The Relationship Between Parental Catastrophizing About Child Pain and Distress in Response to Medical Procedures in the Context of Childhood Cancer Treatment: A Longitudinal Analysis

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Objective Children with leukemia frequently undergo invasive medical procedures, such as lumbar punctures (LPs) and bone marrow aspirations (BMAs). To date, cross-sectional evidence indicates that LP/BMA procedures continue to elicit distress over the course of treatment in children and parents. Method The current study used prospective analyses investigating in 28 children diagnosed with leukemia, the course of parental and child distress when confronted with consecutive LP/BMA procedures and potential moderation by catastrophic thinking. Parents’ level of catastrophic thoughts was assessed before the first treatment-related LP/BMA, while child and parent distress was reported on after each LP/BMA procedure. Results Whereas parental distress decreased over time among low catastrophizing parents, LP/BMA procedures remained highly distressing for high catastrophizing parents. Child distress during LP/BMA procedures increased over time and was positively related with parental distress. Conclusion These findings stress the importance of targeting child and parent distress as early as possible in treatment.

Key words children; hematology; longitudinal research; pain; parent stress.
nature of the parent–child relationship, persistent parental distress may, in turn, have a negative impact on their child’s as well as their own adjustment to the treatment process (Fedele et al., 2013). Indeed, previous research has consistently demonstrated a strong relationship between parents’ and child’s experience of distress in response to medical procedures (Dahlquist, Power, Cox, & Fernabach, 1994; Jay, Ozolins, Elliott, & Caldwell, 1983; Kazak et al., 1995). This has often led health care practitioners/hospitals to prevent parents from being present during child medical procedures, despite preliminary evidence indicating that parents prefer to be given a choice whether or not to be present during medical procedures (Boudreaux, Franics, & Loyacano, 2002; Franck, Cox, Allen, & Winter, 2004).

However, available research is not without limitations and there are a number of important gaps in the literature that remain to be addressed. While previous studies suggest that parental distress in the context of LP/BMA procedures remains substantially present throughout the treatment, these findings are limited by their cross-sectional nature (Katz et al., 1980; Jay et al., 1983; Kazak et al., 1995). Consequently, little is known on how families adjust to the treatment process over time. Furthermore, it is unclear which factors contribute to potentially persistent levels of parental distress in response to consecutive, invasive medical procedures such as LP/BMA procedures. A better understanding of the contributing factors might provide enhanced and early identification of parents at risk for persistent levels of distress throughout treatment. This is particularly important among parents of a child diagnosed with leukemia, given earlier findings indicating persistent distress might be likely (Kazak, 2005). In accordance with individual differences on the role of perceived threat in the attenuation of general stress symptoms in response to childhood cancer (Barakat et al., 1997), the extent to which parents perceive their child’s LP/BMA procedures as threatening (i.e., having catastrophic thoughts) may influence how parental distress responses in the context of LP/BMA procedures evolve over time. Specifically, previous findings in parents of healthy schoolchildren and children with chronic pain indicated that parental catastrophic thoughts about child pain contribute to elevated feelings of distress and protective behavior in response to child pain (Caes, Vervoort, Eccleston, Vandenhende, & Goubert, 2011). However, whether parental catastrophizing contributes to persistence of distress when parents are confronted with multiple, consecutive painful procedures in their child and how this affects their behavior (e.g., preference to be present) remain as yet to be addressed.

Accordingly, the current study, in children diagnosed with leukemia, used a prospective design to investigate how parental distress in the context of child LP/BMA procedures evolves over the course of consecutive procedures throughout the child’s treatment as a function of parental catastrophic thoughts about child procedural pain and whether parental distress persistence is associated with child distress over time. Within the present study, parents were, as part of the Hospital standard protocol, allowed to be present in the treatment room pre- and post-procedure phase but not during the actual LP/BMA procedure. Based on empirical literature, we hypothesized that parental distress would be persistent over time, particularly among parents endorsing high levels of catastrophic thinking about child pain and less so among parents with low levels of catastrophizing; and that parental and child distress would be positively associated over time. Additionally, in light of preliminary findings showing that most parents want to be present during medical procedures (Boudreaux et al., 2002; Franck et al., 2004), despite not being allowed to do so in the present study due to standard hospital procedure, we also explored parental desire to be present during LP/BMA procedures and how this desire evolves over time and relates to catastrophizing.

Method

Participants

The present study reports on longitudinal data collected in the context of the “Ghent - Pain in Child Leukemia - study” (“G-PICL study”) that aimed at investigating the role of parental catastrophic thinking in understanding parental and child responses to invasive medical procedures during pediatric cancer treatment. Cross-sectional data describing the role of parental distress and catastrophic thinking in explaining protective behavior during a single LP/BMA procedure have been reported elsewhere (Caes, Vervoort, Devos, Verloo, Benoit, & Goubert, in press). The present study reports on a unique phase of the study designed to prospectively investigate the associations between parental catastrophic thinking and parent and child level of distress. Participants were children recently diagnosed with leukemia at Ghent University Hospital and their parents. Families were excluded if they did not speak Dutch, if their child had any pre-existing developmental delay, or if their child had relapsed. Additionally, when children had received a bone marrow transplantation during their treatment, they were also excluded from further participation. Of the 38 families invited to participate in this longitudinal part of the G-PICL-study, six families refused participation (response rate: 84.21%, 16 boys;
16 girls). Main reason for nonparticipation was being overwhelmed with the diagnosis. Further, four families were excluded owing to noncompletion of the questionnaires (N = 1), parental absence during most of the LP/BMA procedures (N = 1), child bone marrow transplantation early in treatment (N = 1), or LP/BMA procedures not being performed in accordance with the standard protocol (i.e., the child being sedated during the LP/BMA procedures; N = 1). The final sample size consisted of 28 participating families (15 boys, 13 girls). Most children were diagnosed with acute lymphoblastic leukemia (ALL, N = 22). Remaining children were diagnosed with acute myelogenous leukemia (AML). For most families (N = 18), both parents agreed to participate in the study, yet in most circumstances, only one of the parents (i.e., mostly the mother) attended the preparations and aftercare of the LP/BMA procedure. Accordingly, for most procedures, we obtained data from either the mother or the father (see Descriptive statistics for more details). For the remaining children (N = 10), only the mother provided consent to participate. The mean age of the children was 6.59 years (SD = 4.29, range = 0.6–15). None of the children were able to attend school during the period of the study. Mothers’ mean age was 36.11 years (SD = 5.76, range = 23–47). The mean age of the participating fathers was 39.81 years (SD = 5.48; range = 32–50). Most parents were married or co-habiting (83.7%), and about half of them had received education beyond the age of 18 years (fathers: 50%; mothers: 59.3%). All participating children and parents were Caucasian, of which 96.4% (N = 27) had the Belgian and 3.6% (N = 1) the Dutch nationality. Ethical approval was obtained from the Ethics Committee of Ghent University Hospital.

**Procedure**

Families who met the inclusion criteria and who were at least 3 days post being diagnosed but prior to the first treatment-related LP/BMA procedure (i.e., occurring approximately 8 days after being diagnosed) were consecutively invited to participate in the present study. Consequently, participating children had received prior LP/BMA procedures but only for diagnostic purposes. Families were informed about the aim of the study (i.e., investigating factors influencing parental and child distress during treatment-related LP/BMA procedures). It was also emphasized that they were able to withdraw participation at any time. When families agreed to participate, children (older than 12 years) and their parents provided written consent.

Each LP/BMA procedure the child had to undergo as part of his/her intensive treatment (i.e., induction and consolidation phase in which the child receives intensive chemotherapy requiring frequent hospitalization) was consecutively included in the study. LP/BMA procedures to determine the diagnosis or performed during the maintenance phase of the child’s treatment (i.e., involving less intense chemotherapy and less frequent hospitalizations) were excluded. Following standard clinical protocol of Ghent University Hospital, a eutectic mixture of local anesthetics lidocaine and prilocaine is applied to the child’s skin approximately 1 hour before the LP/BMA procedure (Young, Schwartz, & Sheridan, 1996). During the LP/BMA procedure, children also receive a mixture of nitrogen peroxide–oxygen (i.e., 50% nitrous oxide/50% oxygen), which is a colorless gas that tranquilizes but does not anesthetize the child and has an analgesic impact on the skin (Reinoso-Barbero et al., 2011). The LP/BMA procedure starts after inhalation of this mixture through a facial mask for at least 3 minutes. For most LP/BMA procedures, three staff members are present: a physician, a nurse, and a child life specialist. At the time of the study, the department employed three child life specialists. At the start of treatment, the child is allocated to one of the three child life specialists, who accompanies/supports the child during each painful medical procedure and administers the nitrogen peroxide–oxygen. Prior to the LP/BMA procedure, the child life specialist also explains the procedural aspects to the child and parents. Parents do not receive specific instructions on how to support their child in coping with these procedures. If the responsible child life specialist was not available at the time of the LP/BMA procedure, another child life specialist was briefed and attended the procedure. As part of Ghent University Hospital standard protocol, parents are allowed in the treatment room during pre- and post-procedure phase but are asked to wait outside during the actual LP/BMA procedure.

All participating parents were requested to report on their catastrophic thoughts about child procedural pain before the first treatment-related LP/BMA procedure took place (i.e., the first LP/BMA procedure included in the study). Parents thus reported on their level of catastrophizing after their child had already received at least one LP/BMA procedure to confirm the diagnosis of leukemia. The first author (L.C.) or one of six research assistants was present in the treatment room pre-, during, and post-procedure to record the duration of the LP/BMA procedure. Importantly, the researcher kept the interaction with the staff, parents, and child during the different phases of the procedure to a minimum. After each LP/BMA procedure, the attending parent was requested, once the child and parent had returned to the child’s room, to report on his/her felt distress and desire to be present during the procedure. Furthermore, as a large proportion of the children were too young to provide...
self-reports (i.e., 32% of the children (N = 9) were younger than 4 years; Stinson, Kavanagh, Yamada, Gill, & Stevens, 2006), the child life specialist attending the procedure was asked to rate the child’s distress during each LP/BMA procedure. The study protocol is available on request from the first author.

**Measures**

**Parental Distress During LP/BMA Procedures**

After each LP/BMA procedure, parents were asked to indicate how much distress they had experienced during the LP/BMA procedure. Based on the work of Batson, Fultz, and Schoenrade (1987), parental distress was indexed by means of parental ratings of four emotion adjectives reflecting emotional distress (“worried,” “upset,” “anxious,” and “sad”) rated on an 11-point scale ranging from “not at all” (0) to “extremely” (10). A mean score of parental distress was calculated ranging from 0 to 10. The use of emotional adjectives is a reliable, valid, short, and easy-to-complete methodology, which lends itself well to adapt to assess distress in response to a specific situation, such as a LP/BMA procedures (Caes et al., 2011). Reliability within the current study was excellent (α = .99).

**Parental Desire to Be Present**

After each LP/BMA procedure, parents were also requested to rate to what extent they wanted to be with their child during the LP/BMA procedure (“To what extent did you want to be with your child during the LP/BMA procedure?”) using an 11-point scale ranging from “not at all” (0) to “a lot” (10).

**Parental Catastrophizing Thoughts About Their Child’s Procedural Pain**

Parents’ catastrophic thoughts about their child’s procedural pain were assessed with a state measure of the Pain Catastrophizing Scale for Parents (PCS-P-state; Goubert, Vervoort, Cano, & Crombez, 2009), which, compared with the trait measure of parental catastrophic thinking, is likely to be more compatible with the situation under investigation and thereby may have higher predictive value. Parents completed the PCS-P-state only once, prior to the first treatment-related LP/BMA procedure. In line with previous studies (Caes et al., 2011), the state version of the PCS-P comprised one adapted item from each subscale of the PCS-P assessing catastrophizing thoughts about LP/BMA-related pain. (Rumination: “to what extent did you keep thinking about how painful the LP/BMA procedure is for your child?”; Magnification: to what extent did you think that, because of the pain, something serious might happen to your child?”; Helplessness: “to what extent did you think, that because of the pain of your child, you would not be able to stand the LP/BMA procedure?”). Parents were instructed to indicate, using an 11-point numerical rating scale (0 = not at all; 10 = a lot), to what extent they had experienced these thoughts during their child’s previous LP/BMA procedure (i.e., the LP/BMA procedure performed to confirm the diagnosis of ALL or AML). A mean score of these three items was calculated, ranging from 0 to 10. Cronbach’s alpha was .83 for mothers and .89 for fathers.

**Child Distress During the LP/BMA Procedures**

The child life specialist was, after each LP/BMA procedure, requested to rate the child’s distress (“Specify how anxious you think the child was during the LP/BMA procedure”) using an 11-point rating scale ranging from 0 (not at all) to 10 (a lot).

**Data Analysis**

The data of the present study are hierarchically nested. Specifically, parental/child distress and desire to be present during each LP/BMA procedure (Level 1) are nested within individuals (parents/child; Level 2), which are in turn nested within couples (mother and father of a particular child; Level 3). Therefore, the data were analyzed by means of multilevel modeling (HLM version 6.01, Raudenbush, Bryk, & Congdon, 2004), as this method allows more precise parameter estimates compared with traditional statistical methods, such as repeated-measures analyses of variance (Kenny, Kashy, & Cook, 2006; Nezlek, 2001), and has the ability to handle missing data (Hox, 2010). Moreover, with this technique, we were able to identify a mother and father of the same child as different participants while taking into account that they form a dyad as parents of the same child (Kenny et al., 2006). If only one parent attended the LP/BMA procedure, the data point for that procedure was considered as missing data for the nonattending parent.

The following set of analyses was performed with parental distress and parental desire to be present as dependent variables. In a first step, a baseline model, without any predictors except “time” (i.e., the number of the LP/BMA procedure, e.g., the first = 0, second = 1, third = 2, etc.), was run to calculate the level of variance in the dependent variables accounted for by the variables between dyads (Level 3) and within dyads (Level 2, between parents of the same dyad and Level 1, within parents). In the second step, we controlled for the duration of the LP/BMA procedure and child level of distress by including these variables in the first level. Third, parent sex, PCS-P state, and the interaction terms parent sex × PCS-P state, time × parent...
sex, and time × PCS-P state were entered into the model as Level 2 variables. Finally, to control for the impact of child age, sex, and type of diagnosis (AML or ALL), these variables were added to the third level. A similar analysis was performed with child distress as a dependent variable without adding parental catastrophic thinking and its interactions terms to the analysis. Full maximum likelihood estimation was applied and for each step in this build-up strategy, the likelihood ratio deviance test was used to determine whether the variables at each level were retained, using \( p < .05 \) as criteria. The likelihood ratio deviance test compares the deviance, or lack of fit between model and data, of two models to determine the best-fitting model. In addition, the final, most parsimonious model was determined by using the likelihood ratio deviance test to compare the best-fitting model derived from the build-up strategy with and without the nonsignificant control variables (i.e., \( t \)-test with \( p < .05 \)) included in the model. To further obtain the most parsimonious model, the slopes of first-level variables were fixed if the random error term was nonsignificant \( (p < .05; \text{Nezlek, 2001}) \). The slopes for the effect of the first- and second-level variables were fixed on the third level because dyads do not have enough lower-level units to allow for the slopes to vary \( (\text{Kenny et al., 2006}) \). All continuous variables were standardized and grand mean-centered to allow comparison across parents and more coherent interpretations of the coefficients. The effect size \( r \), with \( r = .10 \) a small effect, \( r = .30 \) a medium effect, and \( r = .50 \) a large effect, was calculated for all significant effects \( (\text{Kenny et al., 2006}) \).

**Results**

**Descriptive Statistics**

A total of 242 LP/BMA procedures were observed with 10 LP/BMA procedures (range = 4–14) on average over the course of the child’s intensive treatment. LPs were most frequent (60.1%), followed by BMA (27.7%) and both procedures consecutively (6.1%). Mean duration of LP/BMA procedure was 8.12 minutes \( (\text{SD} = 5.80, \text{range} = 1.58–36) \). On average, 62.1% of the LP/BMA procedures were attended by mothers, 15.2% by fathers, and 7.9% by both parents. Level of parental catastrophizing about child procedural pain (PCS-P-state) for fathers \( (\text{M} = 5.07; \text{SD}_{\text{fathers}} = 2.44, \text{range} = 1–9) \) and mothers \( (\text{M} = 4.40; \text{SD}_{\text{mothers}} = 2.90, \text{range} = 0–10) \) was rather moderate and did not significantly differ from each other \( (t(21) = 1.26, \text{ns}) \). The average level of distress experienced during LP/BMA procedures was 4.21 \( (\text{SD} = 2.57, \text{range} = 0–10) \) for parents and 4.10 \( (\text{SD} = 2.47, \text{range} = 0–10) \) for children. Parents expressed a relatively high desire to be present during the procedures \( (\text{M} = 7.24, \text{SD} = 2.78, \text{range} = 0–10) \).

**The Influence of Parental Catastrophic Thinking on Parental Feelings of Distress**

The intercept model indicated that 21.74% of the variance in parental distress was accounted for by variables on the third level (between parent–child dyads, i.e., child characteristics), 35.20% by variables on the second level (within parent–child dyads; i.e., parent characteristics), and 43.05% by variables on the first level (within parents, procedure-related characteristics). Adding the first- and second-level variables yielded significant likelihood ratio tests (model with first-level variables vs. intercept model: \( \chi^2(2) = 89.17, p < .001 \); model including first- and second-level variables vs. model only including first-level variables: \( \chi^2(5) = 20.56, p < .001 \)), whereas including the third-level variables yielded a nonsignificant likelihood ratio test (\( \chi^2(3) = 3.48, p = .32 \)). Consequently, only the first- and second-level variables were retained. The model excluding nonsignificant control variables (duration of procedure, parent sex, PCS-P state × parent sex, and time × parent sex) revealed a significant likelihood ratio test when compared with the model including all first- and second-level variables (\( \chi^2(4) = 25.79, p < .001 \)). Therefore, these variables were excluded from the final, best-fitting model. The final model revealed a significant negative effect of time \( (\gamma_{110} = -0.08, t(167) = -2.85, p < .01, r = .16) \) and a positive effect of parental catastrophic thinking \( (\gamma_{100} = 0.78, t(21) = 2.75, p < .05, r = .41) \). However, results also indicated a significant time × parental state catastrophic interaction \( (\gamma_{120} = 0.07, t(167) = 2.22, p < .05, r = .13) \), indicating that whereas parents with low levels of catastrophic thoughts show a slight decrease in their levels of distress over time, feelings of distress remain high throughout treatment among parents highly catastrophizing about their child’s pain (Figure 1). Furthermore, child distress \( (\gamma_{300} = .17, t(167) = 3.45, p < .001, r = .19) \) made a significant contribution in explaining parental distress during LP/BMA procedures, indicating that child and parental distress are positively interrelated. Results for the final model are presented in Table 1.

**The Influence of Parental Catastrophic Thinking on Parental Desire to Be Present**

Large proportions of variance in parental desire to be present were explained by all levels in the model, specifically Level 3 (child characteristic) explained 42.68%; Level 2 (parental characteristics) 30.23%; and Level 1 (within parents or procedure-related characteristics) explained...
27.08%. Similar as to the model for parental distress, only adding the first- and second-level variables yielded significant likelihood ratio tests (model with first-level variables vs. intercept model: $\chi^2(4) = 54.01$, $p < .001$; model including first- and second-level variables vs. model only including first-level variables: $\chi^2(5) = 15.74$, $p < .01$), thereby excluding the third-level variables from the model ($\chi^2(3) = 1.54$, $p > .50$). The model excluding nonsignificant control variables (child distress and parent sex) also fitted the data better compared with the model including all first- and second-level variables ($\chi^2(3) = 47.21$, $p < .001$); therefore, these variables were excluded from the final model. Analyses with the final model indicated a significant time $\times$ parental catastrophic thoughts about child procedural pain interaction ($\beta_{120} = 0.10$, $t(18) = 2.36$, $p < .05$, $r = .41$; Table I). Specifically, parents reporting low levels of catastrophic thinking reported a decrease in their desire to be present during LP/BMA procedures. Conversely, parents endorsing high levels of catastrophic thoughts about child procedural pain during LP/BMA procedures showed an increase over time (Figure 2). Furthermore, the duration of the procedure showed a significant, positive association with parental desire to be present ($\beta_{200} = 0.001$, $t(124) = 2.34$, $p < .05$, $r = .22$), indicating that the longer the procedure took, the higher the parents’ desire to be present during the procedure.

The Course of Child Distress
Analyses indicated that a large proportion of the variance in child distress was due to child (50.63%) and parental characteristics (49.36%). Only 0.01% variance was accounted for by the variables on the first level (within parents or procedure-related variables). Significant likelihood ratio tests were found when adding the first- and second-level variables (model with first-level variables vs. intercept

![Figure 1. Impact of time and parental catastrophic thoughts on parental distress.](image1)

![Figure 2. Impact of time and parental catastrophic thoughts on parental desire to be present.](image2)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Parental distress</th>
<th>Parental desire to be present</th>
<th>Child distress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept ($\gamma_{000}$)</td>
<td>4.72 0.27 17.14***</td>
<td>6.89 0.42 16.32***</td>
<td>3.63 0.37 10.00***</td>
</tr>
<tr>
<td>Time ($\gamma_{100}$)</td>
<td>$-0.08$ 0.03 $-2.85$*</td>
<td>$0.03$ 0.03 1.03</td>
<td>$0.09$ 0.04 2.07*</td>
</tr>
<tr>
<td>Duration of procedure ($\gamma_{200}$)</td>
<td>– – –</td>
<td>$0.001$ 0.0004 2.34*</td>
<td>– – –</td>
</tr>
<tr>
<td>Child distress ($\gamma_{300}$)</td>
<td>0.17 0.05 3.45***</td>
<td>– – –</td>
<td>– – –</td>
</tr>
<tr>
<td>Parent distress ($\gamma_{400}$)</td>
<td>– – –</td>
<td>– – –</td>
<td>– – –</td>
</tr>
<tr>
<td>PCS-P state ($\gamma_{500}$)</td>
<td>0.78 0.28 2.75*</td>
<td>$-0.14$ 0.48 0.31</td>
<td>– – –</td>
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<tr>
<td>Parent sex $\times$ PCS-P state ($\gamma_{600}$)</td>
<td>– – –</td>
<td>0.92 0.46 1.99</td>
<td>– – –</td>
</tr>
<tr>
<td>Time $\times$ PCS-P state ($\gamma_{700}$)</td>
<td>0.07 0.03 2.22*</td>
<td>0.10 0.04 2.36*</td>
<td>– – –</td>
</tr>
</tbody>
</table>

Note. Coeff. = coefficient; PCS-P state = state version of the Pain Catastrophizing Scale – Parent version.

*p < .05; **p < .01; ***p < .001.
model: $\chi^2(11) = 910.36, p < .001$; model including first- and second-level variables vs. model only including first-level variables: $\chi^2(2) = 8.11, p < .05$. However, adding the third-level variables revealed a nonsignificant likelihood ratio test ($\chi^2(3) = 2.76, p > .50$), thus these variables were excluded from the model. The model excluding nonsignificant control variables (duration of procedure, parent sex, and time x parent sex) fitted the data better compared with the model including all first- and second-level variables ($\chi^2(10) = 60.26, p < .001$); therefore, these variables were excluded from the final, best-fitting model. Findings revealed a significant effect of time ($\gamma_{100} = 0.09, t(119) = 2.07, p < .05, r = .19$), indicating increasing levels of child distress during LP/BMA procedures (as reported by the child life specialist) with increasing number of procedures undergone. Parental level of distress also showed a significant contribution, indicating a positive association between parental and child distress experiences ($\gamma_{300} = 0.17, t(27) = 2.25, p < .05, r = .44$). Results of the final model are presented in Table 1.

### Conclusion

The present study investigated, in a sample of children with leukemia and their parents, whether parental distress during LP/BMA procedures persists over time, particularly among parents endorsing high levels of catastrophic thinking about child pain; and whether high levels of parental distress are associated with increased levels of child distress. Additionally, we also explored the preference of parents to remain present during the LP/BMA procedures. The results of the present study were partially in line with expectations. First, findings indicated that parental distress in response to LP/BMA procedures changed over time depending on parental catastrophizing about child procedural pain. Specifically, parental distress gradually decreased over the course of consecutive LP/BMA procedures among parents with low catastrophic thoughts but remained equally high among parents endorsing high levels of catastrophic thinking. A comparable pattern for high versus low catastrophic thinking was apparent for parental desire to be present during LP/BMA procedures. Further, child distress (as reported by the child life specialist) increased over the course of multiple LP/BMA procedures and was positively associated with parental distress.

The current findings are consistent with prior research in parents of healthy schoolchildren and chronic pain samples (Caes et al., 2011), yet extend the earlier results in several ways. First, to our knowledge, this study is the first to prospectively investigate the role of parental pain catastrophizing in the context of consecutive, invasive medical procedures. Second, while exploratory, the present study also provides insight into parental desire to be present during invasive medical procedures, how this evolves over time and relates to parental catastrophic thinking about child pain.

Findings indicated that parental catastrophizing about child pain influences how parents adapt to frequent, consecutively occurring painful medical procedures in their child. Specifically, whereas LP/BMA-related parental distress decreased over time among parents with low levels of catastrophic thinking, LP/BMA procedures remained equally distressing for parents with high levels of catastrophizing. While further research is needed, one potential explanation is that pain catastrophizing affects emotion regulation capacity. Possibly, parents with low levels of catastrophic thinking are able to adopt adequate strategies to regulate distress in response to these consecutive, invasive procedures. A well-documented emotion regulation strategy in the context of pain is distraction, which has been found to be associated with decreased pain aversiveness and increased pain tolerance (Malloy & Milling, 2010). However, both adult and child literature suggests that distraction from pain is particularly effective among individuals with low levels of catastrophic thinking but may be counterproductive for individuals who endorse high levels of catastrophic thinking (Van Damme, Crombez, Nieuwenborgh - Van De Wever, & Goubert, 2008; Verhoeven, Goubert, Jaaniste, Van Ryckeghem, & Crombez, 2012; Vervoort et al., 2011). Applied to our findings, it is plausible that only parents low in catastrophic thinking may benefit from distraction from pain.

While the proposed interpretation on effective use of distraction is speculative at present and requires further empirical investigation, our findings on parental desire to be present may also be interpreted in this light. Specifically, parental absence during invasive medical procedures such as LP/BMA procedures—which is often standard practice (Franck et al., 2004)—may allow parents to distract from child pain. Such explanation may account for our finding that desire to be present, like parental distress, decreased among parents with low levels of catastrophic thinking (i.e., for whom distraction likely works), but increased among parents endorsing catastrophic thoughts about their child’s pain (i.e., for whom distraction is likely to be counterproductive). Yet, as our findings on parental presence are limited to one question, future research is needed on how best to ascertain parental preference to be present. Furthermore, more research on factors influencing parental desire to be present, when parental
presence is less or more beneficial both for the parent as well as the child and why this is the case, is warranted (Boudreaux et al., 2002; Franck et al., 2004). For example, parents’ own experiences and discomfort with medical procedures might downsize parental desire to be present during their child’s procedures and the beneficial effect of parental presence.

Interestingly, our findings also indicated that children do not habituate to the distressing experience of LP/BMA procedures. On the contrary, findings showed that children were perceived by the child life specialist as becoming increasingly distressed over time. Comparable, but cross-sectional, findings have been reported by Katz and colleagues (1980) and Kazak and colleagues (1995), indicating that child anxiety and discomfort do not spontaneously diminish with repeated exposure. Furthermore, we found that parental distress and child distress were positively interrelated over the course of treatment. However, our data do not allow for any conclusion on the direction of this association. Owing to reporting on their distress experience after the post-procedure phase, parental ratings of their distress experience during the LP/BMA procedure might be influenced by their observation of child’s level of distress during the post-procedural phase. Nevertheless, the absence of parents during the LP/BMA procedure does not preclude an influence on their child’s responses. Heightened distress among parents with high catastrophic thoughts might also be apparent in anticipation of the procedure (Caes, Vervoort, Trost, & Goubert, 2012), thereby influencing subsequent child distress during the procedure, even in the absence of parents. Although more research is needed on the direction of this association, these findings further emphasize the importance of targeting both child and parent distress in early stages of treatment. To date, a lot of progress has been made in optimizing pharmacological as well as nonpharmacological interventions to reduce the child’s pain and fear during painful medical procedures (Blount et al., 2009; Conte et al., 1999). However, it is as yet unclear how to assist parents in effectively coping with painful medical procedures, nor is it standard practice to do so (Chambers, 2003). Targeting parental catastrophizing by means of cognitive behavioral therapy-based interventions such as functional analysis and cognitive restructuring (Williams, Eccleston, & Morley, 2012) might prevent development of severe parental and associated child distress during these procedures over time (Dahlquist et al., 1994; Fedele et al., 2013; Kazak, 2005). Alternatively, it may also prove functional to provide parents with adequate strategies to attenuate induced distress without targeting catastrophizing per se. Mindfulness- and acceptance-based approaches, which increase awareness of catastrophic thoughts and associated feelings of distress without judging but instead accepting these inner experiences and thoughts, might constitute a potential pathway to cope with catastrophic thoughts about child pain and associated distress experience (McCracken & Gauntlett-Gilbert, 2011; Schütze, Rees, Preece, & Schütze, 2010).

A number of limitations deserve consideration, each of which point to directions for future research. First, the study sample was small and recruited in only one hospital, utilizing moderate sedation for LP/BMA procedures. Consequently, we may not have been able to detect small effects and generalization of the results, especially in situations where general sedation is used for LP/BMA procedures might be limited. Related to this issue is the wide age range of our participants. Although child age did not impact the current findings, further investigation in different age-groups is needed to explore similarities and differences across development. Second, as many children were too young to provide self-reports, the child life specialists provided ratings on child distress. Consequently, the results need to be interpreted with caution, as the longitudinal analyses might have been limited owing to multiple persons providing ratings at different points in time. Although the briefing they received prior to the procedure may have influenced the observation of child distress by child life specialists unfamiliar to the child, it would have been unethical to eliminate this briefing procedure. Future research is needed to replicate the current findings and investigate whether similar associations can be found when using other measures including child self-reported and observational assessment of child distress. Third, staff members’ behavior during the LP/BMA procedures may have impacted child distress experience. Yet, this influence was not taken into account. Further, as parental state levels of catastrophic thoughts were assessed after the LP/BMA procedure to determine the diagnosis, child distress during this LP/BMA procedure might have influenced parents’ report of catastrophic thinking. Future research might benefit from including assessment of parental catastrophic thinking before any LP/BMA procedures have taken place. Finally, although only six families declined study participation, the main reason for nonparticipation was being too overwhelmed with the diagnosis. Consequently, a self-selection of parents with high levels of distress might have taken place.

These limitations notwithstanding, the current findings attest to the importance of assessing parental pain catastrophizing in the context of repeated painful LP/BMA procedure to advance understanding of associated parent and child distress. Future research is needed to
replicate and explore alternative explanations suggested by the current findings.

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