

# Child Pain In Context (CP-IC)

## Research Protocol

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**TITLE: Children's (mal)adaptive pain behaviors in context: a functional-cognitive perspective.**

## **A. Specific Aims/Objectives**

**AIM #1: To identify the key antecedents and consequences that give rise to and maintain children's pain-related (avoidance) behaviors as it occurs in daily life.**

**Hypothesis 1a:** Higher levels of child pain intensity, catastrophic thinking about pain, pain-related fear, negative mood and worse sleep will predict more subsequent avoidance behavior and less (physical) activity engagement in children.

**Hypothesis 1b:** Certain consequences of child pain-related (avoidance) behaviors (e.g., reduced pain, heightened disability) will subsequently function as antecedents that maintain these behaviors by eliciting them across time.

**AIM #2: To investigate the moderating impact of child pain avoidance and pain acceptance rules upon children's daily pain-related (avoidance) behavior and functioning.**

**Hypothesis 2:** The degree of pain avoidance and pain acceptance rule-following, (measured prior to the diary) in children will *moderate* the strength of the daily associations between a) pain intensity, negative mood, catastrophic thoughts/anxiety about pain, and worse sleep and b) children's (physical) activity engagement and avoidance behavior.

**Hypothesis 2a:** In children demonstrating higher pre-diary levels of pain avoidance rule-following, daily pain, negative mood, catastrophizing/fearful thoughts about pain, and worse sleep will be more strongly related on a daily basis to heightened levels of avoidance behavior, and reduced (physical) activity engagement.

**Hypothesis 2b:** In contrast, higher pre-diary levels of pain acceptance rule-following are expected to buffer against these maladaptive associations: it is expected that in children adhering more strongly to pain acceptance rules, daily associations between pain, negative affect, catastrophizing/fearful thoughts about pain, and worse sleep on the one hand and avoidance behavior/ (physical) activity engagement will be reduced.

**Hypothesis 2c:** Pain acceptance rule-following (measured prior to diary) is also expected to directly impact child outcomes, i.e., higher pre-diary levels of pain acceptance rules in children will predict higher levels of daily (physical) activity engagement and lower levels of daily avoidance behavior in those children compared to children showing low pre-diary levels of pain acceptance rules

**AIM #3: To investigate the role of the social context (e.g. parental acceptance and avoidance rules about child pain-, parental protective behaviors and/or pain acceptance or avoidance instructions provided by others to the child, especially by the parents) in influencing the child's daily pain-related functioning**

**Hypothesis 3:** The characteristics of the child's social (e.g. parental) context will *moderate* the strength of the daily associations between a) children's pain intensity, negative mood, catastrophic thoughts/anxiety about pain, worse sleep and b) children's physical activity engagement and avoidance behavior.

**Hypothesis 3a:** In children who are confronted with high levels of other-provided pain acceptance instructions and low levels of other-provided pain avoidance instructions (averaged over days), daily pain, negative mood, catastrophizing/fearful thoughts about pain, and worse sleep will be *less* strongly related on a daily basis to heightened levels of avoidance behavior, and reduced physical activity engagement.

→**Research question 3a:** we will explore if the influence of other-provided rules differs between rules provided by their parents compared to rules provided by other people in the interpersonal context of the child (e.g. friends, teachers, other family members)..

**Hypothesis 3b:** In children of parents who report low levels of pain acceptance rule-following and high levels of pain avoidance rule-following (as measured prior to diary), daily pain, negative mood, catastrophizing /fearful thoughts about pain, and worse sleep will be more strongly related on a daily basis to heightened levels of avoidance behavior, and reduced physical activity engagement.

**Hypothesis 3c:** In children of parents who show high levels of optimism and general positive affect (as measured prior to diary), daily pain, negative mood, catastrophizing/fearful thoughts about pain, and worse sleep will be less strongly related on a daily basis to heightened levels of avoidance behavior, and reduced physical activity engagement.

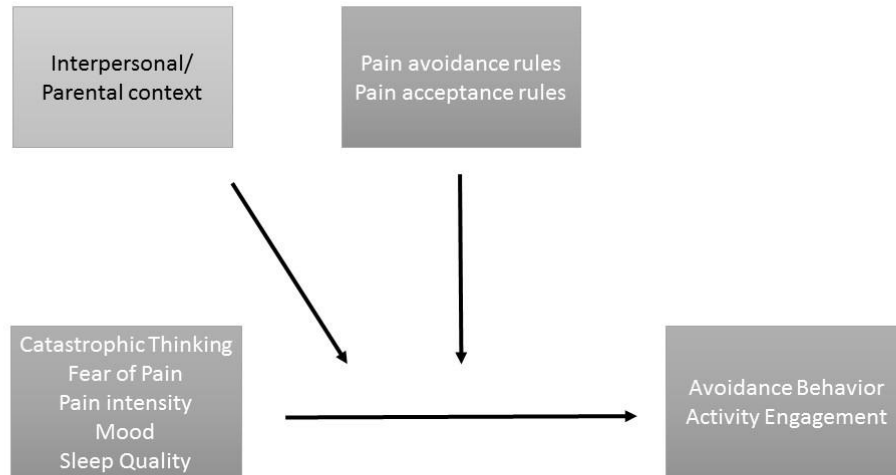


Figure 1: Illustration of the hypothesized relations in Aim 1, Aim 2 and Aim 3.

**Exploratory Aim: To explore the role of parental acceptance and avoidance rules about their child’s pain in influencing parental behaviors in the context of child pain on a daily basis.**

**Explorative research question 4a:** We will explore if parents demonstrating high levels of fearful/catastrophizing thoughts about their child’s pain and high levels of negative mood will subsequently show more protective and solicitous behaviors towards their child in the context of pain.

**Explorative research question 4b:** We will also explore if parental (pain avoidance or acceptance rule-following in the context of child pain *moderates* the relationship stated in hypothesis 4a:

- In parents who show *high* pre-diary levels of child pain acceptance rules, fearful/catastrophizing thoughts and negative mood will be *less* strongly related to protective behaviors towards their child.
- In parents who show *high* pre-diary levels of child pain avoidance rules, fearful/catastrophizing thoughts and negative affect will be *more* strongly related to protective behaviors towards their child.

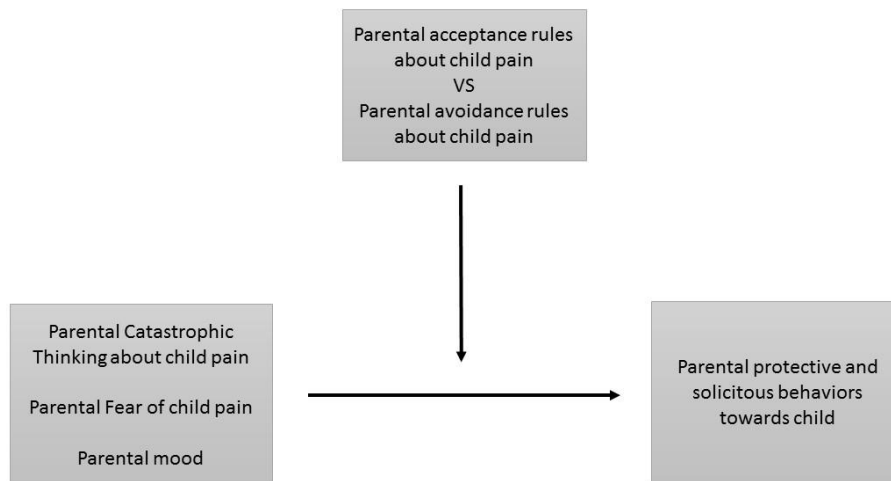


Figure 2: Illustration of the hypothesized parent-related relations in the Exploratory Aim.

**Note from author (5-12-2019)**

At the moment two manuscripts reporting on the data of this study have been published in A1-journals. The central aims and hypotheses in each of these manuscripts have been a subset from the above-mentioned aims. For reasons of clarity we report the specific research questions of each of these two papers below.

**Aims + Hypotheses Manuscript 1:** Beeckman, M., Simons, L. E., Hughes, S., Loeys, T., & Goubert, L. (2019). A network analysis of potential antecedents and consequences of pain-related activity avoidance and activity engagement in adolescents. *Pain Medicine*. <https://doi.org/10.1093/pm/pnz211>

**Hypothesis 1a:** Higher levels of pain intensity, pain catastrophizing, pain-related fear, and negative affect should predict higher levels of activity-avoidance.

**Hypothesis 1b:** Higher levels of activity-avoidance should predict lower levels of pain, pain catastrophizing, pain-related fear, and negative affect at a later point in time.

**Exploratory Hypothesis 2:** We had no *a priori* hypotheses about how these same factors would relate to activity-engagement given this has not been examined previously. Thus these latter relations are examined exploratory.

**Hypothesis 3a:** Finally, we examined the potential resilience-enhancing role of psychological flexibility. We expected, based on previous cross-sectional work, that higher levels of psychological flexibility would predict lower levels of activity-avoidance and higher levels of activity-engagement on a daily basis.

**Hypothesis 3b:** We also hypothesized that psychological flexibility would moderate the impact of pain, pain-related fear, and pain catastrophizing on activity-avoidance and activity-engagement at the within-day level.

**Aims + Hypotheses Manuscript 2:** Beeckman, M., Simons, L. E., Hughes, S., Loeys, T., & Goubert, L. (2019). Investigating how parental instructions and protective responses mediate the relationship between

**Hypothesis 1a:** We expected that higher psychologically flexible parenting and higher parental acceptance of adolescent pain would be indirectly related to lower daily adolescent activity-avoidance via lower parental protective responses displayed on a daily basis.

**Exploratory Hypothesis 1b:** It was explored if psychological flexible parenting and parental acceptance of adolescent pain would be indirectly related to higher daily adolescent activity-engagement via lower parental protective responses.

**Exploratory Hypothesis 2a + 2b:** We explored if the type of parental verbal instructions directed at their adolescent also mediated the abovementioned relationships. Our exploratory hypothesis was that higher levels of parental instructions to engage in pain-related activities would mediate the relationship between parental psychological flexibility and parental acceptance of adolescent pain on the one hand and daily adolescent behavior (i.e., lower avoidance and higher activity engagement) on the other hand.

## B. Background and Significance

Chronic and recurrent pain is a common health problem among children and adolescents [3]. While most children/adolescents experience low levels of disability, a significant number report moderate to severe restrictions in their daily functioning [4], ranging from lowered levels of physical activity [5], to increased absence from school [6,4] and fewer friends [7]. To better understand the origins and persistence of chronic pain in adults [8] and children [9,1,10], researchers have frequently relied on the Fear-Avoidance Model (FAM). At the core of this cognitive-behavioral model is the idea that catastrophic thoughts about pain may set the stage for pain-related fear, which, in turn, may motivate individuals to behave in ways that allow them to avoid pain. Yet, evidence shows that attempts to avoid pain often lead to maladaptive consequences, such as disability and depression [1].

Although the majority of work in this area has focused on adult pain [8], recent evidence suggests that the very same processes may also be central to the development and maintenance of pediatric pain and disability [9,1,10]. Despite the many advances this work has made in pediatric pain, a number of important questions remain. First, when and why do children continue to behave in ways (e.g., avoidance) that do not result in the desired outcomes (e.g., a relief from pain) but do lead to negative consequences (e.g., disability)? Second, what are the contextual factors that give rise to, and maintain, maladaptive pain avoidance behaviors in children? Third, what are the psychological processes that determine why some children continue to function well despite the presence of pain while other children suffer?

Although the FAM has rapidly accelerated our understanding of chronic pain it has been subject to criticism in recent times. Several authors argue that the model has focused too narrowly on catastrophizing/fear/phobias and their relation to a single goal (pain avoidance), and that pain should be viewed within a context of multiple goals (not only pain reduction) [11]. Indeed, the successful attainment of developmental goals and adequate functioning may depend on the ability to behave in ways that allow people to reach important goals (e.g., academic achievement), despite the persistent presence of pain [1]. Others argue that the FAM cannot explain why individuals develop fears for situations which they have not experienced before (i.e., through indirect learning) [12]. Finally, other researchers have indicated that the FAM is mainly concerned with prediction of pain and remains vague in delineating processes of recovery [13].

In the present project we will draw on a modern functional approach, known as Relational Frame Theory (RFT, [14,15,16]) to address these limitations and expand the current literature on the development and maintenance of chronic pain in children. RFT is an influential theory of human language and cognition within a tradition known as Contextual Behavioral Science (CBS). CBS takes the view that behavior is an 'act-in-context' which can only be understood by examining the antecedent settings or context in which it occurs as well as consequences that give rise to and maintain it. By 'act' we mean both the private (e.g.,

catastrophic thinking about pain) and public ways in which children can behave (e.g., facial pain expression) while ‘context’ refers to the current and historical settings or environments in which that behavior has previously occurred. At its core, RFT argues that the basic building block of human language and cognition is the learned ability to derive relations between stimuli and events, especially between stimuli and events that have never been directly related to one another in the past.

(Non)humans can learn to directly relate stimuli in a number of different ways, such as via classical or operant conditioning. Critically, however, humans appear to be unique in their ability to *derive* relations between stimuli that have never been directly experienced or instructed in the past. The capacity to derive allows for a limited number of painful experiences to generalize across a wide variety of stimuli and situations (e.g., having experienced back pain during a bike ride to school may motivate a child to avoid biking, but also other physical activities such as running or even walking). Drawing on our knowledge of the FAM, we argue that children may formulate complex types of derived relations (or *rules*) that allow them to limit their contact with aversive (direct and derived) experiences (e.g., “I need to refrain from engaging in physical activity in order to avoid pain”). Specifically, a particular set of antecedent events (e.g., catastrophic thoughts or “rules for responding”) may set the stage for a characteristic set of behaviors, aimed at the avoidance or escape of discomfiting private events (e.g., pain, thoughts), a type of rule-following referred to as “experiential avoidance” [17,18,20]. In the short term this adherence to pain avoidance rules may have beneficial consequences for the child (i.e., momentarily reduce contact with painful events), and as a result, the probability that the child will act in similar ways in the future increases. Across time and context these “pain-related rules for responding” are reinforced to the point that the child becomes ‘locked’ or ‘trapped’ within an increasingly narrow range of behaviors. This leads to a situation where the child becomes insensitive to the long-term consequences of their actions (e.g., decreased social and school functioning) and persists in “doing what worked before”, even when such actions lead to maladaptive outcomes (disability, increased pain). It also blocks the occurrence of behaviors oriented toward freely chosen positive consequences (“values”), inherent to adaptive child development [18,19]. Given that the ability for rule-following emerges in childhood (when learning language), in interaction with parents [16], the present project will focus upon the investigation of these processes in children.

Furthermore, over the past decades, research has shown that pain is not only a private experience, but one that takes place in a wider social context [20,21]. In the context of pediatric pain, for example, the role of others is very salient as children are especially dependent upon adults (i.e., parents) for care and help. Recently, an extension of the FAM, the *Interpersonal Fear-Avoidance Model* (IFAM) has emerged and highlights the impact parents have in the development and maintenance of (chronic) pediatric pain [22]. This model posits that parents who perceive their child’s pain as very threatening (i.e., have high levels of catastrophic thoughts about the child’s pain) tend to experience high distress and fears regarding that pain. This distress motivates parents to engage in behaviors aimed at avoiding, reducing or controlling their child’s pain. These behaviors are often referred to as “protective parenting behaviors” (e.g., keeping the child home from school, frequent monitoring of the child’s pain). At the same time, parents’ worries and fears may fuel child’s worries/fears through observational learning processes [23], and impact the child’s own tendencies to avoid activities expected to induce pain. In line with this model, accumulating evidence indicates that parents often have catastrophic thoughts about their child’s pain [24,25] and experience high levels of distress when faced with their child’s pain [24], which may motivate them to engage in “protective parenting” behaviors [24,26,27]. Although protective-parenting behaviors may seem like a natural and adaptive response to child pain, evidence suggests that such efforts are often associated with miscarried helping endeavors [28] and maladaptive childhood outcomes such as increased functional disability [27] and decreased school attendance [29]. Drawing on our knowledge of the IFAM and RFT, we argue that when confronted with their child’s pain, parents may formulate complex types of derived relations (*rules*) that guide their behavior. In the context of pediatric pain, the IFAM suggests that parents, in response to the observation of child pain, may develop and adhere to the rule “I need to reduce my child’s pain as soon as possible,” motivating protective parenting behaviors aimed at avoiding/reducing that pain (e.g., keeping their child home from school). Evidence suggests that the strategies humans use to avoid painful thoughts

or experiences may actually be quite harmful and just make things worse [30,31]. Applied to pediatric pain, the fact that verbal rules tend to make people insensitive to environmental contingencies may cause parents to become insensitive to the long-term consequences of their own protective actions (e.g., decreased child functioning, increased parental distress) and lead them to persist in “doing what worked before”, even when such actions lead to maladaptive outcomes in the long run (child disability, increased child pain).

### C. Preliminary Studies

None. This a new protocol.

### D. Design and Methods

- (1) Study Design.** This is a diary study in which children’s pain-related behaviors, hypothesized antecedents (e.g., child catastrophizing/fearful thoughts about pain) and consequences (e.g., reduced distress/fear in the child) will be assessed on a daily basis using a diary methodology. The participants will be children with chronic pain (11-17 years) and one of their parents who are recruited through the Pain Treatment Services in Boston Children’s Hospital or at Stanford Lucile Packard Children’s Hospital . They will both be asked to fill out a daily diary for a period of 14 consecutive days. The child will be asked to do this three times during the day (i.e. in the morning, after school and before bedtime) and the parent will be asked to do this only once a day (i.e. in the evening). The child’s daily physical activity level and sleep quality will also be objectively assessed by means of an ambulatory activity-monitoring device. Prior to the start of the diary the child and parent will be asked to complete self-report questionnaires. The planned project time line is as follows:

Year 1 & 2: recruitment of the participants and data collection.

Year 3: finalizing data collection, analysis of the data and report on the findings.

- (2) Patient Selection and Inclusion/Exclusion Criteria.** The eligible participants for the study will be children with chronic pain (11-17 years) and one parent/guardian to consent and participate. They must have comprehension of instructions in the English language. Patients must have a diagnosis of chronic neuropathic or musculoskeletal pain using IASP pain classification for a duration of at least 3 months to be included. Patients with headache or migraine diagnoses with pain greater than 3 months will also be included for this study. Finally, only families who have Internet access at home will be included in the study, since the diary can only be administered electronically. We aim to recruit at least 100-120 children and (one of) their parents through different ways.

Exclusion criteria are 1) significant cognitive impairment (e.g., mental retardation, severe brain injury) and 2) severe psychiatric or neurological conditions.

Boston Procedure: First, we will recruit patients who participate in the Get Living intervention study. Second, we will include patients who are in weekly outpatient psychology follow-up at the Pain Treatment Service. Children will be asked to complete a survey about their treatment history and current treatment experience in order to control for the influence of certain treatment variables when testing our hypotheses. Based on experience, we expect to recruit children from both the lowest and the highest end of functioning in the aforementioned ways. Furthermore , a question differentiating between the different types of chronic pain will be included in order to control for this in our analyses. Based on the findings from previous research on children’s functional disability in the context of chronic pain [58], we choose to only exclude children with chronic headaches/migraines since other mechanisms might play a role in the association between this type of pain and the child’s functioning and disability. Finally, only families who have Internet access at



home will be included in the study, since the diary can only be administered electronically.

Stanford Procedure: Patients will be recruited when they present to the Stanford Pediatric Pain Management Clinic (PPMC) for their pain evaluation, a follow-up visit, or if they are a part of PReP (Pediatric Rehabilitation Program). They may also be recruited based on interested in participating in research studies based on response to a question about being contacted for future research studies in the Pediatric CHOIR clinical database that is filled out by all patients at the PPMC. Those who have answered "no" to interest in participation of research will not be contacted. During initial clinical evaluations, the patient and their family will be ask by their attending clinicians if they would be interested being a part of research studies. If interested, the clinical research coordinator at the clinic will be notified which families have expressed interest in participating. If a follow-up visit is being conducted with a clinician, he/she will ask the patient and the family if they are interested in participating in the study as well. The study research coordinator or research assistants will approach eligible study participants at their pain clinic appointments to determine the patients' interest in the study. The patients will receive a brochure with more information about the study. At this point, the patient will be given the opportunity to opt out of the study and will not be contact further by the research team. Research assistants will contact interested patients to determine full eligibility and potential enrollment to the study.

- (3) **Description of Study Treatments or Exposures/Predictors.** The predictors in this study will be the daily measurements of experienced pain intensity and disability in children, the child's pain-related fears, distress and thoughts, as well as the child's sleep quality. This will allow us to identify the most important antecedents and consequences of the child's pain-related behavior. At the same time, child pain avoidance and acceptance rules will be assessed prior to the start of the diary to determine the predictive role that these rules play in child pain-related behaviors and functioning across the 14-day period.

Furthermore, we will examine how characteristics of the social context play a (moderating) role in influencing the child's pain-related behaviors and functioning. Daily measurements of instructions provided by their parent(s) and/or other important others (e.g. peers, teacher(s), other family members) and pre-diary measurements of parental pain avoidance and acceptance rules about their child's pain and general positive affect/optimism in the parent will be included.

Finally, we will explore the relationship between parental fears, distress, and thoughts about their child's pain and parental protective behaviors towards their child in pain. This will be measured on a daily basis. Thereby, we will look at the possible role of parental pain avoidance and pain acceptance rules about their child's pain (measured prior to the start of the diary) in moderating this relationship.

- (4) **Definition of Primary and Secondary Outcomes/Endpoints.** In order to investigate the child's pain-related behaviors and his/her engagement in important domains of functioning, the following child daily outcome variables will be included: the child's avoidance of, and participation in school, physical, social and leisure activities, child pain intensity and disability, his/her negative and positive affect and his/her sleep quality. Furthermore, an objective measure of the child's daily physical activity level will be included as an (child) outcome measure. We will also include parental protective behaviors as a secondary outcome/mediator in exploring the role of parents in influencing the child's functioning.

- (5) **Data Collection Methods, Assessments, Interventions and Schedule (what assessments performed, how often).** Prior to the start of the diary, children's and parent's adherence to pain

avoidance and acceptance rules will be assessed by means of self-reports. Currently, we are developing and validating the use of an implicit task to assess these automatic rules about pain in children. This measure will be added to the protocol in an amendment when finished. Administration of the self-reports will be carried out at the hospital after child and parent have provided their informed consent/assent. This can be done in a paper-pencil version, or can be administered electronically on a personal computer or tablet at the hospital. If preferred, families can also choose to complete the self-report tasks at home via REDCap (web-based survey) In such cases, they will be given a web link and a code/token that will allow them to complete the self-report procedures at home ( this link will be sent to them via e-mail)... Some of the data collected for this study is part of the clinic materials (see ‘chart review’) and will not need to be administered separately to children and their parents. Part of the consent/assent will ask for permission to have access to these chart records. Other necessary information such as demographics (e.g. age, gender), medical information (e.g. medication use, type of chronic pain condition) will be extracted from a self-report questionnaire taken once at the beginning of the study.

For the diary both children and one of their parents will be asked to complete a set of daily questions for a period of 14 consecutive days. The child will be asked to do this (through REDCap) three times each day: in the morning, when they come home from school (i.e. around 4h30 PM) and before bedtime. At each of the measurement occasions, the child will be prompted to report on his/her negative/positive mood, pain intensity, pain interference, pain-related fear/ catastrophizing, avoidance of, and engagement in school, physical, social and leisure activities, perceived parent-and other-provided instructions to accept or avoid the pain, , and observed parental (protective) behavior. . They will be asked to report on their sleep quality only once a day, i.e. in the morning. Furthermore, the child’s physical activity and sleep quality will be assessed objectively by means of an ambulatory activity-monitoring device (i.e. ActiGraph). Children will be asked to wear this device during the complete 14-day diary period (day and night). The parent will be asked to give a daily report about their child’s pain intensity and disability their child’s pain-related behavior (i.e. avoidance and engagement in activities), the instructions they gave to their child regarding avoidance or acceptance of pain-related activities, and their own catastrophic thoughts/fears and (protective) behaviors in the context of their child’s pain.

Pre-diary self-report data and daily diary data will be collected using REDCap. REDCap is a secure web-based tool to collect data for research purposes. Children and parents will be provided with a personal password (or token) that gives them access to REDCap for the purpose of filling in the questionnaires and the daily diary. This token will be send to them by e-mail. Participants will be reminded to fill out the diary by means of text messages and/or e-mail (we assume that some of the younger participants will check their mobile device more often than the inbox of their e-mail account). Another way to remind the participants about the diary is to set fixed alarms in the phone of the parent/child on the moments they should complete the diary.

All email correspondence will be conducted via parent and child participants. In compliance with the Clinical Research Program protocol, we will use a password-protected link as a way to authenticate the identity of the participant responding to the survey. Parent and child participants will have separate links to the surveys.

The study team, after verifying the authenticity of the participant and their email address, will send an email including a link to the secure site where data will be collected. All emails will include the instruction “If you have received this email in error, please contact Dr. Laura Simons, study Principal Investigator, at Boston Children’s Hospital by telephone at 617-919-4677 or by email at [laura.simons@childrens.harvard.edu](mailto:laura.simons@childrens.harvard.edu).”No sensitive information, including the title of the study, will

be included in e-mail notifications to study participants. If participants do not start the diary within 3 days or do not complete the diary, a study team member will contact the participant by telephone and/or e-mail to remind them about the diary. In case a participant misses several days due to sickness or a lack of computer access, the period of 14 days can be extended up to a maximum of 7 additional days to eventually obtain data from 14 consecutive days per family. If this 21-day window still isn't sufficient, the data will be incomplete.

Participants will be assigned a confidential study identification number so that data across all moments of time, and between children and their parent, may be combined for statistical analysis. A key linking subjects with ID numbers will be maintained in an encrypted, password protected file that only the PI and select members of the study team have access to. The key will be destroyed upon completion of final study analyses.

No commercial web survey vendors will be used. All data will be stored on internal servers, per guidelines from Clinical Research Program (CRP) staff, working directly with the study team. The CRP consultants will ensure protected access to hospital-approved web-based software and assist in the development and deployment of study surveys.

Participants may elect to complete pre-diary questionnaires on paper at the hospital or at home. If participants prefer the option of completing these questionnaires at home or if there isn't sufficient time to do this at the hospital, a study team member will mail the packet questionnaires to the family. This packet will also include a stamped self-addressed envelope for returning the questionnaires to the hospital. They will be asked to return these questionnaires before the start of the diary period.

Participants will receive a \$10 Amazon gift code after the completion of the pre-diary questionnaires and first week of daily diaries. Upon completing the second week of diaries, participants will receive a \$20 Amazon gift code, therefore making the total compensation of the study \$30 per family.

The total duration of the study will be approximately 15 days. (i) Screening each participant will take about 15 minutes. (ii) After being consented into the study, pre-diary questionnaires will take approximately 30 minutes - 1 hour for the child and parent. Active participation in the daily diary component of the study will last 14 days, 3 times a day for 5-10 minutes per diary entry for the child, and 1 time a day for 5-10 minutes per diary entry for the parent. (iii) Analysis of each individual's data will take roughly twenty four hours.

## **(5.1) MEASURES PRIOR TO THE DIARY**

### **Baseline child and parent functioning measures:**

#### ***Baseline measures from chart review***

*Demographics.* Demographic data collected for this study will include: a) the child's date of birth, b) the child's gender, c) the child's grade in school, d) parental marital status, e) level of parent education, and f) parent occupation. Type of child pain condition will also be obtained from this chart review.

*Child functional Disability Inventory (FDI).* The FDI assesses children's perceived difficulty in physical and psychosocial functioning that is due to physical health. The instrument consists of 15 items and assesses the child's perceptions of their activity limitations during the past two weeks; total scores are computed by summing individual items. Higher scores indicate greater disability. The FDI is characterized by good reliability and validity.

*Pediatric Quality of Life Inventory (Peds\_QL).* The Peds\_QL assesses health-related quality of life by measuring the child's physical, emotional, social, and school functioning. 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 (PCS-C, PCS-P).* The PCS assesses negative thinking associated with (child) pain in children/ parents. Both versions (i.e. child and parent) consists of 13 items which are rated using a 5-point scale. It yields a total score and three subscale scores: Rumination, Magnification, and Helplessness. Internal consistency of the Total Score on this measure is high ( $\alpha = 0.90$ ).

*Fear of Pain Questionnaire for Children (FOPQ-C)* report is a self-report inventory to assess pain-related fears. Each item is rated on a 5-point Likert-type scale from 0 ('strongly disagree') to 4 ('strongly agree'). The FOPQ-C consists of 24 items with strong internal consistency ( $\alpha = .92$ ). This measure has two subscales: Fear of Pain ( $\alpha = .89$ ) and Avoidance of Activities ( $\alpha = .86$ ).

#### ***Other baseline/control measures***

*Child/Parent trait affect. Positive and Negative Affect Scale (PANAS; PANAS-C).* The PANAS [40] and PANAS-C [41] are self-report measures of positive and negative emotions. The child version of the questionnaire consists of 30 items while the parent version contains 20 items. The items are all words that describe a positive or negative emotion. The child/parent will be asked to rate each item using a five-point scale referring to the extent to which they have felt each particular emotion during the past few weeks. A separate score can be obtained for the subscale 'positive affect' and 'negative affect'.

*Graded Chronic Pain Scale (GCPS; child report).* The GCPS [42] is a self-report questionnaire that consists of 8 items that measure child chronic pain severity. Scores can be obtained on two subscales measuring pain intensity and pain disability during the past 6-months. The GCPS also assesses the type of chronic pain condition. The GCPS has been validated in a pediatric samples..

*Parent Fear of Pain Questionnaire (PFOPQ).* The PFOPQ [54] report is a self-report inventory to assess parental fears associated with their child's pain. Each item is rated on a 5-point Likert-type scale from 0 ('strongly disagree') to 4 ('strongly agree'). The PFOPQ consists of 21 items. This measure has two subscales: Parent Fear of Pain and Parent Avoidance of Activities.

*Life Orientation Test – Revised (LOT-R).* The LOT-R [55] is a self-report measure that assesses optimism and positive expectations for future outcomes. This measure will only be administered to parents. The questionnaire consists of 10 items which have to be rated on a 4-point scale. The LOT has been validated in a sample mothers of children undergoing spinal surgery [56].

*Treatment Adherence Measure – parent report (TAM).* We will administer a treatment adherence measure to the parents to assess for the possible role that treatment variables have on the child's pain-related functioning. The TAM measures physical, psychological, medical, and follow-up treatment recommendations. The parent will be asked to answer each question concerning the child's treatment adherence on a dichotomous scale (yes/no).

## *Self-report measures of pain avoidance and pain acceptance rules*

### Child measures

*Chronic Pain Acceptance Questionnaire (CPAQ-A)*. The CPAQ-A [32] is a self-report questionnaire that measures the degree of pain acceptance in adolescents. The questionnaire consists of 20 items that can be divided onto two subscales measuring the child's engagement in life activities despite the pain and their willingness to experience pain. Each item is rated using a seven-point response scale from 0 ('never true') to 6 ('always true'). The CPAQ-A has been validated in a sample of adolescents with chronic pain [63]

*Avoidance and Fusion Questionnaire (AFQ-Y)*. The AFQ-Y [33] is a self-report questionnaire that measures the degree of child/adolescent psychological flexibility. It consists of 17 items that measure three basic processes underlying psychological flexibility: (1) Cognitive fusion (e.g., "My thoughts and feelings mess up my life,"); (2) Experiential avoidance (e.g., "I push away thoughts and feelings that I don't like"); and (3) Inaction or behavioral ineffectiveness in the presence of unwanted internal experiences (e.g., "I can't be a good friend when I feel upset"). The experiential avoidance subscale measures the child's general tendency to avoid unpleasant thoughts and feelings; as such this subscale measures general avoidance rule-following. The child/adolescent will be asked to rate how much each item is true for him/her on a five-point response scale 0 ('not at all true') to 4 ('very true'). Good psychometric properties of the AFQ-Y were shown in a sample of children/adolescents.

*Fear of Pain Questionnaire – Avoidance subscale (FOPQ)*. See description above. The avoidance subscale of the FOPQ will be used to assess child pain avoidance rule-following. This subscale consists of 11 items that measure the degree to which children agree with personal statements that express the tendency to avoid pain and (pain-related) activities. Example items are: "I cancel plans when I am in pain" or "I do not go to school because it makes my pain worse".

### Parent measures

*Parental Psychological Flexibility Questionnaire (PPFQ)*. The PPFQ [37] measures psychological flexibility in parents in the context of their child's pain. It consists of 31 items that can be divided in three subscales: acceptance, cognitive defusion and committed action. The parent is asked to rate the personal applicability of each statement on a seven-point response scale ranging from 0 ('never true') to 6 ('always true'). Sample items are "When my child has pain episodes I am able to realize at the time that it will pass" (i.e. positively reflecting psychological flexibility) and "I suffer terribly from my child's pain and need to make the suffering stop" (i.e. negatively reflecting psychological flexibility). A total score (0-186) can be obtained with higher scores indicating more psychological flexibility in dealing with their child's pain, or framed differently: higher scores indicate a high degree of acceptance and less rigidity in (avoidance) rule-following in the context of their child's pain. Good psychometric properties of the PPFQ were shown in a sample of parents whose adolescents were suffering from chronic pain.

*Parental Acceptance Questionnaire (6-PAQ)*. The 6-PAQ [38] measures psychological flexibility in parents across the six representative ACT processes (i.e. acceptance, defusion, being present, self as context, values and committed action). The 6-PAQ consists of 18 items, which are completed by the parent with reference to the child. A total score and subscale scores for the six processes can be obtained. Preliminary validation shows it to be a reliable and valid measure in a sample of parents of schoolchildren.

*Parent Pain Acceptance Questionnaire (PPAQ)*. The PPAQ [39] is a 15-item tool to assess parent

acceptance of child pain. The measure consists of two subscales: Activity Engagement and Pain-related Thoughts and Feelings, as such these subscales are measuring parental adherence to acceptance rules about the child's pain.

*Parent Fear of Pain Questionnaire – avoidance subscale (PFOPQ)*. See description above. To measure the degree to which the parent adheres to rules about avoiding their child's pain and/or (pain related) activities the avoidance subscale of the PFOPQ will be used. Example items are: “I avoid making plans because of my child's pain” and “ I try to avoid activities that cause my child pain”.

**Table 1:** Pre-diary constructs, measures, variables and role in analyses.

<b>Child</b>			
<b>Construct</b>	<b>Measure(s)</b>	<b>Scores used as variables</b>	<b>Role in analyses</b>
Demographics	Demographics	Age, gender, ethnicity	Descriptive/ Control
Treatment Adherence	Treatment Adherence Measure (TAM)	Report of medical, physical, psychology, and follow-up treatment recommendations/adherence	Control
Trait Affect	Positive and Negative Affect Scale (PANAS-C)	Positive affect and negative affect subscale scores.	Descriptive/ baseline
Chronic Pain	Graded Chronic Pain Scale (GCPS-C)	Baseline pain severity (intensity + disability)	Descriptive/ baseline
Pain-related functioning	Functional Disability Inventory (FDI)	Total score	Control/bas eline
	Pediatric Quality of Life Invenotry (Peds_QL)	Total score Subscale scores: emotional, school, social and physical functioning	
(Pain-related) Acceptance and avoidance rule-following	Chronic Pain Acceptance Questionnaire (CPAQ)	Chronic pain acceptance total score Pain willingness + activity engagement subscale scores.	Moderator/ Predictor
	Avoidance and Fusion Questionnaire (AFQ-Y)	Total psychological inflexibility score Cognitive fusion, experiential avoidance and behavioral ineffectiveness subscale scores	
	Fear of Pain Questionnaire (FOPQ- avoidance subscale)	Avoidance of Activities subscale score	

<b>Parent</b>			
<b>Construct</b>	<b>Measure(s)</b>	<b>Scores used as variables</b>	<b>Role in analyses</b>
Demographics	Demographics	Age, gender, ethnicity, parent marital status, parent educational background, occupation	Descriptive /Control

Parental Trait Affect	Positive and Negative Affect Scale (PANAS)	Positive and negative affect subscale scores	Moderator (Context)
Parental Optimism	Life Orientation Scale (LOT-R)	Total optimism score	Moderator (Context)
Parental acceptance and avoidance rule-following (in the context of their child's pain)	Parental Psychological Flexibility Questionnaire (PPFQ)	Total score. Acceptance, committed action and cognitive defusion subscale scores	Moderator (Context) Predictor
	Parental Acceptance Questionnaire (6-PAQ)	Total score. Subscale scores for acceptance, cognitive defusion, being present, self as context, values and committed action	
	Parent Pain Acceptance Questionnaire (PPAQ)	Total Score. Subscale scores for activity engagement and acceptance of pain-related thoughts and feelings	

## (5.2) DAILY DAIRY MEASURES

**Child daily physical activity and Sleep Quality.** The ActiGraph [48] is an ambulatory activity-monitoring device that registers the child's daily (and nightly) physical activity. The latest version of the ActiGraph is in the form of a wristwatch and can be kept on during the whole day and night. The child only has to take this off when he/she wants to take a shower/bath. The battery of the latest version is constructed to endure for the whole period of 14 days, so normally it will not be necessary to recharge the battery during the study. Before the start of the study the child will be asked to wear the device for a period of 1 week to get baseline physical activity data. The ActiGraph gives an objective and detailed report of the child's physical daily and nightly activity. This report will be used as an incentive for the child and his/her parents, as most of the participants are interested in these results. Additionally the child's sleeping quality will be assessed on a daily basis.

**Daily Diary.** The child will be asked three times each day to report on their pain experiences (i.e. pain intensity, pain interference, pain-related catastrophizing and fear), negative/positive mood, sleep quality (only in the morning), avoidance behaviors, engagement in activities, perceived instructions provided by their parents and/or by other important people and the observation of (protective) behaviors in their parent(s).

The parent will be asked to give a daily report on his/her positive/negative mood, his/her estimation of the child's pain intensity, interference and avoidance and/or engagement in activities, his/her own catastrophizing and fearful thoughts about their child's pain, the degree of his/her (protective) parenting behaviors towards the child, and the instructions to avoid and accept the pain given to their child.

**All diary materials can be found in the Appendices (at the end of this document).**

<b>Table 2:</b> Summary table of all constructs, times of administration, and reporter:						
<b>CHILD REPORT</b>						
<b>Constructs</b>	<b>Chart Review</b>	<b>Prior to diary</b>	<b>Morning (14 days)</b>	<b>After school</b>	<b>Before bedtime</b>	
Demographics	X	X				

Trait affect		X			
Self-reported pain avoidance and pain acceptance rules/rule-following		X			
Daily Mood			X	X	X
Pain intensity	X		X	X	X
Pain interference/disability	X		X	X	X
Pain Catastrophizing thoughts	X		X	X	X
Pain-related fear	X		X	X	X
Sleep Quality		X	X	X	X
Activity avoidance/engagement (social, school, leisure, physical activities)				X	X
Self-appraisal coping				X	X
Child report on Parental Protective behaviors				X	X
Parent- and other-provided instructions (pain avoidance/acceptance)				X	X
Physical Activity Level and Sleep Quality (objective measure)		X	Continually monitored		

<b>PARENT REPORT</b>			
<b>Constructs</b>	<b>Chart review</b>	<b>Prior to diary</b>	<b>Daily report (evening, 14 days)</b>
Demographics	X		
Child Treatment Adherence		X	
Trait Affect		X	
Trait Optimism		X	
Explicit rule-following		X	
Implicit rule-following		X	
Daily Mood			X
Child Type of Chronic Pain	X	X	
Child Pain intensity	X	X	X
Child Pain interference/disability			X
Child Pain (verbal and non-verbal) expressions			X
Child Activity avoidance/engagement	X		X
Parental Pain Catastrophizing thoughts	X		X
Parent Fear of Pain in child		X	X
Parental Protective behaviors			X
Parental verbal pain avoidance and acceptance instructions given to child			X



**(6) Study Timeline (as applicable).** Child and parent will be given the opportunity to complete the pre-diary self-report measures at the hospital or at home (electronically or paper version); this will take 20-25 minutes. The diary itself will take 14 consecutive days. Children will be asked to fill out the diary at three set moments during the day, with each assessment taking no more than 5-10 minutes for the child. Parents will be asked to fill out one daily diary in the evening; this will take no more than 5-10 minutes.

## **E. Adverse Event Criteria and Reporting Procedures**

No adverse events are anticipated in the course of this research. However, if a participant becomes distressed at any point, they will be given the option of ending their participation. Additionally, Dr. Simons (PI) will be available by page (#4340) and voicemail (617-919-4677) for consultation regarding any interviewee that may be experiencing distress. Caregivers will be offered a referral to outpatient (Medical Coping Clinic) psychiatric services, with contact facilitated upon request. Given that we will be assessing psychological distress, plan of action is in place if any risk of suicidality is discovered from reviewing questionnaire data. If there is any indication of risk for harm to self or suicidality, a suicide risk assessment will be conducted and a mental health clinician will decide on the best course of action to ensure the safety of the child or parent. To deal with potential discovery of child abuse, the Child Protection Team at Children's Hospital will be consulted and a 51-A filed in accordance with that consultation.

The assessment of the child's physical activity and sleep quality by means of an ambulatory monitoring device might be experienced as interfering with the child's daily functioning. However, this device is designed and tested such that it should not harm the child in any physical way.

A diary with three administration moments a day is a relative extensive procedure for the participants to complete. It will be explained thoroughly at the beginning of the diary that it is required to fill in the questionnaires three times a day during a period of 14 consecutive days. The participants will be reminded to fill in their diary by a set alarm on their phone and/or an automatic e-mail if they haven't completed the diary yet. Parents should also help their child remind to fill in the diary (and vice versa).

## **F. Data Management Methods**

All questionnaire data collected for the study will be entered into SPSS. Data will be maintained in the REDCap database and on password-protected files on computers at Boston Children's Hospital. Data will be maintained in private, non-shared, protected folders stored on central computers at Boston Children's Hospital. The hospital system provides nightly backup of files stored on its server. All hard copies of questionnaires and interviews will be stored in a locked file cabinet separate from consent forms or other documentation containing identifying information (which will also be stored in locked files). Only approved research staff will have access to these files. Identifying information will not be entered or stored on the computer with the behavioral data; thus, all relevant data other than separated consent forms will be de-identified. Data analysis will be conducted using the SPSS (Statistical Packages for the Social Sciences) statistical package and HLM (Multilevel analysis; Hierarchical Linear Modelling).

The primary source of risk in Internet research is the inappropriate breach of confidentiality. We will monitor the security of the survey data transmitted over the Internet closely at all times. Assessment data will be stored only in encrypted, password-protected files that only members of the study team may access. These encrypted files will be stored on an ISD protected, internal server that employs encryption technology. Personally identifiable data will be stored separately in study team files that are maintained separately from research data. All PHI will be stored on either an ISD server or an ISD-approved server. No data that is collected as part of the research protocol, which includes any of the HIPAA identifiers will be placed on any personal use device, including home computers, Palm Pilots, and PDAs. All study data will be kept until

final analyses have been completed and the requirements for adequately storing clinical research data have been fulfilled.

## G. Quality Control Method

All paper questionnaire data (i.e. self-reports) collected for the study will be entered using SPSS. All entered data will be reviewed by the PIs for accuracy and completeness. Most data are expected to be completed via electronic methods.

## H. Data Analysis Plan

Preliminary analyses: We will test the underlying assumptions of each statistical procedure (i.e. normal distribution, multi-collinearity, homogeneity of variance). We will plot all variables of interest against each other to check if these linear assumptions apply. Bivariate correlation analyses will be conducted to examine relationships among the variables. Any demographic or other descriptive variables (e.g. type of chronic condition/pain diagnostic group) that correlate with the outcome variables of interest will be included as covariates in the multilevel (regression) analyses described below. We will examine the psychometric properties (e.g. internal reliability) of the measures used in the study to confirm whether they operated as expected in our sample.

Hypothesis testing: Given the nested structure of the data (daily diary moments nested within individuals), the data will be analyzed using (lagged) multilevel analyses (i.e. longitudinal multilevel analyses). Next to the planned lagged multilevel analyses (as described below), we will also run non-lagged multilevel regression analyses first to determine the cross-sectional associations between the variables.

### **AIM #1: To identify the key antecedents and consequences that give rise to and maintain children's pain-related (avoidance) behaviors as it occurs in daily life.**

Hypothesis 1a: Higher levels of child pain intensity, catastrophic thinking about pain, pain-related fear, negative mood and worse sleep will predict more subsequent avoidance behavior and less (physical) activity engagement in children.

➔ **Planned analyses: (lagged) multilevel analyses.** Lagged multilevel analyses is a way to address questions of causality with the correlational data gathered by the diary. The assumption underlying this type of analyses is that causes *precede* effects. If  $x$  at diary moment  $n$  is related to  $y$  at diary moment  $n+1$ , then  $x$  can be considered to be a possible cause of  $y$  (cited from Nezlek (2012), p. 111 [59]).

**Predicting variables ( $x$ ) on diary moment ( $n$ ):** child pain intensity, catastrophic thinking, pain-related fear, negative/positive affect, sleep quality.

**Outcome variables ( $y$ ) on diary moment ( $n+1$ ):** child's (physical) activity engagement and avoidance behavior. We will perform a separate multilevel regression analysis for each of the outcome variables. .

Hypothesis 1b: Certain consequences of child pain-related (avoidance) behaviors (e.g., reduced pain, heightened disability) will subsequently function as antecedents that maintain these behaviors by eliciting them across time.

➔ **Planned analyses: (cross-)lagged multilevel analysis/cross-lagged SEM**

A first possibility to analyze this hypothesis is through *lagged multilevel analyses*: the recursive impact of variables identified as outcome measures and predictors in Hypothesis 1a will be modelled over time. We will examine whether variables considered predictors at diary moment  $n$  (see hypothesis 1a) predict child's physical activity engagement/avoidance behavior at diary moment  $n+1$ , and whether

this, in their turn, predict the same variables (e.g., pain intensity, general affect) at diary moment  $n+2$  (i.e. consequences of engagement/avoidance behavior).

Another possible way to analyze this hypothesis is through *cross-lagged multilevel analyses*. This is a more sophisticated approach to test for causal relationships between variables  $x$  and  $y$ . It also takes the association between  $y$  and  $x$  into account. The *cross* refers to the visual cross that can be made by drawing lines between variable  $x$  at time  $n$  and variable  $y$  at time  $n+1$  on the one hand and between variable  $y$  at time  $n$  and variable  $x$  at time  $n+1$  [59]. In our hypothesis, variable  $x$  might then be the child's activity engagement and avoidance behavior, whereas the  $y$  refers to the antecedents/consequences that maintain these behaviors.

**Table 3:** Overview of included measures related to the study's specific aims and hypotheses.

<b>AIM 1</b>	
<b>Hypotheses 1a + 1b</b>	
<b>ANTECEDENTS (DIARY MOMENT 1)</b>	<b>MEASURES</b>
Child pain catastrophizing	Child diary
Child fear of pain	Child diary
Child (negative) mood	Child diary
Child (low) sleep quality	Child diary
<b>OUTCOME VARIABLES (DIARY MOMENT 2)</b>	
Child avoidance behaviors	Child diary
Child activity engagement	Child diary
Child physical activity engagement	Activity monitoring device
<b>CONSEQUENCES (DIARY MOMENT 3)</b>	
Child pain intensity	Child diary
Child pain disability	Child diary
Child distress/mood	Child diary

**AIM #2: To investigate the moderating impact of child pain avoidance and pain acceptance rule-following upon children's daily pain-related (avoidance) behavior and functioning.**

Hypothesis 2: The degree of rule-following (i.e. pain avoidance and pain acceptance rule-following, measured prior to the diary) in children will *moderate* the strength of the daily associations between a) pain intensity, negative mood, catastrophic thoughts/anxiety about pain, worse sleep and b) children's (physical) activity engagement and avoidance behavior.

Hypothesis 2a: In children demonstrating higher pre-diary levels of pain avoidance rule-following, daily pain, negative affect, catastrophizing/fearful thoughts about pain, and worse sleep will be more strongly related on a daily basis to heightened levels of avoidance behavior, and reduced (physical) activity engagement.

➔ **Planned analyses: (lagged) multilevel moderation analyses.**

**Moderating variable (measured prior to diary):** child pain avoidance rule-following. This will be measured before the start of the diary by means of self-report questionnaires

**Predicting variables at diary moment  $n$ :** child pain intensity, catastrophic thinking, pain-related fear, negative/positive mood, and sleep quality.

**Outcome variables at diary moment n+1:** degree of (physical) activity engagement and avoidance behavior.

**Hypothesis 2b:** In contrast, higher pre-diary levels of pain acceptance rule-following are expected to buffer against these maladaptive associations: it is expected that in children adhering more strongly to pain acceptance rules, daily associations between pain, negative affect, catastrophizing/fearful thoughts about pain, and worse sleep on the one hand and avoidance behavior/(physical)activityengagement will be reduced.

→ **Planned analyses: (lagged) multilevel moderation analyses.**

**Moderating variable (measured prior to diary):** degree of child pain acceptance rule-following (self-report measures; measured prior to the diary).

**Predicting variables at dairy moment n:** child pain intensity, catastrophic thinking, pain-related fear, negative/positive mood, and sleep quality.

**Outcome variables at diary moment n+1:** degree of physical activity engagement and avoidance behavior.

**Hypothesis 2c:** Pain acceptance rule-following (measured prior to diary) is also expected to directly impact child outcomes, i.e., will be related to higher levels of daily (physical) activity engagement and lower levels of daily avoidance behavior .

→ **Planned analyses: (lagged) multilevel analyses**

**Predicting variable (measured prior to diary):** the degree of child pain acceptance rule-following. This will be measured prior to the diary by means of self-report measures questioning (pain) acceptance.

**Outcome variable** daily levels of child (physical) activity engagement and avoidance behavior (

AIM 2	
Hypotheses 2a + 2b	
MODERATOR (PRIOR TO DIARY)	MEASURES
Child rule-following: pain acceptance rules pain avoidance rules	Child questionnaires - CPAQ - AFQ-Y - FOPQ (avoidance scale)
PREDICTOR (DIARY MOMENT 1)	
Child pain catastrophizing	Child diary
Child fear of pain	Child diary
Child (negative) mood	Child diary
Child (low) sleep quality	Child diary
OUTCOME (DIARY MOMENT 2)	
Child avoidance behaviors	Child diary
Child activity engagement	Child diary
Child physical activity engagement	Child diary
Hypothesis 2c	
PREDICTOR (PRIOR TO DAIRY)	MEASURES
Child rule-following: pain acceptance rules pain avoidance rules	Child questionnaires - CPAQ - AFQ-Y

	- FOPQ (avoidance scale)
<b>OUTCOME (DAILY DIARY ASSESSMENT))</b>	
Child daily physical activity engagement	Activity monitoring device
Child daily activity engagement	Child diary (+ parent report)
Child daily avoidance behaviors	Child diary (+ parent report)

**AIM #3: To investigate the role of the social context (e.g. parental acceptance and avoidance rules about child pain-, parental protective behaviors and/or pain acceptance or avoidance instructions provided by others to the child, especially by the parents) in influencing the child's daily pain-related functioning**

**Hypothesis 3:** The characteristics of the child's social (e.g. parental) context will *moderate* the strength of the daily associations between a) children's pain intensity, negative mood, catastrophic thoughts/anxiety about pain, worse sleep and b) children's physical activity engagement and avoidance behavior.

**Hypothesis 3a:** In children who are confronted with high levels of other-provided pain acceptance instructions and low levels of other-provided pain avoidance instructions (averaged over days), daily pain, negative mood, catastrophizing/fearful thoughts about pain, and worse sleep will be *less* strongly related on a daily basis to heightened levels of avoidance behavior, and reduced physical activity engagement.

→**Research question 3a:** we will explore if the influence of other-provided rules differs between rules provided by their parents compared to rules provided by other people in the interpersonal context of the child (e.g. friends, teachers, other family members).

→**Planned Analyses: (lagged) multilevel moderation analyses.**

**Moderating variable (averaged over days):** average degree of child's perception of other-provided pain acceptance and pain avoidance rules.

**Explorative variables:** degree of child's perception of other-provided pain acceptance/avoidance rules and parental-provided pain acceptance/avoidance rules.

**Predicting variables at time n:** child pain intensity, mood, catastrophizing/fearful thoughts, sleep quality.

**Outcome variables at time n+1:** degree of child (physical) activity engagement and avoidance behavior.

**Hypothesis 3b:** In children of parents who report low levels of pain acceptance rule-following and high levels of pain avoidance rule-following (as measured prior to diary), daily pain, negative mood, catastrophizing /fearful thoughts about pain, and worse sleep will be more strongly related on a daily basis to heightened levels of avoidance behavior, and reduced physical activity engagement.

→**Planned Analyses: (lagged) multilevel moderation analyses**

**Moderating variable (measured prior to diary):** parental pain acceptance rule-following measured prior to the diary by means of self-reports..

**Predicting variables at time n:** child pain intensity, mood, catastrophizing/fearful thoughts, sleep quality.

**Outcome variables at time n+1:** degree of child (physical) activity engagement and avoidance behavior.

**Hypothesis 3c:** In children of parents who show high levels of optimism and general positive affect (as measured prior to diary), daily pain, negative mood, catastrophizing/fearful thoughts about pain,

and worse sleep will be less strongly related on a daily basis to heightened levels of avoidance behavior, and reduced physical activity engagement. → **Planned Analyses:**

**Moderating variable (measured prior to diary):** degree of parental general optimism about the future and general positive affect measured prior to the diary by means of self-reports.

**Predicting variables at time n:** pain intensity, mood, catastrophizing/fearful thoughts, sleep quality.

**Outcome variables at time n+1:** degree of child (physical) activity engagement and avoidance behavior.

<b>AIM 3</b>	
<b>Hypothesis 3a</b>	
<b>MODERATOR (AVERAGED OVER 14 DAYS)</b>	<b>MEASURES</b>
Other-provided pain avoidance/pain acceptance instructions	Child diary
Parent-provided pain avoidance/pain acceptance instructions	Child diary + Parent diary
<b>PREDICTOR (DIARY MOMENT 1)</b>	
Child pain catastrophizing	Child diary
Child fear of pain	Child diary
Child (negative) mood	Child diary
Child (low) sleep quality	Child diary
<b>OUTCOME (DIARY MOMENT 2)</b>	
Child avoidance behaviors	Child diary
Child activity engagement	Child diary
Child physical activity engagement	Child diary
<b>Hypothesis 3b</b>	
<b>MODERATOR (PRIOR TO DIARY)</b>	<b>MEASURES</b>
Parental rule-following - (child pain) acceptance rules - (child pain) avoidance rules	Parent questionnaires - PPFQ - 6-PAQ - PPAQ - PFOPQ (avoidance scale)
<b>PREDICTOR (DIARY MOMENT 1)</b>	
Child pain catastrophizing	Child diary
Child fear of pain	Child diary
Child (negative) mood	Child diary
Child (low) sleep quality	Child diary
<b>OUTCOME (DIARY MOMENT 2)</b>	
Child avoidance behaviors	Child diary
Child activity engagement	Child diary
Child physical activity engagement	Child diary

<b>Hypothesis 3c</b>	
<b>MODERATOR (PRIOR TO DIARY)</b>	<b>MEASURES</b>
Parental general positive affect	PANAS (PA)
Parental general optimism	LOT-R
<b>PREDICTOR (DIARY MOMENT 1)</b>	
Child pain catastrophizing	Child diary
Child fear of pain	Child diary
Child (negative) mood	Child diary
Child (low) sleep quality	Child diary
<b>OUTCOME (DIARY MOMENT 2)</b>	
Child avoidance behaviors	Child diary
Child activity engagement	Child diary
Child physical activity engagement	Child diary

**Exploratory Aim: To explore the role of parental acceptance and avoidance rules about their child's pain in influencing parental behaviors in the context of child pain on a daily basis.**

**Explorative research question 4a:** We will explore if parents demonstrating high levels of fearful/catastrophizing thoughts about their child's pain and high levels of negative mood will subsequently show more protective and solicitous behaviors towards their child in the context of pain.

→ **Planned Analyses: (lagged) multilevel analyses**

**Predicting variables at time  $n$ :** parental fearful thoughts about child pain, parental catastrophizing about child pain, parental mood

**Outcome variable at time  $n+1$ :** parental protective behaviors.

**Explorative research question 4b:** We will also explore if parental (pain avoidance or acceptance rule-following in the context of child pain *moderates* the relationship stated in hypothesis 4a:

- In parents who show *high* pre-diary levels of child pain acceptance rules, fearful/catastrophizing thoughts and negative mood will be *less* strongly related to protective behaviors towards their child.
- In parents who show *high* pre-diary levels of child pain avoidance rules, fearful/catastrophizing thoughts and negative affect will be *more* strongly related to protective behaviors towards their child.

→ **Planned Analyses: (lagged) multilevel moderation analyses**

**Moderating variable (measured prior to diary):** degree of parental pain avoidance/pain acceptance rules in the context of child pain.

**Predicting variables at time  $n$ :** parental fearful thoughts about child pain, parental catastrophizing about child pain, parental mood.

**Outcome variable at time  $n+1$ :** parental protective behaviors.

#### **AIM 4**

##### **Explorative research question 4a**

<b>PARENTAL INDEPENDENT VARIABLE (DIARY MOMENT 1)</b>	<b>MEASURES</b>
Parent pain catastrophizing (about child pain)	Parent diary
Parent fear of child pain	Parent diary
Parent negative mood	Parent diary
<b>PARENTAL DEPENDENT VARIABLE (DIARY MOMENT 2)</b>	
Parental protective behaviors	Parent diary
<b>Explorative research question 4b</b>	
<b>PARENTAL MODERATING VARIABLE (PRIOR TO DIARY)</b>	<b>MEASURES</b>
Parental rule-following: - (child pain) acceptance rules - (child pain) avoidance rules	Parent questionnaires - PPFQ - 6-PAQ - PPAQ - PFOPQ (avoidance scale)
<b>PARENTAL INDEPENDENT VARIABLE (DIARY MOMENT 1)</b>	
Parent pain catastrophizing (about child pain)	Parent diary
Parent fear of child pain	Parent diary
Parent negative mood	Parent diary
<b>PARENTAL DEPENDENT VARIABLE (DIARY MOMENT 2)</b>	
Parental protective behaviors	Parent diary

#### **Additional note from author (5-12-2019)**

#### **Specific analytic plan Manuscript 1 (see “A. Specific Aims/Objectives” for more info)**

To answer our research questions network analyses were performed by means of the *lme4* package (52) in R (53). A multilevel approach to vector autoregressive (VAR) modelling was used. Multilevel models can account for the hierarchical data structure (i.e., multiple observations nested within individuals) without violating the assumption of independence of observations and assume that observations are missing at random (54). In a VAR model variable  $Y$  (i.e., the dependent variable) at moment  $t$  (in this study: the evening) is regressed on lagged versions of that same variable  $Y$  and all other independent variables in the model at moment  $t - 1$  (in this study: the afternoon). Two network models of six variables were inferred – one for activity-avoidance and another for activity-engagement.

**Hypothesis 1 - 2:** To examine if pain-related activity-avoidance behavior in the evening was predicted by any other variable included in the network (in the afternoon), lagged versions of the level-1 predictors (i.e., pain intensity, pain-related fear, pain catastrophizing, positive and negative affect) were created. In a next step, activity-avoidance assessed in the evening was regressed on activity-avoidance assessed in the afternoon simultaneously with all other predicting variables in the afternoon. Next, similar multilevel VAR models were fitted with every independent variable now considered as an outcome. The same procedure was followed



to explore if activity-engagement in the evening was predicted by any other variable in the afternoon. Activity-avoidance and activity-engagement were therefore never incorporated into the same model. Age and gender (level-2 predictors) were included as possible confounders in all models. Normality of the residuals was checked and all variables were standardized (i.e. Z-scores) prior to the analyses. In all models random intercepts were assumed, all slopes were fixed because preliminary analyses of the variances of the effects showed no evidence against the assumption of homogeneous effects. Estimating the fixed effects resulted in a weighted network structure which was visualized by means of the *qgraph* package in R.

**Hypothesis 3:** Four additional models were fitted to test the predictive and/or moderating role of psychological flexibility for activity-avoidance and activity-engagement. All models included the same predicting variables as outlined above with psychological flexibility as an additional level-2 predictor. To test if psychological flexibility moderated the strength of within-day associations between pain intensity, pain-related fear, pain catastrophizing, and pain-related behavior, cross-level interaction terms between each of the three predictors (level 1) and psychological flexibility (level 2) were created and added as predictors in these models.

### Specific analytic plan Manuscript 2 (see “A. Specific Aims/Objectives” for more info)

**Hypothesis 1 – 2** → Multilevel mediation analyses were performed in R (v. 3.5.2; R Foundation of Statistical Computing) using the *lme4*-package ([Bates et al., 2015](#)), and 95% confidence intervals for the indirect effects were obtained using the *boot*-package ([Davison and Hinkley, 1997](#); [Canty and Ripley, 2019](#)). Multilevel modeling can account for the hierarchical data structure (i.e., multiple observations nested within dyads) without violating the assumption of independence of observations and assumes that observations are missing at random ([Snijders and Bosker, 2012](#)).

## General Statistical Power and Sample Considerations

The study will include a sample of at least 100-120 children with chronic pain and one of their parents. Based on literature a sample size of 50 or more at level two is sufficient for multilevel modeling [52, 59]. Nezlek (2012) states that two weeks of daily data and 100 participant should suffice. This number of observations/participants at level two is considered to be the most important one for having enough power to find effects. To our knowledge, there doesn't exist a widely used formal model to calculate power prior to the start of a diary study. A possible way to calculate power is to perform simulations that include parameter estimates based upon pilot studies or previous research [59, 61]. Some research has been done performing lagged multilevel analyses with both parent and child diaries. Based on similar research about relating child pain, child pain-related behavior and family variables [62] we might expect to see moderate effect sizes (i.e. Cohen's  $d = 0.50$ ), although this is very hypothetical since this largely depends on the type of hypothesis and the studied constructs. A possible way to estimate or at least get a view on the potential power *prior* to the start of the study is with the help of a guiding figure/table out of a book about power analysis for experimental research from Baussel & Li (2002) [60]. This figure gives guidelines to estimate power based on expected effect-sizes (ES) and sample size (N). We do expect to overall find moderate effect sizes (Cohen's  $d = 0.50$ ) for our hypothesized effects and plan to have about 100 participants at level two (i.e. 'N'). Using these parameters, the table shows

a power of 0.94.. However, this table should merely be seen as a guide for choosing sample size in our studies and not as method to calculate power.

Figure 2: table from book Baussel & Li (2002) [60].

Table 2.1. *The relationship between power and sample size (alpha = 0.05; two-tailed)*

N/group	ES		
	0.20	0.50	0.80
15	0.07	0.26	0.57
25	0.10	0.41	0.79
50	0.16	0.70	0.98
100	0.29	0.94	★ <sup>a</sup>
150	0.41	0.99	★ <sup>a</sup>

Notes:

<sup>a</sup> Power value is equal to or greater than 0.995.

## I. Study Organization

N/A

## J. Data Safety and Monitoring Plan

N/A

## K. Risks and Discomforts

The risks and discomfort to participants are believed to be minimal, with no physical risks and with study procedures not expected to be harmful or dangerous in any way. However, one risk of participation involves the burden of completing the study questionnaires. This risk seems minimal as participants will likely need 40 minutes to complete the pre-diary measures and implicit assessment as well as 5-10 minutes daily to complete the diaries. Some patients and/or parents may feel uncomfortable reporting on their mood symptoms, psychological symptoms, family stress/relationships, and personal health complications as related to their/their child's chronic pain. The researchers will explain to participants that all information will be kept confidential and anonymous and that the goal of the study is to help children living with chronic pain as well as their families.

## L. Potential Benefits

There is no direct benefit as a result of participating in this study. Participants may feel positively about contributing to research that may help future pain patients and their families, and the results of this study will provide important information about how to better treat children with chronic pain and their families. Although no direct benefit can be guaranteed, the risks of participation are low.

## M. Privacy Provisions

To protect the privacy of the child participant, both the child and caregiver will be informed that the assessments are private and no information will be shared with the parent unless the child consents or there is the possibility of immediate harm to the participant.

## **N. Confidentiality Provisions**

Boston: Data will be maintained in password-protected files on computers at Boston Children's Hospital. The hospital system provides a nightly backup of files stored on its server. All hard copies of questionnaires will be stored in a locked file cabinet separate from consent forms or other documentation containing identifying information (which will also be stored in locked files). Only approved research staff will have access to these files. Identifying information will not be entered or stored on the computer with the behavioral data; thus all relevant data other than separated consent forms will be de-identified.

Stanford: All devices that will be used to collect and manage data for this study will be encrypted, password secured, and protected up to Stanford data security standards. All surveys will be collected using REDCap. E-mail and Text Messaging reminders and link to the REDCap surveys are all secured and approved for research use as per REDCap and Stanford Security standards. All de-identified data that is shared with multisite institutions will be sent via secure electronic transfer (i.e. MedSecure).

Boston, Stanford, & Ghent University: Information collected during the study that does not become part of the child's medical record and will be stored in separate research files maintained by the investigator as detailed in the paragraph above. These research records will not be made available to any individuals who are not part of the research team unless requested by the caregiver or as required by law. The data is coded by a unique study participant number that will be assigned once they are enrolled in the study. The key to the code will be maintained in a password protected document by the clinical research coordinator in a private folder on a private server.

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## P. APPENDICES

### Child Morning Diary

Good morning!

Please read each of the instructions and diary questions carefully and choose the answer that best fits the way that you are feeling or thinking **this morning**. This will take 3 to 5 minutes to complete.

Remember, there are no right or wrong answers.

Thank you for your participation

#### **GENERAL INSTRUCTIONS:**

Please indicate how true each of the following statements are for you this morning on a scale from **'not at all true'** to **'totally true.'**

There are no right or wrong answers.

a. Mood

> This morning, I feel...

**'0' = not at all true; 1= a little true; 2= somewhat true; 3= mostly true; 4= totally true.**

1. Joyful
2. Miserable
3. Cheerful
4. Blue
5. Happy
6. Afraid
7. Lively
8. Scared
9. Proud

b. Pain intensity

➤ This morning, what was your overall level of pain?

**Slider-scale from '0' = no pain to '10'= worst possible pain. (vertical scale, labels are: 0,5 and 10)**

c. Pain Catastrophizing

This morning...

➤ ...I think something serious might happen to me because of the pain.

0      1      2      3      4

Not at all true

Totally true

➤ ... I keep thinking about how much pain I am experiencing.

0      1      2      3      4

Not at all true

Totally true

➤ ...I feel I can't go on much longer because of the pain.

0      1      2      3      4

Not at all true

Totally true

d. Pain-related Fear

This morning...

➤ ...my pain is causing my heart to beat fast or race.

0      1      2      3      4

Not at all true

Totally true

➤ ...feelings of pain are scary for me.

0      1      2      3      4

Not at all true

Totally true

➤ ...I worry about my pain.

0      1      2      3      4

Not at all true

Totally true

**Instruction:** Please indicate **which kind of activities you are planning to do today** (you can indicate more than one).

- Going to school
- Spending time with friends
- Spending time with family

- Hobbies
- Sports
- Household chores/tasks
- Other activities that are not in the list.

Try to answer each of the following questions **about the member of your family who is also filling out a diary** (e.g. your mother, father, or other guardian) .

a. Caregiver-provided pain avoidance/acceptance instructions

- Have you had any contact with him/her this morning (e.g. have you seen, talked in person or via phone, text messages, or e-mailed him/her)?

YES/NO

items that are conditional on the answer on the question above being YES are marked with a

\*

This morning he/she...

- \*... told me I should stop and/or cancel activities when in pain.

0      1      2      3      4

Not at all true

Totally true

- \*... told me I should keep doing fun or important activities (or any other activities I usually do) when in pain.

0      1      2      3      4

Not at all true

Totally true

## COMMENTS

If you have any comments about the items in this diary that you'd like to share with us, please feel free to write them down in the space below.

Open text box for comments.

# Child Afternoon/Evening Diary

Good afternoon/evening!

Please read each of the instructions and diary questions carefully and choose the answer that best fits the way you have felt or thought in the period between you last completed your diary and now. This will take about 5 minutes to complete.

Remember, there are no right or wrong answers.

Thank you!

## GENERAL INSTRUCTIONS:

Please indicate how true each of the following statements are for you if you think about the period since you last filled out your diary and now.

Please rate each item on a scale from **'not at all true'** to **'totally true'**.

There are no right or wrong answers.

e. Mood

**Since the previous diary entry, I have felt**

**'0' = not at all true; 1= a little true; 2= somewhat true; 3= mostly true; 4= totally true.**

1. Joyful
2. Miserable
3. Cheerful
4. Blue
5. Happy
6. Afraid

- 7. Lively
- 8. Scared
- 9. Proud

f. Pain intensity

➤ Have you felt any pain since the last time you filled out your diary?  
YES/NO

➤ **Since the previous diary entry**, what was your overall level of pain?  
**Slider-scale from ‘0’ = no pain to ‘10’= worst possible pain. (labels are: 0,5 and 10)**

Items that are marked with a ‘\*’ are conditional → participants do not get to see the items if their answer is NO on the first scale AND 0 on the second scale

g. Pain Catastrophizing

**Since the previous diary entry,**

➤ ...I thought something serious might happen to me because of the pain.

0      1      2      3      4

Not at all true

Totally true

➤ ...I kept thinking about how much pain I was experiencing.

0      1      2      3      4

Not at all true

Totally true

➤ ...I felt I couldn't go on much longer because of the pain.

0      1      2      3      4

Not at all true

Totally true

h. Pain-related Fear

➤ ...my pain has caused my heart to beat fast or race.

0 1 2 3 4

Not at all true

Totally true

➤ ..feelings of pain were scary for me.

0 1 2 3 4

Not at all true

Totally true

➤ ...I worried about my pain.

0 1 2 3 4

Not at all true

Totally true

i. Activities → these items are **only** assessed in the **evening diary**.

**Instruction:** Please indicate **which kind of activities you did today** (you can indicate more than one).

- Spending time with friends
- Spending time with family
- Hobbies
- Sports
- Household chores/tasks
- Other activities that are not in the list.

j. School attendance → these items are only assessed in the **evening diary**.

➤ Did you attend a **full** day of school today?

YES/NO

➤ Why didn't you attend a **full** day of school today?

(showed if they choose 'NO')

- There was no school because of a holiday or weekend.

- I did not attend school because of my pain.







—\*

**Since I completed my last diary he/she ...**

- —\*... told me I should stop and/or cancel activities when in pain.

0      1      2      3      4

Not at all true

Totally true

- —\*... told me I should keep doing fun or important activities (or any other activities I usually do) when in pain.

0      1      2      3      4

Not at all true

Totally true

**b. Parental observable protective/solicitous behavior:**

- \*...made sure I did not have to do certain activities (e.g. household chores, going to school, gym class) because of my pain.

0      1      2      3      4

Not at all true

Totally true

- \*... cancelled his/her personal activities (e.g. job-related duties, household chores and/or hobbies) so that he/she could be with me.

0      1      2      3      4

Not at all true

Totally true

Please think about all the people you've come into contact with, **apart from your parents or guardian**, since you last filled out your diary. This could be at home, at school, via internet or telephone. *Examples include* friends, teachers, your brother/sister or other family members who are not your parent/guardian.

Answer the following questions about these people.

- Have you had any contact with other people than your parents/guardian since you completed your last diary (e.g. in person, over the phone, text message, or e-mail)?

YES/NO

items that should be on the answer on the question above being YES are marked with a \*

**Since I completed my last diary, other people (not my parents/guardians)...**

- \*... told me I should stop and/or cancel activities when in pain.

0      1      2      3      4

Not at all true

Totally true

- \*... told me I should keep on doing fun or important activities (or any other activities I usually do) when in pain.

0      1      2      3      4

Not at all true

Totally true

### COMMENTS

If you have any comments about the items in this diary that you'd like to share with us, please feel free to write them down in the space below.

Open text box for comments.

# PARENT DIARY

Good Evening!

Please read each of the diary questions and instructions carefully and choose the answer that best describes how you felt, thought or acted today.

There are no right or wrong answers, we just want to get a realistic picture of your child's and your day.

This will only take you about 5-10 minutes to complete!

Thank you!

## GENERAL INSTRUCTIONS

Please indicate how true each of the following statements have been for you today.

Please rate each item on a scale from '**not at all true**' to '**totally true**'.

There are no right or wrong answers

Today I have felt...

'0' = not at all true; 1= a little true; 2= somewhat true; 3= mostly true; 4= totally true.

1. Upset
2. Hostile
3. Alert
4. Ashamed
5. Inspired
6. Nervous
7. Determined
8. Attentive
9. Afraid
10. Active

The following questions will ask you about **YOUR** thoughts on how **your child** experienced his/her day.

- b. Parent report on child pain intensity

- Did your child experience any pain today?  
YES  
NO
- What was, according to you, the overall level of pain your child experienced today?  
**Slider-scale from '0' = no pain to '10'= worst possible pain. (labels are: 0,5 and 10)**

c. Parent report on child's pain-related behavior

The following pain-related items (and all other items that are related to the fact if their child did or did not experience pain today) are **conditional** on their answer on the child pain intensity scale = pain-related items are not presented if their answer is NO AND below 0 → items which I think should be conditional are marked with a \*

\*When my child was in pain today he/she...

- \* ...overtly showed that he/she was in pain. For example: *made facial pain expressions, walked slowly or moved carefully because of the pain.*

0	1	2	3	4
Not at all true			Totally true	

- \*...talked to me about his/her feelings about his/her pain

0	1	2	3	4
Not at all true			Totally true	

d. Parent report on child's activities

**Instruction:** Please indicate **which kind of activities your child did today.**  
(you can indicate more than one).

- Spending time with friends
- Spending time with family
- Hobbies
- Sports

- Household chores/tasks
- Other activities that are not in the list.
- I don't know what (kind of) activities my child did today.

e. Parent report on the child's school attendance

- Did your child attend a **full** day of school today?  
YES/NO
- Why didn't he/she attend a **full** day of school today?  
(showed if they choose 'NO')
  - There was no school because of a holiday or weekend.
  - My child did not attend school because of his/her pain.
  - Other reason for not attending school:....

f. Parent report on the child's (pain-related) interference/ disability

**Today...**

- ... my child experienced problems with completing activities.

0	1	2	3	4
Not at all true			Totally true	

- \*... my child experienced problems with completing activities because of the pain.

0	1	2	3	4
Not at all true			Totally true	

g. Parent report on child's activity engagement

- ... my child thought it was important to (at least) try to complete activities.

0	1	2	3	4
Not at all true			Totally true	

- \* ...my child has put effort into completing activities that he/she finds important or fun, while he/she was in pain.

0	1	2	3	4
---	---	---	---	---

Not at all true

Totally true

- \* ... my child persisted in carrying out his/her planned activities while he/she was in pain.

0      1      2      3      4

Not at all true

Totally true

**Hint: Think about the activities you think your child had planned to do today.**

h. Parent report on child's avoidance of activities

- ... my child skipped activities because he/she expected them to trigger or increase pain.

0      1      2      3      4

Not at all true

Totally true

- ... my child stopped what he/she was doing because the pain started to get worse.

0      1      2      3      4

Not at all true

Totally true

- ... my child has spent time resting instead of doing activities because of the pain.

0      1      2      3      4

Not at all true

Totally true

The following questions will ask you about **YOUR** thoughts and feelings about the pain of your child today.

i. Parental pain catastrophizing thoughts

Today...

- ... I thought something serious might happen to my child because of the pain.

0 1 2 3 4

Not at all true

Totally true

- ... I kept thinking about how much pain my child was experiencing.

0 1 2 3 4

Not at all true

Totally true

- ... I felt I couldn't go on much longer because of my child's pain.

0 1 2 3 4

Not at all true

Totally true

j. Parental pain-related fear

Today...

- ... my child's pain has caused my heart to beat fast or race.

0 1 2 3 4

Not at all true

Totally true

- ... my child's feelings of pain were scary for me.

0 1 2 3 4

Not at all true

Totally true

- ... I worried about my child's pain.

0 1 2 3 4

Not at all true

Totally true

k. Parental verbal instructions in the context of child pain

- ... I told my child to stop and/or cancel activities when in pain.

0 1 2 3 4

Not at all true

Totally true

- ... I told my child to keep doing fun or important activities (and other activities he/she usually does) when in pain.

0      1      2      3      4

Not at all true

Totally true

l. Parental protective behaviors in the context of child pain

Today...

- ...I made sure that my child did not have to do certain activities (e.g. household chores, going to school, gym class) because of his/her pain.

0      1      2      3      4

Not at all true

Totally true

- ...I cancelled my personal activities (e.g. job-related duties, household chores and/or hobbies) so that I could be with my child.

0      1      2      3      4

Not at all true

Totally true

m. Parent report on the child's planned activities for the next day

Indicate in the following list which kind of activities **you think** your child has planned for **tomorrow** (*you can indicate more than one*).

- Going to school
- Spending time with friends
- Spending time with family
- Hobbies
- Sports
- Household chores/tasks
- Other activities that are not in the list.



- I don't know what (kind of) activities my child has planned for tomorrow

## **COMMENTS**

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