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PRISM: a screening measure of stress and behaviors for parents of children with chronic pain

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Thesis

**PRISM: A SCREENING MEASURE OF STRESS
AND BEHAVIORS FOR PARENTS OF
CHILDREN WITH CHRONIC PAIN**

by

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DEDICATION

I dedicate this project to all of the incredible, resilient, hopeful families

I met in this clinic. Your perseverance inspires me.

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To my family, friends, and David: Your reassurance and unconditional love have sustained me throughout this entire journey. My thanks will never be enough.

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ABSTRACT

Having a child who is suffering with chronic pain can profoundly impact a parent's life. Reciprocally, parent cognitive, emotional, and behavioral responses to their child's chronic pain can influence the child pain experience. We developed the Parent Risk and Impact Screening Measure (PRISM) to assess parent physical and emotional functioning, behavioral responses to child pain, and impact on daily life due to their child's chronic pain. In an effort to validate this screening tool, we examined the PRISM in relation to existing measures of parent distress, parent behavior, and child functioning. The 30-item PRISM was administered via RedCAP survey to 112 parents of children with persistent pain presenting to a multidisciplinary pain clinic at Boston Children's Hospital. Parents also completed the Patient Reported Outcomes Measurement Information System (PROMIS-29), Bath Adolescent Pain Questionnaire-Parental Impact Questionnaire (BAQ-PIQ), Adult Responses to Children's Symptoms (ARCS), and Pain Catastrophizing Scale (PCS). Children completed the Functional Disability Inventory (FDI), Fear of Pain Questionnaire (FOPQ), and Pediatric Quality of Life Inventory (PedsQL). Parents were predominantly mothers (84%), married (74%), and college-educated (70%). Their children (ages 8-18) were predominantly female (88%) and endorsed daily pain (84%; Mean=6/10). PRISM total scores were strongly correlated with

parent general symptoms of depression, anxiety, fatigue, social restrictions, and pain interference (PROMIS-29; $r=0.47, 0.54, 0.59, 0.57, 0.38$). PRISM total scores were also highly associated with parent pain-specific domains including self-blame and helplessness (BAP-PIQ; $r=0.62$), parent behavior (BAP-PIQ; $r=0.54$), and protective responses (ARCS; $r=0.59$). For child outcomes, higher PRISM scores correlated with more disability (FDI; $r=0.49$), higher fear of pain (FOPQ; $r=0.53$), and lower functioning within emotional, social, and psychosocial domains (PedsQL; $r=0.36, 0.34, 0.48$).

Altogether the PRISM tool appears to be a brief and clinically important means of screening parent distress and behaviors associated with child pain-related dysfunction. Future work will include item level analysis with the goal of reducing the length of this screening tool.

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LIST OF ABBREVIATIONS

ARCS	Adult Response to Child Symptoms questionnaire
BAP-PIQ	Bath Adolescent Pain: Parent Impact Questionnaire
FDI	Functional Disability Inventory
FOPQ	Fear of Pain Questionnaire
PCS	Pain Catastrophizing Scale (Parent and Child)
PedsQL	Pediatric Quality of Life Inventory
PPST	Pediatric Pain Screening Tool
PRISM	Parent Risk and Impact Screening Measure
PRISM2	Parent Risk and Impact Screening Measure: dichotomous response scale
PRISM4	Parent Risk and Impact Screening Measure: four-response scale
PROMIS-29	Patient Reported Outcome Measurement Information System

INTRODUCTION

Children and adolescents presenting with chronic pain are vulnerable to the psychosocial consequences of their pain (Eccleston *et al.*, 2004; Hunfeld *et al.*, 2002; Kashikar-Zuck *et al.*, 2001). Individuals who experience acute pain must make short-term pain-related adaptations in response to often etiologically clear circumstances (e.g., injury, surgery) with a typically rapid resolution of pain symptoms. Conversely, youth with persistent pain often experience a complicated course of recovery, sometimes even among those with an etiologically clear case. These children seem to be more prone to develop maladaptive behaviors that not only uniquely exacerbate pain-related disability but also induce greater distress, prolong pain duration, and threaten quality of life. In one study by Eccleston and colleagues, the emotional distress of adolescents with chronic pain most strongly correlated with the extent to which the adolescents catastrophize – the extent to which one irrationally inflates the consequences of pain – and seek social support to cope with their pain (Eccleston *et al.*, 2004). As such, pain-related thoughts and attempts to cope contributed to pain-related emotional distress. The same study also reported a strong tendency for children and adolescents to have heightened levels of anxiety and depression as compared to children without pain. Similarly, children who develop chronic pain may develop a coinciding fear of pain that extends to fear of activities that may cause pain and promote underlying anxiety (Kashikar-Zuck *et al.*, 2001 & 2002). Such heightened depression and anxiety has been confirmed in children with persistent tension headaches and migraines, which may have a genetic etiology or be

a repercussion of the chronicity of the pain (Anttila *et al.*, 2004). As such, if due to pain duration, children experiencing other forms of persistent pain are similarly vulnerable to psychiatric comorbidities. Chronic pain also has the potential to limit functionality in daily life ranging from school and leisure activities to routines of self-care and independence (Varni *et al.*, 2001; Walker & Greene, 1991). As such, clinically significant chronic pain has introduced appendages of psychosocial distress, functional impairments, and restrictions in quality of life superseding somatic complaints. Ultimately, psychological distress and functional disability exacerbate and complicate the pain experience for affected children and adolescents and are warranted fields of study to inform holistic treatment modalities for these individuals.

Impact of child chronic pain on parents

The emotional and social distress accompanying chronic pain undoubtedly extends beyond the individual. For parents, having a child who is suffering with chronic pain can profoundly impact a parent's life (Eccleston *et al.*, 2004; Hunfeld *et al.*, 2002). Parenting stress in response to child pain can be predicted by child depression, young age of the child, and prolonged child pain duration (Eccleston *et al.*, 2004). Such implications may be rooted in increased child dependence characteristic of younger, more afflicted children, thereby restricting other activities in parents' lives outside their caregiving responsibilities. In some instances, parent perception of their child's pain strongly impacts their stress and quality of life. It has been shown that mothers who perceived more intense pain in their child also reported more restrictions in their social life (Hunfeld *et al.*, 2002). Thus, parents who perceive their child to be in greater distress

extend their caregiving at the expense of other activities and personal needs, which may contribute to their own distress. These burdensome effects are also evident in financial, emotional, social, and relational strain; not to mention, the agony of feeling unable to ease the pain is particularly distressing and also unfortunately common for parents of children with persistent pain problems (Hechlerl *et al.*, 2011; Palermo & Eccleston, 2009). Overall, parent distress appears to be influenced by child distress and disability, restricted engagement outside of caregiving, and a sense of helplessness in alleviating their child's pain.

Parent influences on child pain experience

Pain catastrophizing. Reciprocally, parents' cognitive, emotional, and behavioral responses to their child's chronic pain can impact the child pain experience (Smith *et al.*, 2014). One common example is the pattern of pain catastrophizing: creating cognitive distortions about pain that outweigh the threat of the pain experience. Parent pain catastrophizing has been shown to influence child pain catastrophizing while also exacerbating parent distress (Goubert *et al.*, 2006). Parents' heightened perception of pain consequences adds to their worry of how their child is affected by pain, solidifying irrational fears about pain outcomes. It is not unreasonable to believe that parent pain catastrophizing influences the child's perception of the consequences of their pain.

Parent Protective Behavior. Similarly, the extent to which parents exhibit protective behavior has been associated with prolonged pain duration and decreased child functionality (Walker *et al.*, 2006). It is unclear whether this functional disability is inherent in the lack of activity engagement that results from parent protectiveness or if

this functional disability reflects exacerbated impairments. Regardless, children in pain can be cushioned by parent protectiveness to the extent that restricts child adaptability and engagement in activities despite pain. A study by Simons and colleagues examined parental responses to pain as related to child behaviors and found an interaction effect between adolescent's passive coping mechanisms and parent protectiveness as they relate to functional disability (Simons *et al.*, 2008). Interestingly, for adolescents employing more passive coping strategies, parent protectiveness was not predictive of disability. However, the study also assessed for levels of active coping, such as problem solving and seeking support in the face of pain. And for adolescents who utilized fewer passive or fewer active coping strategies, parental protectiveness was predictive of higher disability. Investigators rationalized this finding by inferring that adolescents who have employed neither active nor passive coping strategies that may influence their pain outcome are still vulnerable to exacerbation of their disability via parental protectiveness, limiting their engagement in activities and stunting their adaptation process. Thus, even for children who may have established some protective factors, such as an absence of maladaptive passive coping mechanisms, parental protectiveness may still contribute to disability and is thus worth considering in relation to child outcomes. All of these findings suggest that parent stress and responses to child pain are transitive to the child's pain experience.

Family functioning. Undoubtedly, unique cognitive, emotional, and behavioral response patterns that develop in children with chronic pain and their families yield multifactorial interactions. Studies have shown that families affected by pediatric chronic pain report poorer family functioning as compared with families of healthy children

(Lewandowski *et al.*, 2010; Anttila *et al.*, 2004). Poorer family functioning may be derived from the concurrent distress of parents and children as well as the adjustment in activities to cater to the child in chronic pain. Parents also appear to develop pain-related fears that are cultivated by their own pain catastrophizing in addition to their child's fear of pain (Simons *et al.*, 2015). Though pain-related fears are distinct from pain catastrophizing and pain anxiety, it is reasonable to think that pain related fears, along with anxiety and catastrophizing, underlie and contribute to avoidant behaviors. Parent behaviors that promote the avoidance of activities have the potential to cause greater child pain as a consequence of disuse and deconditioning (Simons *et al.*, 2015). In a study by Caes and colleagues, higher levels of parental catastrophic thoughts were strongly associated with parent feelings of distress and their tendency to stop their child from further engagement in a cold-pressor task (Caes *et al.*, 2011). Parental sympathy was also significantly positively correlated with parental feelings of distress, stop tendency, and ratings of their child's pain intensity. Thus, catastrophic thoughts about pain and related parent distress affect parents' perception of their child's pain intensity, parent protectiveness, and children's activity level in potentially painful activities. Parental contribution to limiting activities then slows the progress of child adaptation to living with chronic pain. Ultimately, both parent protectiveness and catastrophizing promote further functional disability for the child experiencing pain. In a study assessing the acceptance of pain, children with pain demonstrated strong correlations between low acceptance and high depression, pain catastrophizing, and functional disability (Weiss *et al.*, 2013). Thus, the tendency to avoid, rather than accept, the reality and persistence of

chronic pain may be a risk factor for psychological distress and further functional disability. Child pain acceptance also has implications for parent impressions of pain. Simons and colleagues measured parents' perceptions of child pain acceptance; parent beliefs of child acceptance were negatively associated with parents' maladaptive responses to pain: catastrophizing, fear of pain, and protective behaviors (Simons *et al.*, 2011). Thus, promoting pain acceptance as a part of pain management and treatment may alleviate the tendency to fear and catastrophize pain. The study also compartmentalized pain acceptance into domains of pain willingness and activity engagement, with the intent of distinguishing between willingness to accept their child's pain and encouraging participation in daily routines in spite of pain. As a result, the study found that child functionality is linked with a parent's tendency to encourage participation in activities despite their levels of pain. However, both parent pain catastrophizing and pain-related fear were strongly associated with willingness to see pain as a part of their child's life but unrelated to activity engagement. Thus, negative and fearful perceptions of pain are inherently distinct from avoidant and protective behavior, though both mediate perceptions of pain acceptance. As a result, pain catastrophizing and fear of pain are worthy considerations when examining parents' pain acceptance and willingness to encourage their child to engage in activities. Similarly, decreases in child functional disability correlate with increases in parent acceptance of pain. Thus, not only is there potential for pain acceptance to be protective against emotional distress, but parent pain acceptance may be a useful marker for treatment. Interestingly, parent understanding of child acceptance has not shown a relationship with child pain intensity (Simons *et al.*,

2011), indicating that pain acceptance is independent of pain intensity but has implications for the child's adaptability and willingness to engage in activities. Thus, the interactions of pain response elements may not all be representative of or warranted for child pain-derived distress; rather, the responses to pain may be attributable to other factors. Yet, these risk factors have implications for the child's pain experience and are worth exploring to understand pain outcomes and provide appropriate treatment. This is to also say that a child's report of pain intensity in a clinical setting may not be predictive of pain-related distress. As such, pain-related responses should be considered as potential factors contributing to pain outcomes.

Parent health and history of pain. Another important factor to consider is the parents' basal levels of functioning. Eccleston and colleagues found that parents of children with chronic pain exhibit higher levels (31%) of clinically significant anxiety and depression (Eccleston *et al.*, 2004), although it is unclear what percent of these depressive or anxious disorders occurred before the onset of their child's pain; these disorders do not appear to directly contribute to a child's disability. For example, it has been shown that more anxious mothers demonstrate more pain catastrophizing than fathers and non-anxious mothers, and this catastrophizing contributes to child pain intensity (Hechlerl *et al.*, 2011). Thus baseline parent anxiety may be worth routinely assessing in pediatric pain populations. Similarly, incidence of chronic pain in one or both parents may lend insight into the role of pain in a family setting. A meta-analysis by Higgins and colleagues investigated health-related outcomes among the offspring of parents with chronic pain. Children whose parents have chronic pain problems are at

greater risk of physical and psychological health issues than children of parents without pain complaints (Higgins *et al.*, 2015). Of particular interest is children's increased risk of chronic pain when one or both parents suffered from persistent pain problems. However, it is unclear whether these findings can be attributed to genetic health issues or the social-learning experience of pain.

Ultimately, a multitude of parental risk factors contribute to the pediatric pain experience, and it is likely these factors interact to exacerbate pain conditions. A study by Sieberg and colleagues acknowledged the heightened levels of clinical distress among parents of children with pain and examined parent protectiveness as a mediating variable between parent distress and child functional disability (Sieberg *et al.*, 2011). Ultimately, parent "global and pain specific distress variables" were closely associated but were not reflective of child outcomes, which Sieberg attributes to a potential compartmentalization of distress: pain-related distress as induced by child disability and global distress as predicted by clinically significant depression or anxiety. Thus, to holistically assess parent distress, both mental health and pain-specific factors should be considered. Additionally, Sieberg found parent protectiveness to partially mediate the association between parent depression, anxiety, and pain catastrophizing and child functional disability while fully mediating the association between parent helplessness and child functional disability. Hence, screening, recognizing, and addressing parent protectiveness in the context of pediatric pain could alleviate child disability induced by complex elements of parent distress.

Considering parent factors in treatment

Assessing the pediatric chronic pain experience with parental factors in mind has numerous potential treatment implications. Cognitive behavioral therapy focusing on children's thought patterns associated with maladaptive behavioral responses to chronic pain may be augmented with parent involvement and attention to parental factors; separate cognitive behavioral therapy may even be indicated for parents of children with chronic pain (Eccleston *et al.*, 2004). Similarly, aforementioned parent baseline anxiety and depression are linked to emotional distress that may be a limiting factor in the treatment of their child's chronic pain (Eccleston *et al.*, 2004). To date, an array of assessments exist to gauge psychosocial factors and parent responses to child pain (Goubert *et al.*, 2006; Crombez *et al.*, 2003; Claar *et al.*, 2010; Varni *et al.*, 2001; Jordan *et al.*, 2008). Despite the consensus that individual and familial psychosocial factors contribute to children's experience of chronic pain, integrative assessment modalities that consider parenting behaviors and perceptions in relation to impact on child functional outcome are limited (Palermo & Chambers, 2005). Also, the referenced assessments are lengthy and time-consuming when used in conjunction such that they may need to be completed outside of a clinical setting. As such, there are limited opportunities to promote parent and child compliance in completing these measures, and clinical feedback is less sensitive to the screened factors when the measures are not completed.

A comprehensive review by Jordan and colleagues suggested that continued development of multidimensional, theoretically driven measures specific to concerns of parents of children and adolescents with persistent pain are necessary (Jordan *et al.*,

2008) The development of such measures would facilitate examination of the extent to which parent factors and child pain-related factors are associated. Such measures would also provide information on potential targets for interventions for the parents/caregivers of children and adolescents with chronic pain. Subsequent design and validation of assessments mandates attention to clinical utilization and implications for treatment (Holmbeck & Devine, 2009). Similarly, clinical efficiency mandates the brevity of screening tools in such a way that concise measures do not sacrifice clinical precision.

Rationale for the Parent Risk and Impact Screening Measure (PRISM)

The primary objective of this study is to evaluate the construct validity of a clinical screening tool for parents' psychosocial functioning and behavioral responses to child pain in relation to child outcomes. The Parent Risk and Impact Screening Measure (PRISM) contains four theoretical domains: distressing thoughts and emotions, protective behavior, impact on life, and parent health and pain history. The PRISM was considered in relation to validated measures of parent distress and behavior as well as child adjustment, functioning, and quality of life. As such, the PRISM incorporates items and factors otherwise assessed independently into a single measure.

A secondary objective of the study involves an item-level analysis to inform the reduction of the 30-item PRISM to 15 items. Shortening the PRISM promotes efficiency for use in a busy clinical setting, promoting parent and child compliance and decreasing the likelihood of responder fatigue.

The purpose of this study also extends to ascertaining the clinical significance of the explored domains of parent functioning and child outcomes. By validating the PRISM

as a screening tool, simplifying the clinical screening process will promote fast and accurate assessment of parental factors that contribute to the child pain experience and equally clinically important treatment targets to alleviate parent distress and burden. It was hypothesized that higher PRISM scores would correlate with poorer parent psychological functioning (depressive and anxiety symptoms, pain catastrophizing), physical functioning, and activity engagement as well as higher levels of child pain-related physical and emotional dysfunction. Ultimately, understanding cognitive, emotional, and behavioral components to parent and child responses to chronic pain not only sheds valuable insight into pediatric pain experiences but also serves as an impetus for holistic and effective treatment modalities that incorporate the parent not only as the consultant, collaborator, and co-client (Simons & Basch, 2016), but also as the *primary* client.

METHODS

Participants and procedure

Children with persistent pain (age 8 to 18) and their parents who presented to the Pain Treatment Service at Boston Children's Hospital and met eligibility criteria were recruited for participation in the study and asked to complete several questionnaires. Potentially eligible families were identified in advance of clinic appointments and asked to participate during their clinic appointment. Participants completed study questionnaires at their initial clinic evaluation or at home online after the appointment. Additional inclusion criteria required the ability to speak sufficient English to complete questionnaire measures (given the lack of demonstrated validity of these measures in other languages) and the absence of developmental delays.

Patients and their parents were consented/assented for the study by a research assistant and asked if their responses to the clinic evaluation measures could be used in addition to measures that were completed as part of this IRB-approved study. All measures were completed via REDCap (Research Electronic Data Capture), a secure, web-based application designed to support data capture for research studies. REDCap provides 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources (Harris *et al.*, 2009). In an effort to limit the potential bias introduced to the study due to discrepancies in access to computers and the Internet, participants could elect to complete questionnaires on paper.

PRISM Initial item development and validation measure

To generate the PRISM, 19 specialists in pediatric pain were invited to review the preliminary screening tool that initially consisted of 15 items across multiple domains of parent pain-related thoughts and behaviors. Panel members were instructed to rate each item for suitability in the screening tool from 0 = not at all important to 4 = very important. They were also prompted to provide any suggested changes to items or additional items to potentially include. Based on feedback from 13 specialists, the wording of several items was modified and additional items were added to yield a final group of 30 items. Items all begin with the stem, “Thinking about the last two weeks...” Sample items include “Our family life is stressful,” and “My child’s pain controls my life.” Two versions of the measure were generated based on specialist reviewer suggestions, one with a dichotomous response option: “Disagree” or, “Agree” and another Likert version with four response options, “strongly disagree”, “disagree”, “agree”, and “strongly agree.” These two versions were separated at the beginning and end of the measures administered.

Measures

Demographic and Child Pain Characteristics

Family Demographic Questionnaire. Demographic data collected on the parents include a) date of birth b) relation of caretaker to child, c) marital status, d) race and ethnicity, e) employment status, f) level of education, g) annual income, h) insurance status, and i) family history of pain problems. For this study, we report child age, relation of caretaker to child, marital status, employment status, education level, ethnicity, and

family history of pain problems.

Pain Questionnaire. The Pain Questionnaire assesses pain symptoms during the past month within the child. This questionnaire was designed specifically for this study. Its items provide information regarding the location(s), frequency, duration, and intensity of the child's pain, as well as identification of the primary pain problem. Both the parent and child complete this measure. For this study, we report child pain intensity, frequency, and location.

PRISM Construct Validity

Patient Reported Outcomes Measurement Information System (PROMIS-29). The 29-item PROMIS measure assesses several domains of adult functioning, partitioned into the following subscales: Physical Function, Anxiety, Depression, Fatigue, Limitations in Social Roles and Activities, Pain Interference, and Pain Intensity. There are 4 items per subscale, with the exception of the single item pain intensity scale. Except for the pain intensity item that ranges from 0-10, all item responses range in value from 1 to 5. Raw subscale scores are created by summing all items for each domain. In all cases, a higher score reflects more difficulty or distress (i.e., greater limitations in social roles, depression, pain interference, etc.).

Bath Adolescent Pain-Parental Impact Questionnaire (BAP-PIQ): The BAP-PIQ uses multiple scales to assess changes in functioning and behavior associated with parenting an adolescent with chronic pain. The BAP-PIQ is scored separately for all 8 subscales (depression, anxiety, child related catastrophizing, self-blame and helplessness, partner relationship, leisure functioning, parental behavior, and parental strain. Only the

self-blame and parent behavior subscales were utilized in this study.

Adult Responses to Children's Symptoms (ARCS): The ARCS is comprised of three factors used to assess parent behavior in response to child pain: Protect, Minimize, and Encourage/Monitor. Each item begins with the stem "When your child has pain, how often do you...?" Responses are indicated on a 5-point scale ranging from never = (0) to always = (4). Factor scores are computed by calculating the average ratings for items within each factor. Higher scores reflect more frequent use of each response.

Pain Catastrophizing Scale, parent report (PCS-P). The PCS-P assesses parent negative thinking associated with child pain. It consists of 13 items, which participants rate on a 5-point scale. It yields a total score and three subscales scores: Rumination, Magnification, and Helplessness. Each item begins with the stem "When my child is in pain" and sample items include "I can't stand it anymore" and "I can't keep it out of my mind."

Criterion-related validity

Functional Disability Inventory (FDI). The FDI compiles children's reports of difficulty in physical and psychosocial functioning that is due to physical health. The measure consists of 15 items assessing the child's perceptions of their activity limitations during the past two weeks; total scores are computed by summing the items. Higher scores indicate greater disability.

Pediatric Pain Screening Tool (PPST). The 9-item PPST identifies pediatric pain patients with low, medium, and high levels of prognostic risk factors to inform clinicians

with pain treatment recommendations and optimize treatment interventions. The first 8 items begin with the stem “Thinking about the last 2 weeks...” Sample items are “My pain is in more than one body part” and “I worry about my pain a lot.” The dichotomous response options are “Disagree” and “Agree.”

Pediatric Quality of Life Inventory (PedsQL). The PedsQL, parent and child reports, assesses the health-related quality of life by measuring physical, emotional, social, and school functioning of the child. Items all begin with the stem, “In the past one month, how much of a problem has this been for you/your child...” and response options range from 0, “Never” to 4, “Almost Always.” Example items are “Paying attention in class,” and “Getting along with other teens.” Raw scores are transformed into standard scores on a 0-100 scale with higher score indicating better functioning (less impairment).

Pain Catastrophizing Scale, child report (PCS-C). The PCS-C assesses negative thinking associated with child pain. It consists of 13 items, which participants rate on a 5-point scale. All items begin with “When I have pain,” and sample items include “I can’t go on” and “I can’t keep it out of my mind.” It yields a total score and three subscales scores: Rumination, Magnification, and Helplessness. Higher scores indicate higher pain catastrophizing. Higher scores indicate higher pain catastrophizing.

Fear of Pain Questionnaire (FOPQ) The child version of the FOPQ (Simons *et al.*, 2011) measures fear and anxiety associated with pain. Each of the 24 items presents a statement, for which the response options range from 0, “Strongly Disagree” to 4, “Strongly Agree.” Domains include fear of pain and avoidance, and responders are

scored into low or high fear categorizations. Sample items include “I walk in constant fear of pain” and “My pain controls my life.”

Data analysis was conducted using the SPSS (Statistical Packages for the Social Sciences) statistical package. Descriptive statistics were conducted to examine underlying assumptions of normality for all variables of interest. To refine the items on the PRISM measure, response patterns were examined for most and least frequently endorsed items. Item-total correlations were calculated for the total PRISM score and examined against validated measures of parent distress and behaviors as well as child outcomes using Pearson correlations. Parent measures yielding insignificant correlations to the PRISM measure were examined in relation to child variables of interest. Consistency across demographic variables and construct and predictive validity of the PRISM were examined with bivariate correlations, t-tests, and one-way ANOVAs.

RESULTS

Demographics

Of the 112 patients enrolled, 104 completed sufficient data to be included in the present analysis. Table 1 describes the demographics and pain-related history of the parent sample. Parents were mostly biological mothers (84%), married (74%), and college-educated (70%). The majority of parents identify as Caucasian. More than half of parents work full time, with another 20% working part-time. Only 15% primarily identified as homemakers. Interestingly, half of parents reported a history of chronic pain, while roughly a quarter (27%) of parents endorsed a current pain problem of at least three months' duration.

Table 2 describes the demographics and pain characteristics of the child sample. Child participants were predominantly female (88%) with an average age of 14 (SD 2.6, age 8-18). Most of the children reported daily pain problems (84%) at an average pain intensity of 6/10 (SD 1.7). The most prevalent pain sites included leg or foot (80%), back (61%), shoulder or neck (47%), and head (43%). Just as many children attributed their pain to an injury (39.8%) as those who did not know the source of their pain. Only a small portion of children could attribute their pain to surgery, illness, infection, or chronic disease.

Table 1. Parent demographics and pain characteristics

Variable	Frequency
<i>Demographic Characteristics</i>	
Relationship to Child	
Biological Mother	82.9%
Biological Father	15.2%
Adoptive Mother	1.9%
Ethnicity	
Caucasian	96%
Hispanic	6.7%
Black or African-American	1.3%
Asian	1.3%
Parent Marital Status	
Married	79%
Divorced/Separated	14.3%
Single	5.7%
Spouse deceased	1%
Employment Status	
Full Time	55.2%
Part Time	21.9%
Homemaker	15.2%
Unemployed or Disabled	7.6%
Education	
High school or less	2.9%
Some college	26.7%
College or higher	70.5%
<i>Pain Characteristics</i>	
History of chronic pain	50%
Current pain problem	27%

Table 2. Child demographics and pain characteristics

Variable	Range	Mean (SD)	Frequency
<i>Demographic Characteristics</i>			
Age	8-18	13.7 (2.6)	104
Gender			
Male			11.4%
Female			87.6%
Other			1.0%
<i>Pain Characteristics</i>			
Pain Intensity	1-10	5.9 (1.7)	
Cause of Pain			
Surgery			3.9%
Injury			39.8%
Infection/Illness			4.9%
Chronic Disease			11.7%
Don't know or other			39.8%
Pain Site			
Head			43.1%
Face, or Jaw			20.6%
Shoulder or Neck			47.1%
Back			61.8%
Abdomen or Stomach			38.2%
Chest			28.4%
Arm or Hand			34.3%
Leg or Foot			79.4%
Other			27.5%
Days with pain in the past month			
Not at all			1.0%
1-3 times per week			5.9%
4-6 times per week			8.8%
Daily			84.3%

Item-Level Analysis

Tables 3 and 4 represent item-level analyses for PRISM4 and PRISM2, respectively. The two most frequently endorsed and two least frequently endorsed items of the 30-item PRISM measure are presented. Note, some items are reverse-coded; endorsement is meant to signify a positive contribution to a respondent's PRISM score. Also, for PRISM4 the endorsements were grouped by summing "agree" and "strongly agree" responses to create the percentage of agreement while "disagree" and "strongly disagree" responses were summed to represent the disagree percentage.

Table 3. Frequency of PRISM4 Item Endorsement

PRISM4 Item	Agree	Disagree
Most endorsed		
I have the tools I need to help manage my child's pain. *	23.1%	76.9%
I have felt tense.	83.7%	16.3%
Least endorsed		
I have spent time doing activities I enjoy. *	88.2%	11.8%
I help my child with his/her self care activities	11.5%	88.5%

Note. For PRISM4, patients respond, "strongly agree," "agree," "disagree," and "strongly disagree." Responses of "strongly agree" and "agree" are in the agree column, while "strongly disagree" and "disagree" are in the disagree column.

Note. * Items are reverse-coded when calculating PRISM scores.

Table 4. Frequency of PRISM2 Item Endorsement

PRISM2 Item	Agree	Disagree
Most endorsed		
I have the tools I need to help manage my child's pain. *	24.2%	75.8%
I have felt tense.	81.8%	18.2%
Least endorsed		
My own health makes it difficult for me to be physically active.	16.2%	83.8%
I help my child with his/her self care activities	17.2%	82.8%

Note. * Items are reverse-coded.

Parents most frequently reported that they do not feel they have the tools to manage their child's pain. This item was consistently the most endorsed across PRISM4 and PRISM2. A majority of parents also reported feeling tense, both on the PRISM4 and PRISM2. Interestingly, feeling tense was more frequently reported than worrying about their child's pain.

Across PRISM4 and PRISM2, most parents denied helping their children with his/her self-care activities. Fortunately, the majority of parents also reported doing enjoyable activities and neglected to report that their own health makes it difficult to be physically active.

PRISM scores with demographic and pain characteristics.

Table 5 displays one-way ANOVAs to examine differences in PRISM scores by parent demographics and pain-related history. There were no differences in PRISM total scores based upon education, race, or ethnicity. However, there were differences in PRISM scores based on relationship to child and on employment status. Post-hoc analyses revealed a trend for biological mothers of patients to have higher PRISM scores than biological fathers, while adoptive mothers did not have significantly different PRISM scores from biological parents. Similarly, disabled and unemployed parents scored higher on the PRISM than working parents or parents who primarily identified as homemakers. Pairwise tests did not yield significant differences, likely due to the small sample size of disabled and unemployed parents. But the significant difference for the group appears to be driven by the disabled and unemployed parent samples. Additional t-tests revealed no differences in PRISM scores among parents based on pain history or current pain problems.

One-way ANOVAs were also conducted to explore differences in PRISM scores based on child pain variables (Table 6). Pain causes, sites, or frequency had no significant influence on PRISM scores. In addition to the ANOVAs, Pearson correlations were conducted to examine variability in PRISM scores based on child age and pain intensity, which revealed no significant differences across groups. A t-test also demonstrated that PRISM scores did not differ significantly based on child gender. Thus, child demographic or pain-related variables do not significantly influence the PRISM scores of their parents.

Table 5: ANOVA of PRISM scores with parent demographics and pain history

Variable	PRISM 2 Score	PRISM 4 Score	N
<i>Relationship to child</i>			
Biological Mother	14.6 (5.8) ^a	43.4 (10.1) ^a	86
Biological Father	10.2 (5.0) ^b	35.4 (10.5) ^b	16
Adoptive Mother	13.5 (5.8) ^{a,b}	40.0 (7.1) ^{a,b}	2
f-value	4.17*	4.22*	
<i>Education</i>			
High school or less	12.7 (7.1)	42.0 (9.5)	3
Vocational/some college	14.4 (6.4)	43.9 (10.9)	26
College	14.3 (5.5)	42.9 (10.9)	45
Graduate/professional school	12.9 (5.8)	39.3 (9.3)	29
f-value	0.42	1.01	
<i>Employment</i>			
Full time	13.0 (6.1)	40.4 (10.0)	58
Part time	14.9 (5.5)	44.2 (10.7)	22
Homemaker	13.7 (4.8)	40.9 (8.7)	16
Currently unemployed	16.0 (2.8)	52.5 (14.8)	2
Disabled	18.6 (5.7)	52.8 (11.8)	5
f-value	1.39	2.64*	
<i>Ethnicity</i>			
Hispanic or Latino	13 (7.2)	45.2 (13.0)	5
Not Hispanic or Latino	13.3 (5.7)	41.7 (10.9)	68
Unknown	22 (n/a)	46 (n/a)	1
f-value	1.11	0.29	
<i>Race</i>			
Caucasian	13.4 (5.8)	41.8 (10.8)	69
Black or African American	22 (n/a)	65 (n/a)	1
Asian	12 (n/a)	43 (n/a)	1
Other	13 (n/a)	37 (n/a)	1
f-value	0.74	1.59	

Note. * $p < 0.05$

Table 6: ANOVA of PRISM scores with child demographics and pain variables

Variable	PRISM 2 Score	PRISM 4 Score	N
<i>Cause of Pain</i>			
Surgery	20 (3.4)	50.8 (1.5)	4
Injury	13.7 (5.4)	41.6 (9.7)	40
Infection/Illness	15 (7.2)	47.2 (10.8)	5
Chronic Disease	14.7 (6.3)	41.2 (13.6)	12
Automobile accident	16 (n/a)	46 (n/a)	1
Other	13.3 (2.1)	38.3 (2.5)	3
Don't know	13.3 (6.3)	42.2 (11.3)	34
f-value	0.86	0.74	
<i>Pain Site</i>			
Head	13.3 (6.1)	42.4 (5.5)	8
Face or Jaw	13.0 (n/a)	41 (n/a)	1
Shoulder or Neck	19.8 (2.6)	44.4 (6.0)	5
Chest	10 (n/a)	37 (n/a)	1
Arm or Hand	10.6 (5.5)	36.4 (11.6)	5
Abdomen or Stomach	17.2 (3.1)	47.1 (8.1)	10
Back	13.8 (6.3)	12.2 (3.1)	16
Leg or Foot	13.3 (6.0)	41.1 (10.9)	52
f-value	1.5	0.68	
<i>Days of month with pain</i>			
None	16 (n/a)	44 (n/a)	1
1 time per week	15.5 (2.1)	44.5 (4.9)	2
2-3 times per week	10.5 (6.6)	39.3 (11.4)	4
4-6 times per week	13.2 (5.1)	37.0 (7.5)	9
Daily	13.9 (6.0)	42.3 (10.5)	84
f-value	0.42	0.65	

Construct validity.

Table 7 displays the matrix of PRISM4 and PRISM2 scores in relation to each of the measures of construct validity. Parent functioning, anxiety, depression, engagement in social limitations, pain interference, and fatigue were captured by the PROMIS-29. The BAP-PIQ measures parent behavior and parent helplessness. Parent responses of protection, minimization, and distraction are components of the ARCS. Pain catastrophizing is incorporated as measured by the parent scale of the PCS.

Of interest were the correlations between the two PRISM response scales. PRISM4 and PRISM2 score correlations were highly significant. Five participants did not finish the survey administered during their clinical appointment, accounting for the discrepancy in response rate between PRISM2 (N=99) and PRISM4 (N=104).

Of considerable significance are PROMIS-29 measures of anxiety, depression, social limitations, and fatigue as they relate to PRISM 2 scores. These domains, in addition to pain interference, were also significantly related to PRISM 4 scores. Of note, the correlation for pain interference differs in significance between PRISM2 and PRISM4 scores ($\alpha < 0.05$ versus $\alpha < 0.01$, respectively). Regarding the BAP-PIQ factors, parent behavior and helplessness were highly significant in relation to PRISM4 and PRISM2 scores. The ARCS was scored in three factors: protect, minimize, and distract. Protective behaviors were significantly correlated with PRISM4 and PRISM2 scores. In contrast, minimization was not significantly related to PRISM4 or PRISM2 scores. Parent pain catastrophizing also strongly correlated with PRISM4 and PRISM2 scores.

Table 7: Bivariate correlations between PRISM scores and parent distress and behavior

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14
PRISM														
1. PRISM 4-item	--	.85**	.17	.54**	.47**	.57**	.38**	.59**	.54**	.62**	.59**	.24*	.16	.49**
2. PRISM 2-item		--	.08	.57**	.56**	.52**	.25*	.53**	.53**	.58**	.55**	.20*	.19	.43**
Parent Distress & Behavior														
3. Functioning			--	.05	.01	.42**	.73**	.41**	.06	-.05	.06	.01	.07	-.03
4. Anxiety				--	.66**	.41**	.19	.47**	.20*	.52**	.29**	.05	.09	.47**
5. Depression					--	.40**	.17	.47**	.26**	.59**	.15	.09	-.07	.24*
6. Social Limitations						--	.46**	.58**	.20*	.39**	.21*	.19	.00	.08
7. Pain Interference							--	.45**	.16	.12	.20*	-.01	.07	.03
8. Fatigue								--	.26**	.44**	.27**	.14	.07	.17
9. Behavior									--	.29**	.47**	.15	.29**	.31**
10. Helplessness										--	.33**	.21*	-.02	.51**
11. Protect											--	.13	.53**	.45**
12. Minimize												--	-.04	.20*
13. Distract													--	.36**
14. Catastrophize														--
Mean	42	14	1.2	4.0	2.5	4.7	2.6	6.6	23	10	1.3	0.7	2.9	24.5
Standard Deviation	10	5.8	2.8	3.1	2.8	3.8	3.8	4.4	5.3	5.8	0.5	0.6	0.7	9.6
Respondents	104	99	103	104	102	103	104	103	104	104	105	105	105	105

Note. * $p < 0.05$

Note. ** $p < 0.01$

Criterion Validity

Table 8 displays the matrix of PRISM4 and PRISM2 scores as they relate to validated measures of child outcomes. The child scale of the PCS measured pain catastrophizing. The FDI measured functional disability. Child fear scores, as measured by the FOPQ, were calculated in two factors: fear and avoidance. Quality of life scores, as captured by the PEDSQL, are calculated in four factors: physical, emotional, social, and psychosocial.

Child pain catastrophizing was highly significant as correlated with scores for PRISM4 and PRISM2. Of note, parent pain catastrophizing more strongly correlated with PRISM scores than did child catastrophizing. Similarly, scores for functional disability, fear, and avoidance were also strongly related to PRISM4 and PRISM2 scores. In contrast, physical quality of life scores were marginally insignificant as correlated with scores for PRISM4 and PRISM2. However, emotional, social, and psychosocial scores were significantly and negatively correlated with scores for both PRISM4 and PRISM2.

Table 8: Bivariate correlations between PRISM scores and child outcomes

Variable	2	3	4	5	6	7	8	9	10	11	M	SD	N
PRISM													
1. PRISM 4-item	.85**	.36**	.49**	.44**	.53**	-.15	-.36**	-.34**	-.48**	-.43**	42	10	104
2. PRISM 2-item	--	.36**	.53**	.43**	.53**	-.20	-.40**	-.34**	-.49**	-.42**	14	5.8	99
Child Outcomes													
3. Catastrophize	--	.34**	.74**	.52**	-.19*	-.64**	-.39**	-.64**	-.46**		28	10	107
4. Functional Disability		--	.56**	.59**	-.46**	-.49**	-.38**	-.58**	-.49**		22	11	107
5. Fear			--	.65**	-.26**	-.58**	-.38**	-.63**	-.50**		25	10	107
6. Avoidance				--	-.28**	-.37**	-.35**	-.58**	-.63**		19	9	107
7. Quality of Life: Physical					--	.40**	.35**	.48**	.37**		61	18	107
8. Quality of Life: Emotional						--	.41**	.79**	.43**		47	21	107
9. Quality of Life: Social							--	.75**	.40**		36	19	107
10. Quality of Life: Psychosocial								--	.80**		45	15	107
11. Quality of Life: School									--		51	22	107

Note. * $p < 0.05$

Note. ** $p < 0.01$

Table 9 shows the variables of parent distress and behaviors that were insignificantly related to PRISM scores and their correlation with measures of child outcomes. Pearson correlations were conducted to examine parent functioning, minimization and distraction. Parent functioning and minimizing were insignificant with respect to all explored measures of child outcomes. Similarly, distracting parental responses were not significantly correlated with any measure of the child pain experience, except with child fear of pain.

Table 9: Bivariate correlations between parent and child variables

Variable	2	3	4	5	6	7	8	9	10	11	12
Parent Measures											
1. Parent Functioning	.01	.07	-.17	.09	.01	.01	-.02	-.06	-.14	-.06	-.05
2. Minimize	--	-.04	.17	.11	.12	.17	-.01	-.08	-.15	-.07	-.04
3. Distract	--	.19	.13	.29**	.17	-.06	-.02	-.04	-.04	-.04	-.08
Child Outcomes											
4. Catastrophize	--	.34**	.74**	.52**	-.19*	-.64**	-.39**	-.64**	-.46**		
5. Functional Disability		--	.56**	.59**	-.46**	-.49**	-.38**	-.58**	-.49**		
6. Fear			--	.65**	-.26**	-.58**	-.38**	-.63**	-.50**		
7. Avoidance				--	-.28**	-.37**	-.35**	-.58**	-.63**		
8. Quality of Life: Physical					--	.4**	.35**	.48**	.37**		
9. Quality of Life: Emotional						--	.41**	.79**	.43**		
10. Quality of Life: Social							--	.75**	.4**		
11. Quality of Life: Psychosocial								--	.80**		
12. Quality of Life: School									--		

Note. * $p < 0.05$

Note. ** $p < 0.01$

DISCUSSION

The primary objective of this study entails validating the Parent Risk and Impact Screening Measure (PRISM) as a useful assessment tool for parent factors that effect child pain outcomes. Secondary aims include exploring the correlations of parent behavior and response variables in relation to child pain factors. Data also analyze the content and criterion validity of a two- and four-response scale for the PRISM to maximize clinical utility. The PRISM was examined in relation to validated measures of parent and child variables.

Analyses of PRISM scores across demographic and pain-related characteristics yielded few differences based on groups. PRISM scores did not vary across parent race, ethnicity, marital status, education, or history/presence of pain problems. Additionally, PRISM scores were not significantly influenced by child age, gender, or qualities of their pain: frequency, intensity, site, or cause. These results credit the PRISM with generalizability across demographic factors and a variety of pain profiles. However, biological mothers reported significantly higher PRISM scores than biological fathers. This pattern may be a reflection of a socially enforced tendency for mothers to respond more anxiously and intensely to child distress. Employment status also influenced PRISM scores, as disabled and unemployed parents reported higher PRISM4 scores than parents who work or identify primarily as homemakers. Though not reflected in PRISM2 scores, this observation may reflect a distressing lack of escape for these parents from the experience and implications of their child's pain. Parents identifying as homemakers may be accustomed to their environment being encompassed by their child's pain experience

than those who used to or are unable to work. These findings do not appear to threaten the generalizability of the PRISM; rather, certain groups may be identified as possessing greater risk for parental distress in response to their child's pain.

Item-level analysis of each PRISM measure exposes response patterns for the most and least frequently endorsed items. According to this analysis, the most frequently endorsed item reflected parents' tendency to feel tense. Because a large majority of parents reported feeling tense, this item may not have sufficient variability to be clinically meaningful. Interestingly, this item achieved a higher rate of endorsement than the item specific to pain-related worry. Thus, addressing general tense feelings may not be useful as a therapeutic intervention specific to parents of children with pain, as tense feelings may reflect general parenthood or response to child illness of any kind. Another item subject to floor effects reflects parents having the tools to manage their child's pain, the most widely counter-endorsed item across the measure. These findings are encouraging as parents recognize their own limitations and are open to receiving clinical guidance to address their child's pain. It is also understandable that parents may not feel they have the resources to manage their child's pain simply because the pain has persisted despite all clinical efforts to alleviate it. Because of its low response variability, this item may be excluded in future iterations of the PRISM, as helplessness may be a more clinically useful domain in addressing parent distress. However, this item appears to be critical in indicating parent openness and the need for family resources. Therefore, the item may lack sufficient variability to be included in a shorter screening tool but suggests an urgency to better equip families struggling with pediatric pain.

Least endorsed items across the PRISM reflect parents assisting their children with self-care activities, lacking their own enjoyable activities, and reporting impairments in physical activity. It thus appears that most of the child sample has a pain problem that, while distressing, does not affect activities of daily living. While this item may be excluded in future iterations of PRISM, these response patterns suggests the pain profile of children is generally not too severe to be manipulated in therapeutic interventions that rely on child independence. Similarly, it is encouraging to know parents generally make time for their own pleasurable activities. Thus, targeting pain-related distress for parents may not need to mimic general self-care but rather be more specific to how parents respond to pain and utilize relevant resources.

Also of interest is parents' low endorsement rate of impairments in physical activity, particularly in conjunction with the low correlation of physical quality of life for child participants. Though a large portion of parents have experienced (50%) or are experiencing (27%) chronic pain, fewer of them are experiencing difficulty being physically active. As such, parent pain profiles involve more distress in psychological domains, which likely have a stronger impact exacerbating their response to their child's pain. This finding occurs alongside the observation that pediatric quality of life is least affected in the physical domain. Thus, screening for psychological stress and behavioral responses as a part of pain profiles present a clinical utility that is distinct from physical quality of life and related impairments.

PRISM4 and PRISM2 scores were strongly correlated with most measures of parent behaviors, functioning, and response to pain. Insignificant correlations for the

PRISM include parent functioning by the PROMIS-29, distraction and minimization as measured by the ARCS, and physical quality of life as measured by the PEDSQL. The marginal insignificance for physical quality of life is of interest because pediatric quality of life factors affected by parent variables appear to be most impactful in the social, psychosocial, and emotional domains of quality of life. These results allude to the psychological exacerbation of the pain experience due to parent factors, which may supersede physical impairment and pain severity.

Correlations of parent functioning and minimization were insignificant with respect to functional disability, pediatric quality of life, child fear of pain, and pain catastrophizing. As such, the former measures are less associated with the validated measures of the child pain experience chosen to examine criterion validity. Therefore, parent functioning and minimization appear less clinically useful in relation to the validity of the PRISM to predict parental influence of child outcomes. Similarly, distracting parental responses were not significantly correlated with any measure of the child pain experience except child fear of pain. Hence, there is little consequence for the PRISM's lack of correlation with parent minimization or distraction as responses to child symptoms or measures of parent functioning.

As expected, the dichotomous scale format of PRISM (PRISM2) strongly correlated with the four-response PRISM, PRISM4 ($R=0.85$, $\alpha<0.0001$). Each examined measure for criterion and content validity correlated equally with PRISM2 as with PRISM4, with the exception of parental pain interference as measured by the PROMIS-29. PRISM4 is more sensitive to the effect of pain interference of parent

functioning than PRIM2 ($\alpha < 0.01$ versus $\alpha < 0.05$, respectively). Based on the clinical setting, the applicability of either response scale depends on the likelihood that parent pain contributes to exacerbating the child pain experience. From a clinical perspective, winnowing less influential pain interference creates stronger ground for intervening in cases of significant pain interference for the parent. However, pain interference also strongly correlated ($\alpha < 0.01$) with functional disability. Thus, if functional disability is of particular clinical interest, the four-response scale may be the desired PRISM format.

Of interest, among the strongest correlations with child outcomes include parent protectiveness, social limitations, parent behavior, parent helplessness, and parent pain catastrophizing. Parent protectiveness may play a role in insulating a child from experiences that may induce pain to the extent that child functionality is restored at a slower rate or stunted altogether. Likely related is a parent's tendency to catastrophize; pain catastrophizing may be the cognitive mechanism underlying enhanced parent protectiveness because parents with inflated fear would feel warranted as they accommodate their child's pain and develop more defensive behavioral patterns. Not surprisingly, parent pain catastrophizing also strongly predicts child pain catastrophizing, as parents likely transfer intensified pain-related fears to their children.

Parental social limitation reflects the impairment in social engagement; as such, PRISM scores are strongly associated with increased social isolation. Parents whose children are extremely dependent due to their pain likely limit their engagement in other life areas, including social relationships. As measured by the BAP-PIQ, parent

avoidant/accommodating behavior and helplessness were strongly related to almost all metrics of child pain outcomes. Perhaps similar to social isolation, feelings of helplessness as related to child pain may represent parent distress as a byproduct of their child's etiologically unclear pain condition. On the other hand, parent helplessness may be influential for child distress as they understand and respond to their own pain. Of note, PRISM scores strongly correlated with all of these parent factors.

Approximately a quarter (27%) of parents endorsed current pain problems, while half of parents reported a history of chronic pain within their lifetime. It is not clear whether some of the pain conditions represented in this sample are inherited from chronic disease or represent a genetic predisposition to experience pain. However, only a small percentage of families attributed child pain to chronic disease (12%), while approximately 40% attribute their pain to an injury and another 40% are unsure of their pain etiology. In other words, this sample does not likely represent parent-child pairs whose pain connection is entirely genetic or inherited. As such, these results suggest pediatric pain may be influenced by social learning within the household. Another potential influence includes a sense of camaraderie among parent-child pairs who mutually experience persistent pain problems. Though PRISM scores were not significantly different based on parental pain history, future studies could incorporate a correlation analysis of parent and child measures specific to families with histories of chronic pain. Such an analysis may lend insight to the transference of pain variables, related distress, and behavioral response patterns. Future research could also investigate genetic factors contributing to pain, to control for inheritable forms of pain and infer

parent connection is primarily psychosocial. This study fails to examine genetic predisposition to pain problems as predicted by parent pain, which would be much more difficult to ascertain.

Future explorations of parent and child pain experiences could intentionally consider distress and behavioral response patterns across gender, education, and socioeconomic profiles. While every effort is made to recruit a diverse pool of participants, the sample of families presenting to the clinic did not include many fathers, male patients, or people of color. Similarly, a large majority of parent respondents are employed and college-educated. As such, our study is limited in its ability to extract relationships between demographic characteristics of affected families and the pain experience as a whole, though PRISM scores did not vary across these groups.

An additional limitation of this study is the purely quantitative nature of the data, leaving little room for context and input from parent and child relationships. Few items intentionally aim to distinguish between baseline and pain-related distress (i.e., “our family life is stressful” versus “our family life is stressful due to my child’s pain” and “I feel tense” versus “I worry about my child’s pain”). Yet, the incorporation of interview data would permit the exploration of parent and child insight as it relates to the family’s experience of pain. Similarly, the study is purely correlational and unidirectional. As such, no inferences can be made concerning parent functioning as a main contributor to the exacerbation of the child pain experience. It is also unclear if, reciprocally, parent distress and behavioral responses are manifestations of poor child outcomes. However, from a clinical vantage, parental distress is intensely and globally connected to the child

pain experience – whether as a contributing factor to or result of pain-related problems in their children. Thus, while familial interventions may not be efficacious in alleviating child distress or improving functioning, such an understanding of parents’ response to their child’s chronic pain may direct therapeutic attention to an overlooked population of afflicted caregivers.

LIST OF JOURNAL ABBREVIATIONS

Clin J. Pain	The Clinical Journal of Pain
Eur J. Pain	European Journal of Pain (London, England)
J. Am Acad Child Adolesc Psychiatry	Journal of the American Academy of Child and Adolescent Psychiatry
J. Biomed Inform	Journal of Biomedical Informatics
J. Pain	The Journal of Pain: Official Journal of the American Pain Society
J. Pediatr Psychol	Journal of Pediatric Psychology
Med Care	Medical Care
Pain Manag	Pain Management
Psychol Psychother	Psychology and Psychotherapy

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CURRICULUM VITAE

EMILY CATHERINE BROMAN

Address: 277 Babcock Street #1095, Boston, MA 02215 | Phone: 434.401.5301

Email: ecbroman@bu.edu | Year of Birth: 1991

EDUCATION

Boston University School of Medicine, Boston, MA, Aug 2014 – May 2016

M.S. in Medical Sciences, Concentration in Mental Health Counseling and Behavioral Medicine

The University of Alabama, Tuscaloosa, Alabama, Aug 2010 - May 2014

B.S. in Chemical Engineering | B.S. in Psychology | University Honors | University Fellow

North Carolina State University, McKimmon Center for Continuing Education, Dec 2013

Certificate in Spanish for Health Professionals

RESEARCH, INTERNSHIP, AND TEACHING EXPERIENCE

Clinical Research Intern, Division of Pain Medicine, Department of Psychiatry, Boston Children's Hospital, Boston, MA, August 2015 – May 2016

- Recruit, consent, and administer surveys to patients and parents; manage database
- Focus in assessment design, implementation, tracking, and validation
- Peer-review manuscripts for publication
- Literature reviews and data analysis for masters thesis

Co-Investigator, Art to Life, Univ. of Alabama Honors College, May 2012 – July 2015

- Authored study on cognitive-behavioral impact of art therapy for persons with dementia
- Implement service-learning program based on community outreach and research-driven goals
- IRB submission; patient recruitment & interviews; data management, synthesis, presentation
- Coordinate efforts among providers, community partners, students, participants, and families

Senior Research Associate, Center for Community-Based Partnerships, August 2012 – 2014

- Promote enhancement of engaged scholarship among university and community partners
- Staff presentations, grant applications, manuscript review, and research mentorship

Senior Teaching Fellowship, Univ. of Alabama Honors College, May - December 2013

- Designed and taught original honors seminar course, *Biological Models*, comparing industrial technologies with natural phenomena and exploring associated ethics

- Authored curriculum, designed course interface, delivered weekly lectures, assessed learning

Intern, Oncology Cell Culture, CHRISTUS Stehlin Foundation, Houston, TX, May - June 2013

- Cultured and treated cell lines for chemotherapy of desmoplastic small round cell tumors

Research Assistant, Psychopathy Group, Univ. of Alabama, January 2011 - May 2012

- Examined emotional perceptions and problem solving abilities of detained adolescents
- Participant recruitment; interview execution; data collection, organization and analysis

Intern, Corrosion Engineering, ARENA NP, Lynchburg, VA, Aug 2011 - Jan 2012

- Investigated water coolant technology of nuclear power reactors; authored executive reports

CLINICAL EXPERIENCE

Student Facilitator, Art to Life, Caring Days Adult Day Care, May 2011 – May 2014

- Initiative promoting empathy with dementia patients via art therapy and dignifying activity
- Facilitate reminiscence therapy and create “life story projects” of patients’ memorabilia
- Create program syllabus, coordinate lectures and logistics, mentor student volunteers

Clinic Volunteer, Sowing Seeds of Hope Free Clinic, August 2011 – May 2012

- Vital signs, nutrition counseling, and motivational interviewing in hypertension clinic

Clinic Volunteer and Interpreter, International Service Learning trip, Nicaragua, March 2012

- Conducted home visits, facilitated free clinic, distributed medications, and attended to numerous patients in Spanish

Shadowing 100 hours in family medicine, obstetrics & gynecology, psychiatry, and neurology

LEADERSHIP AND COMMUNITY INVOLVEMENT

Graduate Resident Assistant, Boston Univ. Office of Residence Life, August 2015 – May 2016

- Lead staff of resident assistants, promoting safe and engaging community in university housing
- Conduct staff meetings, monitor weekly reports, host individual progress sessions
- Facilitate conflict mediation and respond to crises on a rotating on-call basis

University Fellows Experience, Honors College, Univ. of Alabama, August 2010 — May 2014

- *Selected to a cohort of 25 among 500 honors-eligible applicants; program encourages innovative scholarship and leadership, providing expert faculty mentors, cultural immersion opportunities, and project development experience*
- Launched donation center for immediate disaster relief, serving 50 families, May 2011
- Facilitate numerous seminars on leadership and project development for freshman cohorts
- Interviewed and contributed to selections of incoming candidates

Cuba Immersion Experience, Univ. of Havana and Univ. of Alabama, March 2013 & 2014

- Lead pilot teams exploring political, historical, and economic contexts of Cuban culture and Cuba-US relations

Executive Vice President, Honors College Assembly, Univ. of Alabama, May 2013 - 2014

- Advised project development and conducted progress meetings for nine student branches
- Authored bylaws and protocols, built online resources, organized retreats, lead symposia
- Launched systemic change of organizational structure; recruited and hired new leadership

Director of Civic Engagement, Honors College Assembly, Univ. of Alabama, May 2011 - 2013

- Initiated and orchestrated numerous volunteer initiatives and events: mentoring programs, non-profit events, tornado relief, fundraisers, environmental conservation, volunteer fairs

Honors College Ambassador, Honors College, Univ. of Alabama, February 2011- May 2014

- Deliver recruitment speeches, host lunches, and conduct tours for university donors and prospective honors students

Project Leader, Alabama Action, Univ. of Alabama, February 2011 – August 2013

- Designed and implemented projects in local schools while mentoring honors freshmen

PRESENTATIONS AND PUBLICATIONS

- PRISM: A Screening Measure of Distress and Behaviors for Parents of Children with Chronic Pain. Poster presentation at the American Pain Society meeting, Austin, TX, May 2016.
- Assessing Psychosocial Risk in Parents of Children with Chronic Pain: Development of the PRISM Screening Tool. Poster presentation at the Society of Pediatric Psychology annual conference, Atlanta, GA, April 2016.
- Bringing Art to Life: An Intergenerational Service Learning Course and Visual Art Therapy Intervention for College Students, Persons with Alzheimer's Disease and Dementia, and Caregivers. Poster presentation at the Alzheimer's Association International Conference, Washington, DC, July 2015.
- Broman, E. (2014). Art to Life: The Preservation of Personhood. *Journal of Community Engagement and Scholarship*, 7(2).
- Art to Life: Quantifying the Preservation of Personhood. Plenary presentation finalist at the University Fellows Symposium, University of Alabama, Tuscaloosa, AL March 2014.
- Art to Life: Quantifying the Preservation of Personhood. Oral presentation at the Senior Fellows Summit, University of Alabama, Tuscaloosa, AL, March 2014.
- Art to Life: The Preservation of Personhood. Oral presentation at the Engaged Scholarship Consortium, Texas Tech University, Lubbock, TX, October 2013.
- Art to Life: Promoting Relational Validation through Present-Centered Endeavors. Peer-nominated speaker at Tide Talks, *The University of Alabama's forum for emerging leaders in innovation and culture change, based on the TEDx format*, October 2013.
- The Preservation of Personhood. Poster presentation at the National Outreach Scholarship Conference, University of Alabama, Tuscaloosa, AL, October 2012.

HONORS AND AWARDS

The Presidential Scholarship, Honors College, Univ. of Alabama, March 2010

- Full tuition and yearly stipend based on academic and extracurricular merit

AREVA NP National Merit Scholarship, June 2010

- One of two nationally recognized students for academic merit four-year scholarship

The XXXI, Univ. of Alabama, Spring 2013

- Women's honorary recognizing 31 females among students, faculty, and alumni for exemplary contributions in leadership and service to campus and the community

The Anderson Society, Univ. of Alabama, Spring 2013

- Senior honorary seeking to promote excellence in student leadership and service as well as high academic standards. Each year 24 members are selected in recognition of their outstanding contributions to the university.