functioning. It is possible that families enter the pain clinic appointments with more of a biomedical perspective and expect exploration for etiology of pain concerns as opposed to treatment for the pain itself (Quintner, Cohen, Buchanan, Katz, & Williamson, 2008).

A different angle for understanding these data could be linked to the phenomenon of pain dismissal. Several studies have pointed to behavior on the part of medical providers who have engaged in pain dismissal behavior. In Defenderfer, Bauer, Igler, Uihlein, & Davies (2018), it was found that 40% of respondents reported having a medical provider dismiss their pain at some point during their adolescence. This study also found that upwards of 1 in 5 reported that their physician attributed the pain solely to psychogenic causes (such as anxiety or depression), which aligns with other data that suggest that female patients are more likely to have their pain attributed to psychogenic causes (Konijnenberg et al., 2004). It is likely that medical providers are recognizing the underlying impacts of mental and behavioral health on chronic pain and functioning, but the delivery of this information may not be grounded in a biopsychosocial approach which comprehensively addresses biological, psychological, and social aspects of pain and functioning. Further, this may help to explain why sometimes patients do not recognize the association between behavioral health and chronic pain treatment. It may also reflect a reaction against the inclination to access behavioral health services because of previous pain dismissal experiences which result in the minimization of pain concerns on the part of medical providers.

While the most logical location for addressing pain dismissal concerns and a biopsychosocial model of care to patients would be primary care, these yearly visits tend to be comprehensive and inclusive of other medical screening and assessment activities. Barring the immediate availability of a pediatric psychologist to briefly assess a patient's pain concerns in the context of their medical visit, other avenues for intervention need to be explored. Perhaps education and assessment from Mhealth technologies would help to educate and inform patients and families about the biopsychosocial approach to understanding and managing pain. In 2018 a work group made a call to update and expand the present biopsychosocial model (Engel, 1977) to include a "biopsychosocial digital" in response to the increasingly digital world and digital delivery of healthcare and intervention (Ahmadvand, Gatchel, Brownstein, & Nissen, 2018). In adult chronic pain management, efforts to provide these assessments are just starting to emerge, though to date, the author is not aware of any studies that assess and inform pediatric chronic pain patients of the biopsychosocial impacts of pain aside from web-based chronic pain specific interventions which act as resources for families (such as the Comfort Ability program).

Research Implications

Regarding applications of this work, to the author's knowledge, there are presently no perceived behavioral control measures for pediatric chronic pain concerns or treatment recommendations, so this project took a unique lens in analyzing how well this theory would apply to a pediatric pain population. The Theory of Planned Behavior is a well-established psychological framework for understanding behavioral change both on an individual as well as a population level, but, interestingly, it is not used often in the context of pediatric health behavioral change. After reflecting on the factor structure of the patient and parent measures, it may point to some of the limitations of using this particular framework for understanding pediatric behavioral change. It became clear that parent proxy reports of child self-efficacy and perceived behavioral control were uncorrelated, thus perhaps pointing to the need to have parental and family supports purposefully and explicitly represented within a model of behavior change. In this spirit, other longitudinal models that include perceptions of behavioral adherence and self-management may be better suited to this population and to the unique elements of various multidisciplinary pain treatment team recommendations.

While the lifestyle and psychotherapy items did not hold within the factor structure of either the child or parent proxy measures, it is likely that the items still have face validity and are important clinically for understanding a family’s perceptions of their abilities to carry out such recommendations. Further qualitative research efforts should explore the reasons why items such as these may not rise to a family’s awareness when attending a tertiary level pain appointment. Other constructs in the Theory of Planned Behavior model may also help to better explain these elements, such as *attitudes* which may be present toward these types of recommendations, or the *subjective norm*.

Limitations

The most significant limitation of the study was the time-period during which the data were collected. Unfortunately, this study was proposed and approved on March 11, 2020, which marked the start of the COVID-19 pandemic. The pandemic led to significant changes in the daily lives of families with profound impacts to schools and delivery of educational instruction, impacts to jobs and related employer-sponsored benefits such as health insurance, etc. (Bivens & Zipperer, 2020). Because of this significant and ongoing pandemic, the typical routine of many of the patients and families that this particular pain clinic serves were significantly altered and as such, some of the measures and responses that centered around functioning during a typical, non-pandemic time frame, may have been impacted. For example, schools and functioning in the context of schools looked very different during the collection timeframe.

Another limitation of the study was the rather racially/ethnically homogenous sample, which was composed of majority non-hispanic White respondents. Unfortunately, the literature has demonstrated significant differences in access to care for minoritized patients as well as differences in the clinical assessment and treatment of minoritized patients who report both acute and chronic pain in a variety of treatment settings. In an Institute of Medicine of the National Academies (IOM) publication about disparities in healthcare for minoritized patient, it was determined that two primary areas contribute to the inequities in care. The research described inequities that stem from disparities in healthcare systems, regulatory and legal climate in which these systems exist, and discrimination related to medical providers’ clinical communications and clinical decision making processes (Green et al., 2005; Smedley, Stith, & Nelson, 2003). Many of these factors impact who is cared for by the medical community as well as the quality of that care.

In a review completed by Green and colleagues, the authors aimed to better understand the differences between pain assessment and treatment for racial/ethnic minoritized patients. The review revealed differences between minoritized patients across different types of reported pain and in different treatment settings. The authors point to a variety of reasons for these disparities in assessment and treatment including individual patient differences, medical provider differences, and broader systemic issues (Green et al., 2005). In another set of studies completed by (Hoffman, Trawalter, Axt, & Oliver, 2016), the authors aimed to understand factors related to differential pain assessment and treatment recommendations for Black patients. This two-study design revealed that nearly half of the sample of self-identified White medical students endorsed false beliefs about pain in Black patients and furthermore, were more likely to make incorrect treatment recommendations for the pain concerns. While much of the literature does focus on adult pain patients, it provides context and data to demonstrate the need to better understand the experiences of pain treatment with patients who identify as racial/ethnic minorities overall. Further, it may in part, provide context for the relatively homogenous sample of the present study in that access issues and referral processes for minoritized patients with pain concerns continue to be a larger systemic issue. Future research must continue to address these inequities in access to care broadly, but also in pain research more specifically.

While 75% of the respondents in the present study were female, this does tend to fit with the proportion of patients who present to chronic pain clinics for intervention (Mulvaney, Lambert, Garber, & Walker, 2006; Perquin et al., 2000). Theories about sex differences in pain medicine have been posed, though the reasons for the differences in who presents for pain concerns, what type of treatment they receive, and overall reports of pain and functioning are continued areas that need further exploration. In a review completed by Bartley & Fillingim, 2013, several possible reasons for these differences were described. First, the authors present evidence that hormones may account for some of the differences in that some studies point to hormonal differences regarding pain activation. Another area of exploration centers on psychosocial factors related to coping with pain. The review cited evidence of differences in pain self-efficacy and pain catastrophizing, with women reporting lower self-efficacy and higher pain catastrophizing. While some of these explanations may help to support our understanding of differences, it is important to analyze larger systemic issues related to pain functioning, including bias, while attempting to understand differences in assessment and treatment of pain concerns. Women experience differential pain assessment and treatment which oftentimes results in under assessment and under treatment of pain complaints (as cited in Igler et al., 2017; (Hoffmann & Tarzian, 2001; Stålnacke et al., 2015).

A final limitation of the study was the use of the PSEQ in the sample of 10–12-year-old patients, as the measure has only been validated in samples of patients age 13+. In the present sample of 10–12-year-old patients (n=40), the PSEQ was found to be reliable with a Cronbach's alpha of .935. While it is not indicated to run concurrent validity statistics on samples below the recommended sample size (minimum of 100), the reliability statistics indicate excellent internal consistency for the measure for this portion of the larger sample. Future research should complete comprehensive analyses on the PSEQ in younger respondents because it could serve as an excellent measure to use longitudinally in terms of understanding self-efficacy with regard to functioning while in pain.

Future Directions

This research fills a gap in the pediatric psychology literature, as there currently exists no measure of perceived behavioral control for the management of pediatric chronic pain. The purpose of this study was to ultimately disseminate a validated measure for clinical use prior to multidisciplinary pain treatment intake appointments. It is the hope of the author that the measure will help clinicians to better understand and proactively intervene when patients and families indicate they may have difficulty implementing certain team recommendations. This measurement development was the first step of a wider research program that will aim to provide longitudinal data about the predictive validity of this instrument. Thus, continued validation of the current measure would be helpful to understand if the present factor structure holds through a confirmatory factor analysis. Additionally, if the factor structure holds, it would be appropriate to analyze its use longitudinally to see if it has predictive validity for other portions of the model such as behavioral intentions as well as behavioral adherence to treatment recommendations.

Because the psychological intervention items did not hold up in this study, or eventually account for variance in the current structure, further analysis about pain referral information as well as attitudes toward psychological support as a part of pain treatment may also be necessary for understanding, as described above in the discussion of primary and specialty care referral.

Summary

The aim of the present study was to develop and validate measures of perceived behavioral control for chronic pain treatment recommendations with adolescent patients and their parents/caregivers. The measure underwent development, clinical data were collected, and an EFA was conducted on both the patient and parent proxy versions of the measure. The resulting measures demonstrated content validity, construct validity, and emerging construct validity. Implications for future directions include further validation of the study measures as well as further analysis into reasons why certain hypothesized recommendations did not emerge or appear as relevant factors including lifestyle changes and psychotherapy. Next steps for the measure development include sampling a new clinical sample to determine if the factor structure holds.

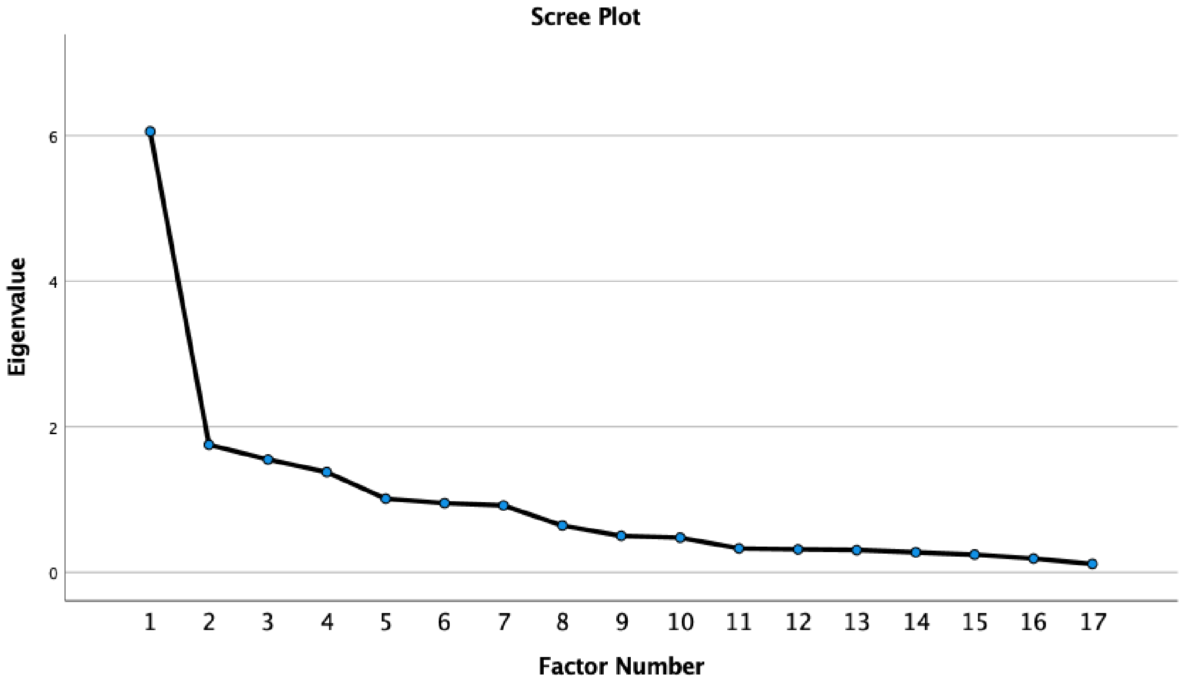


Figure 1. Scree plot of EFA on patient measure with initial item pool

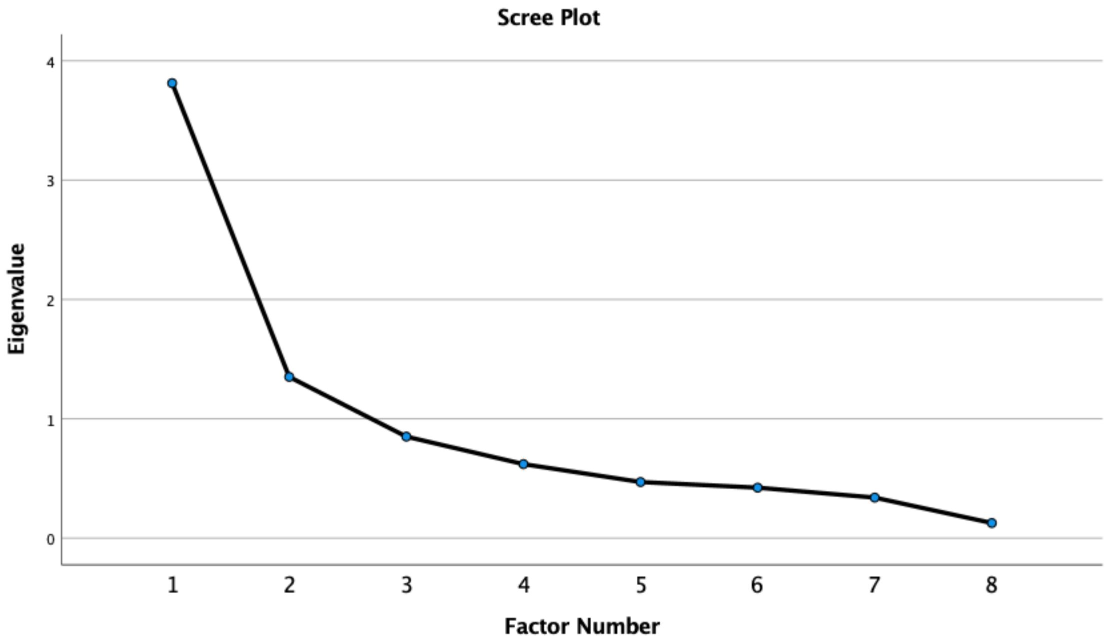


Figure 2. Scree plot of EFA on patient measure with final item pool

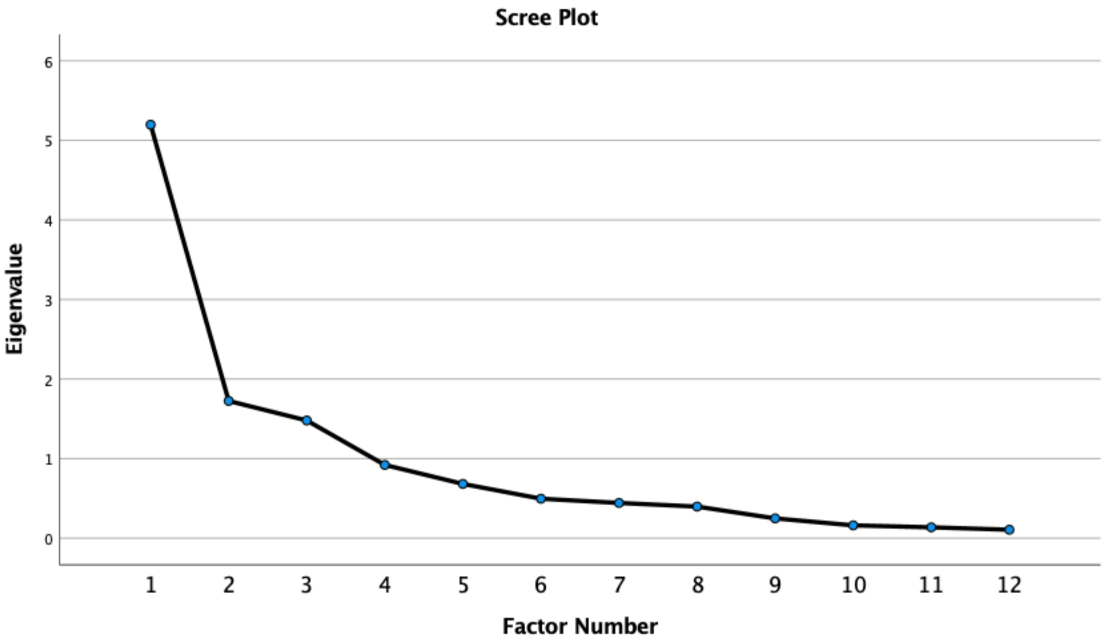


Figure 3. Scree plot of EFA on parent measure with initial item pool

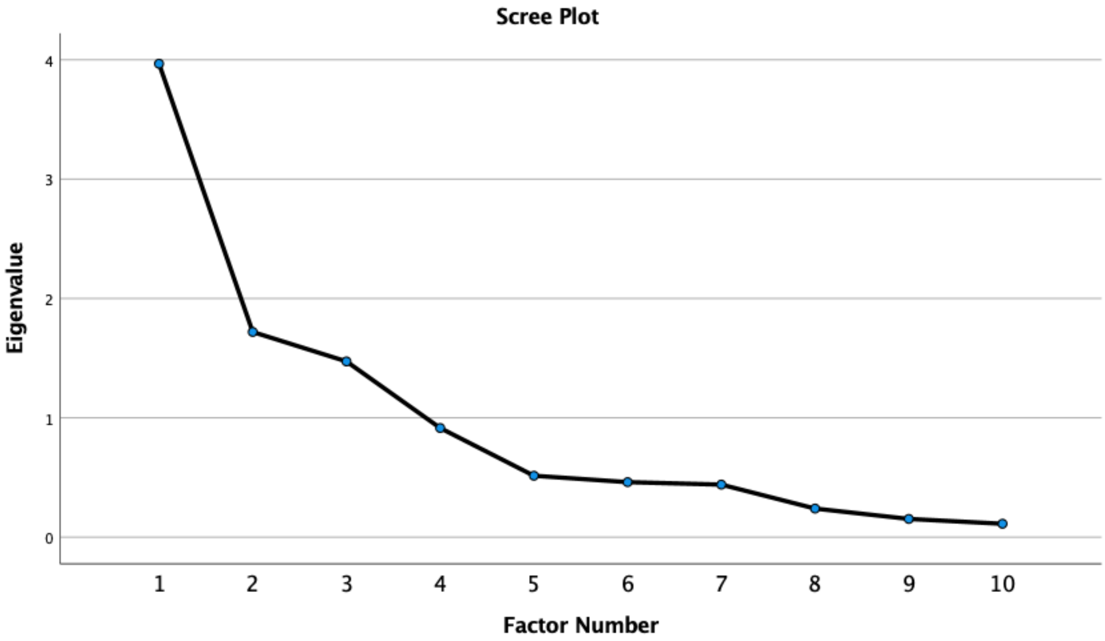


Figure 4. Scree plot of EFA on parent measure with final item pool

Table 1

Participant demographics

Variable	**Total (*N*=143)**
Age	*M*=14.12 (*SD*=2.10)
Sex	
Female	75.5%
Male	24.5%
Race	
Caucasian/White	83.9%
African American/Black	10.5%
Asian	2.1%
Multiracial	0.7%
Did not answer	2.8%
Ethnicity	
Hispanic or Latino	8.4
Non-hispanic or Latino	91.6
Pain Duration (in months)	*M*=23.10, (*SD*= 24.44); Mdn=12.00
Pain Location	
Head/Neck	65.7%
Trunk	13.3%
Limb(s)	8.4%
Musculoskeletal	1.4%
Whole Body Pain (e.g., fibromyalgia)	1.4%
Other Pain (e.g., myofascial pain or POTS)	8.4%
Psychiatric Diagnosis or Somatization Disorder	1.4%

Table 2

Patient item pool with hypothesized content representation by factor

Item Description	Medical	Therapies	Lifestyle
1. Sleep between 8-10 hours per night			X
2. Drink more water every day			X
3. Move your body more			X
4. Go to a therapist for talk therapy		X	
5. Practice exercises your therapist tells you to do at home		X	
6. Do relaxation exercises			X
7. Do breathing exercises			X
8. Start a new medicine that you take every day	X		
9. Start a medicine and take only when you have pain	X		
10. Ask your parent for your medicine when you have pain	X		
11. Ask your school nurse or teacher for your medicine when you have pain	X		
12. Get more medical tests to help the doctors understand more about your pain	X		
13. Go to more doctor appointments about your pain	X		
14. Exercise 30 minutes per day			X
15. Go to physical therapy for your pain		X	
16. Practice physical therapy exercises for your pain at home		X	
17. Double your water intake			X
18. Go to occupational therapy for your pain		X	
19. Practice occupational therapy exercises for your pain at home		X	

Note: The question stem is: “Pretend your doctors tell you to do some different things to help you with your chronic pain. Please show how easy or hard each of these things would be for you to do.” 1=Very hard; 2=A little hard; 3=Neither hard nor easy; 4=A little easy; 5=Very easy; Cronbach’s alpha for the total score was .878.

Table 3

Parent item pool with hypothesized content representation by factor

Item Description	Medical	Therapies	Lifestyle
1. Sleep between 8-10 hours per night			X
2. Drink more water every day			X
3. Increase their physical activity level			X
4. Start to see a therapist for talk therapy		X	
5. Practice the exercises that their therapist tells them to do at home		X	
6. Do relaxation exercises			X
7. Do breathing exercises			X
8. Start a new medicine that they take every day	X		
9. Start a medication and take only when they have pain	X		
10. Get more medical tests to help the doctors understand more about their pain	X		
11. Go to more doctor appointments about their pain	X		
12. Exercise 30 minutes per day			X
13. Go to physical therapy for pain management		X	
14. Complete daily physical therapy exercises specifically for pain		X	
15. Go to occupational therapy for pain management		X	
16. Complete daily occupational therapy exercises specifically for pain		X	

Note: The question stem is: “Imagine your child’s doctors tell your child to do several different things to help treat their chronic pain. Please show how easy or difficult each of these things would be for your child to do.” 1=Very difficult; 2=Somewhat difficult; 3=Neither easy nor difficult; 4=Somewhat easy; 5=Very easy; Cronbach’s alpha for the total score was .871.

Table 4

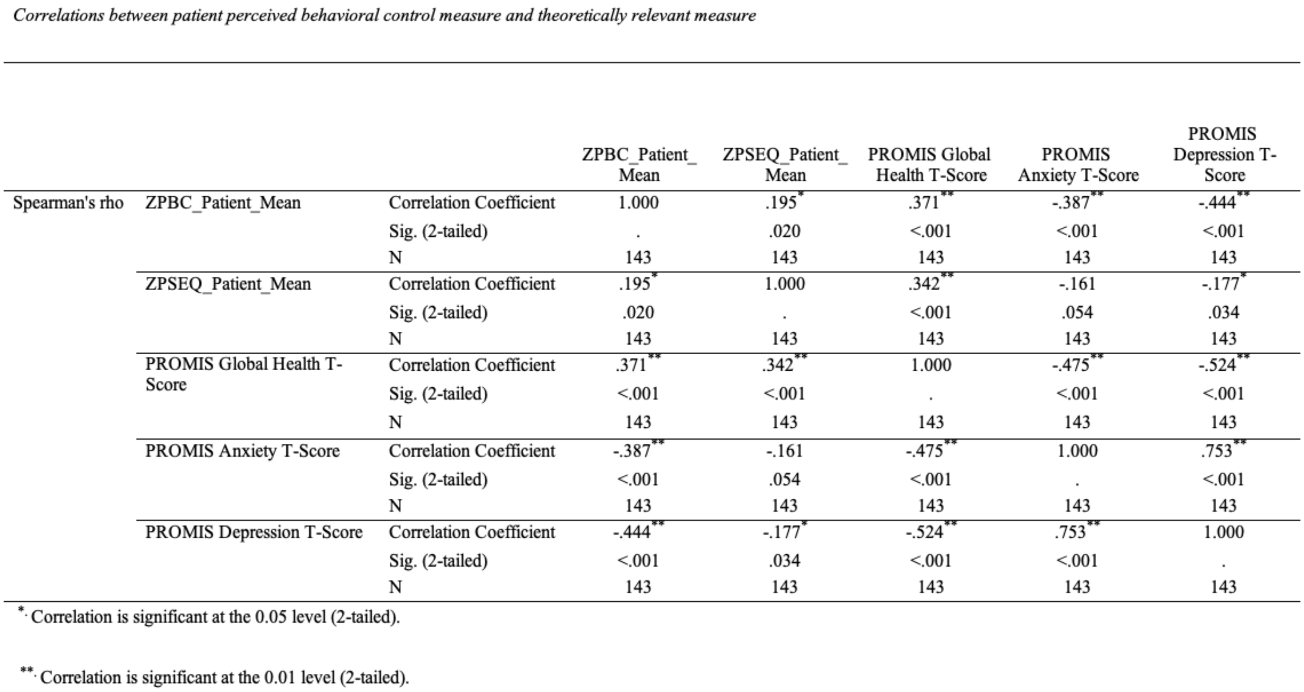
Patient perceived behavioral control measure - Direct oblimin rotated factor loadings for the two-factor structure for an EFA with reduced item pool

Item Description	1	2
1. Go to occupational therapy for your pain	**.823**	-.174
2. Practice occupational therapy exercises for your pain at home	**.786**	.153
3. Go to physical therapy for your pain	**.783**	-.051
4. Practice physical therapy exercises for your pain at home	**.667**	.274
5. Practice exercises your therapist tells you to do at home	**.526**	.237
6. Start a medicine and take only when you have pain	-.103	**.804**
7. Start a new medicine that you take every day	.052	**.537**
8. Ask your parent for your medicine when you have pain	.124	**.497**

Note: The question stem is: “Pretend your doctors tell you to do some different things to help you with your chronic pain. Please show how easy or hard each of these things would be for you to do.” 1=Very hard; 2=A little hard; 3=Neither hard nor easy; 4=A little easy; 5=Very easy; Cronbach’s alpha for the total score was .832.

Table 5

Correlations between patient perceived behavioral control measure and theoretically relevant measures



Correlations between patient perceived behavioral control measure and theoretically relevant measure

			ZPBC_Patient_Mean	ZPSEQ_Patient_Mean	PROMIS Global Health T-Score	PROMIS Anxiety T-Score	PROMIS Depression T-Score
Spearman's rho	ZPBC_Patient_Mean	Correlation Coefficient	1.000	.195*	.371**	-.387**	-.444**
		Sig. (2-tailed)	.	.020	<.001	<.001	<.001
		N	143	143	143	143	143
	ZPSEQ_Patient_Mean	Correlation Coefficient	.195*	1.000	.342**	-.161	-.177*
		Sig. (2-tailed)	.020	.	<.001	.054	.034
		N	143	143	143	143	143
	PROMIS Global Health T-Score	Correlation Coefficient	.371**	.342**	1.000	-.475**	-.524**
		Sig. (2-tailed)	<.001	<.001	.	<.001	<.001
		N	143	143	143	143	143
	PROMIS Anxiety T-Score	Correlation Coefficient	-.387**	-.161	-.475**	1.000	.753**
		Sig. (2-tailed)	<.001	.054	<.001	.	<.001
		N	143	143	143	143	143
	PROMIS Depression T-Score	Correlation Coefficient	-.444**	-.177*	-.524**	.753**	1.000
		Sig. (2-tailed)	<.001	.034	<.001	<.001	.
		N	143	143	143	143	143

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

Table 6

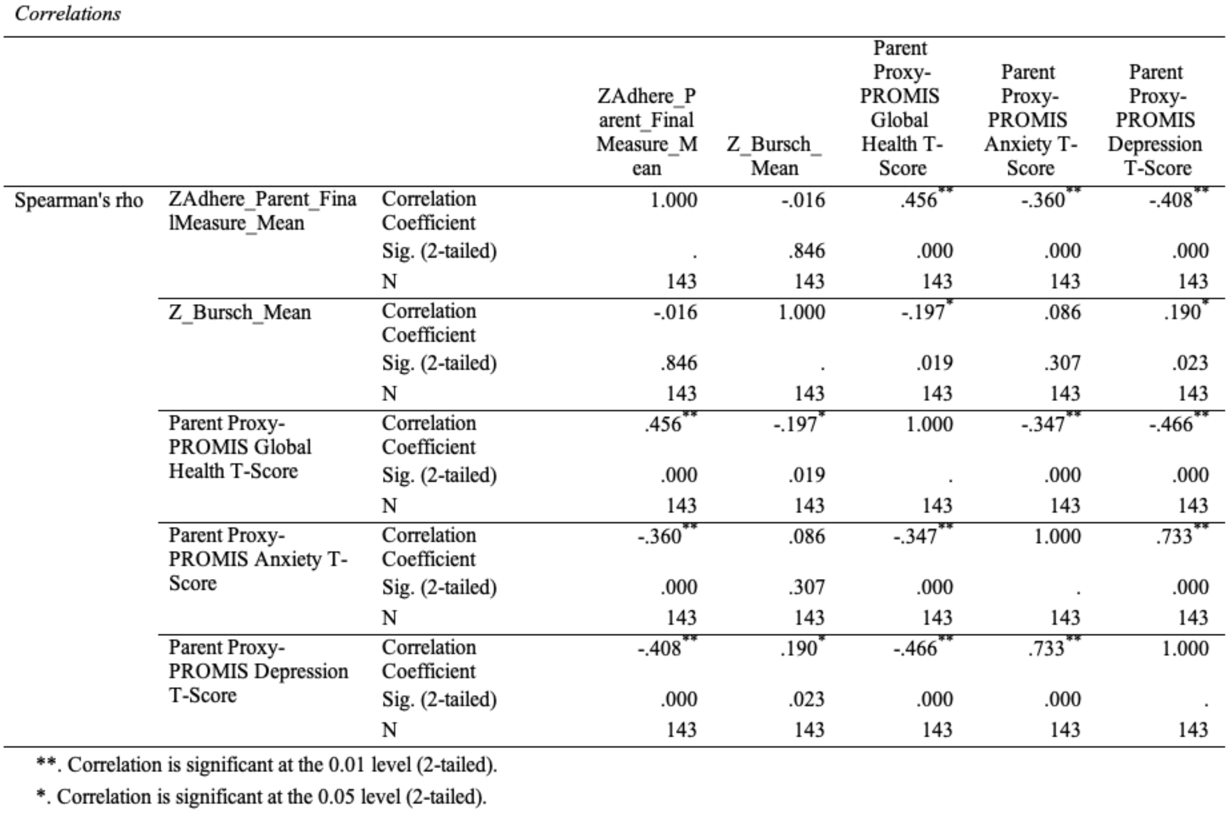
Parent proxy perceived behavioral control measure – Direct oblimin rotated factor loadings for the three-factor structure for an EFA with reduced item pool

Item Description	1	2	3
1. Do relaxation exercises	**.900**	-.010	-.028
2. Practice breathing exercises	**.855**	-.086	.033
3. Practice exercises that their therapist tells them to do at home	**.640**	.114	.115
4. Exercise 30 minutes per day	**.441**	.376	.042
5. Go to occupational therapy for pain management	.040	**.967**	-.069
6. Go to physical therapy for pain management	-.002	**.871**	-.032
7. Increase their activity level	.345	**.467**	.056
8. Start a medication and take only when they have pain	.127	-.098	**.802**
9. Start a new medicine that they take every day	.037	-.050	**.695**
10. Go to more doctor appointments about their pain	-.187	.367	**.416**

Note: The question stem is: “Imagine your child’s doctors tell your child to do several different things to help treat their chronic pain. Please show how easy or difficult each of these things would be for your child to do.” 1=Very difficult; 2=Somewhat difficult; 3=Neither easy nor difficult; 4=Somewhat easy; 5=Very easy; Cronbach’s alpha for the total score was .824.

Table 7

Correlations between parent proxy perceived behavioral control measure and theoretically relevant measures



Correlations

			ZAdhere_Parent_FinalMeasure_Mean	Z_Bursch_Mean	Parent Proxy-PROMIS Global Health T-Score	Parent Proxy-PROMIS Anxiety T-Score	Parent Proxy-PROMIS Depression T-Score
Spearman's rho	ZAdhere_Parent_FinalMeasure_Mean	Correlation Coefficient	1.000	-.016	.456**	-.360**	-.408**
		Sig. (2-tailed)	.	.846	.000	.000	.000
		N	143	143	143	143	143
	Z_Bursch_Mean	Correlation Coefficient	-.016	1.000	-.197*	.086	.190*
		Sig. (2-tailed)	.846	.	.019	.307	.023
		N	143	143	143	143	143
	Parent Proxy-PROMIS Global Health T-Score	Correlation Coefficient	.456**	-.197*	1.000	-.347**	-.466**
		Sig. (2-tailed)	.000	.019	.	.000	.000
		N	143	143	143	143	143
	Parent Proxy-PROMIS Anxiety T-Score	Correlation Coefficient	-.360**	.086	-.347**	1.000	.733**
		Sig. (2-tailed)	.000	.307	.000	.	.000
		N	143	143	143	143	143
	Parent Proxy-PROMIS Depression T-Score	Correlation Coefficient	-.408**	.190*	-.466**	.733**	1.000
		Sig. (2-tailed)	.000	.023	.000	.000	.
		N	143	143	143	143	143

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

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