Journal of Pain Research

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ORIGINAL RESEARCH

A preliminary validation of the Swedish version of the Pain Catastrophizing Scale for Children (PCS-C) for children and adolescents with cancer

This article was published in the following Dove Press journal:
Journal of Pain Research

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Objectives: Pain is reported as one of the most common and difficult symptoms for children and adolescents with cancer to cope with. Pain catastrophizing has been identified as a process clearly related to pain intensity and disability. The Pain Catastrophizing Scale for Children (PCS-C) has been validated in several languages and populations but remains to be validated in pediatric oncology. The aim of the study was to validate a Swedish version of the PCS-C for children and adolescents with cancer.

Methods: All children, 7–18 years of age, being treated for cancer in Sweden at the time of the study were invited to participate. Study material was sent out to the registered address. Internal consistency, test–retest reliability and convergent validity were calculated. Factor structure was examined using principal component analysis (PCA). Descriptive statistics were used to investigate background data and norm values.

Results: 61 children/adolescents were included in the analyses. The results did not support the original three-factor structure of the PCS-C, but rather suggested that a two-factor structure excluding item 8 best represented the data. The internal consistency of that solution was good (α=0.87), the test–rest reliability was excellent (ICC=0.75) and convergent validity was demonstrated (r=0.46). The mean (SD) for the PCS-C in the sample was 19.1 (9.2), without item 8. A statistically significant difference was shown between genders, where girls reported a higher level of pain catastrophizing than boys. No difference was found with regard to age.

Discussion: The Swedish version of the PCS-C is now preliminarily validated for children and adolescents with cancer, for whom gender- and age-specific norm values are now available. Questions remain regarding the optimal factor structure of the PCS-C.

Keywords: The Pain Catastrophizing Scale for Children, instrument validation, children, adolescents, cancer, pain

Introduction

It has become more and more apparent that pain and emotions are closely interconnected and that they influence each other neurophysiologically.[1,2] This means that pain does not only cause psychological distress, but that psychological distress also, in fact, amplifies the nerve transmission of pain impulses.[3–5] Brain-imaging studies have shown that positive emotions neurologically weaken pain impulses, while negative emotions strengthen them.[6] If the pain is perceived as a threat, pain impulses are neurophysiologically amplified.[7] The role of pain catastrophizing and how it affects the pain

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DovePress
http://doi.org/10.2147/JPR.S191378

experience has been emphasized in pain research since the 1980s.[8] Pain catastrophizing refers to the process where pain is interpreted as very threatful.[9] It can be understood as the cognitive element of the fear[10] and is associated with an inability to shift attention away from pain.[11,12] Pain catastrophizing is associated with disability in both pain patients[13-16] and the general population.[17] In accordance with the reciprocity between pain and emotions, pain catastrophizing is further related to intensified pain.[7,18–24] The Pain Catastrophizing Scale (PCS)[25] was developed in the 1990s and has been widely used and validated in many languages since.[26–36] It contains three subscales measuring different aspects of pain catastrophizing: rumination, magnification and helplessness. The rumination subscale contains items measuring ruminative thoughts, worry and an inability to inhibit pain-related thoughts. The magnification subscale reflects the intensification of the unpleasantness of pain and expectancy of negative outcomes. The helplessness subscale reflects an inability to deal with pain. The PCS has shown good internal consistency and temporal stability and correlates with measures of psychological distress, functional disability and pain intensity.[21,22,25,37] The child version of the Pain Catastrophizing Scale, the PCS for children (PCS-C) was developed in 2003[38] and was shown to have the same three-factor structure as the original version, good-to-excellent internal consistency and predictive and concurrent validity. The PCS-C has since been validated in different languages and for different populations,[39–42] supporting its psychometric properties, yet showing different results with regard to factor structure. In two studies with community samples, by Solé et al[42] and Parkerson et al,[39] the three-factor model was supported. In two other studies with chronic pain samples, by Kröner-Herwig et als[40] and Pielech et al,[41] the results rather suggested a one-factor model. The results of the Parkerson study[39] and the Pielech study[41] further indicated that the scale might benefit from removing two items, yet different ones in the two studies. The Pielech study provided clinical reference points from a sample of children with chronic pain. Furthermore, the Kröner–Herwig study[40] showed higher scores in girls than boys. Taken together, the PCS-C is a well-validated scale with good psychometric properties that yet would benefit from further validation, particularly in clinical populations. The factor structure deserves further investigation, including number of items, as well as reference points, preferably that are age and gender specific.

Pain in children is common due to different causes. Everyday pain in active play and sport is very common but usually not medically significant. Acute pain may be caused by illness, trauma or medical procedures. Recurrent pain, such as stomachaches, headaches or limb pain, are experienced occasionally to frequently by up to a third of children. Children may also suffer from chronic or disease-related pain.[43] For children with cancer, pain is reported as one of the most common and burdensome symptoms throughout their cancer trajectory.[44] The pain is most often caused by the disease itself, side effects of cancer treatment and/or medical procedures.[45,46] Given the reciprocity between pain and emotions, pain management would benefit from a multimodal approach acknowledging its psychological mechanisms to a higher extent. This would likely improve pain management in general, and for children with cancer in particular. Furthermore, in order to optimize treatments, processes of change need to be investigated. For that purpose instruments measuring these processes of change are needed. The PCS-C is one such instrument. To be able to evaluate mechanisms of change in different treatments for different populations, validation of relevant instruments for the population at hand is important. For children with cancer, the pain may be interpreted as particularly threatful, and for whom pain catastrophizing may play an even more significant role. Validation of the PCS-C in the context of pediatric cancer is therefore of great importance.

Aim

The aim of the study was to validate the Swedish version of the Pain Catastrophizing Scale for Children (PCS-C) in a sample of children and adolescents with cancer, by examining its factor structure, internal consistency, test–retest reliability, convergent validity and norm values.

Methods

Design

The study was a psychometric validation study with a cross-sectional design.

Context

The study was part of a larger project for which the overall aim was to develop psychological interventions to help children with cancer to cope with the pain that is often

associated with cancer and its treatment. In this larger project, scales for measuring psychological flexibility in relation to pain, often called pain acceptance, were developed for children with cancer (The Pain Flexibility Scale for Children (PFS-C)),[47] and their parents (The Pain Flexibility Scale for Parents (PFS-P)).[48] The PCS-C was used as a validation measure for the PFS-C.

Participants

All children, 7–18 years of age, who were being treated for cancer in Sweden at the time of the study, were invited to participate. Two hundred and thirty-three patients were identified by the Swedish Childhood Cancer Registry. The patient information supplied by the Swedish Childhood Cancer Registry contained name and surname, social security number, address, center where the child was treated, time since diagnosis and start of treatment. For one child, the patient data were insufficient and the child was excluded. The research nurses at the six pediatric oncology centers in Sweden were consulted to double-check that none of the children had gone into palliation or deceased after data withdrawal, in order to make sure that these children were not contacted. One child was recognized as having gone into palliation and was therefore excluded.

Data collection

Two hundred and thirty-one children were invited via e-mail at their registered addresses. The study material comprised information about the study, a questionnaire for background information, the test version of the scale under development (the PFS-C),[47] evaluation questions, and two validation measures, of which the PCS-C was one. Three different versions of the patient information were used: one for children 7 to 12 years of age, one for adolescents 13 to 18 years of age and one for parents. The patient information specified that the study concerned pain. Background information included age, gender, type and date of diagnosis, date of end of treatment if applicable and current and average (over the last week) level of pain and discomfort of pain, rated on a Numerical Rating Scale (NRS) from 0="No pain/discomfort at all" to 10="Unbearably lot of pain/discomfort".[49] The children were offered to be included in a lottery of movie tickets for participating in the study. Consent was given through participation in the study. For children under the age of 15, written parental consent was also required. Upon no reply, a reminder was sent out 2 weeks after the first post. Upon participation, the test material was sent out again 1 month after reception of the first measurement for the purpose of test–retest analysis. All study material was coded. The code key was only accessible to one of the researchers. Three posts were returned by the Postal Service. Sixty-two children participated in the study of which 39 participated in both measurements and 23 participated at one measurement. One was excluded due to inadequate completion of the questionnaires. Ten children declined participation. One hundred and fifty-six children did not respond. The study was approved by the Regional Ethical Review Board in Uppsala, Sweden [Dnr 2014/375].

Measures

Apart from the scale of focus for validation, a measure for validation was used.

The Pain Catastrophizing Scale for Children (PCS-C)

The PCS-C measures catastrophizing thoughts in children and adolescents in pain.[25,38] The scale consists of 13 statements beginning with the phrase "When I have pain, …". The respondent rate their agreement with the statement on a 5-point Likert scale, the score range is 0–52 and higher scores indicate a higher level of catastrophizing. The rumination subscale contains the four following statements: "…, I want pain to go away", "…, I can't keep it out of my mind", "…, I keep thinking about how much it hurts" and "…, I keep thinking about how much I want the pain to stop". The magnification subscale contains the three statements "…, I am afraid that pain will get worse", "…, I keep thinking of other painful events" and "…, I wonder whether something serious will happen". The helplessness subscale contains the following six statements: "…, I worry all the time whether pain will end", "…, I feel I can't go on", "…, it's terrible and I think it's never going to be better", "…, it's awful and I feel it takes over me", "…, I can't stand it anymore" and "…, there's nothing I can do reduce pain". Cronbach's alpha has been shown to be α=0.81–0.90 and the scale has been shown to correlate with pain intensity, disability, anxiety sensitivity and pain coping and to predict pain and disability.[38–42] A Swedish version of the PCS-C was used.

Measure for validation

Due to the aim of the larger study, to develop a scale for measuring psychological flexibility in relation to pain in children with cancer, the Avoidance and Fusion Questionnaire for Youth (AFQ-Y) was used to assess

convergent validity. The AFQ-Y measures psychological inflexibility in youths.[50,51] Psychological inflexibility has been proposed as a trans-diagnostic factor[52,53] and to constitute a generalized vulnerability for psychopathology.[54] Interventions targeting psychological inflexibility in relation to pain, promoting the counter process acceptance instead, have been shown to predict increased pain tolerance and decreased pain intensity and discomfort of pain in experimentally induced pain.[55–59] A pilot study preliminarily evaluating an acceptance-based intervention for children with cancer experiencing acute pain has also shown reductions in pain intensity and discomfort of pain.[60] Psychological inflexibility and pain catastrophizing have been shown to be related constructs.[61] In the AFQ-Y, respondents rate their agreement with statements targeting experiential avoidance and cognitive fusion such as "The bad things I think about myself must be true" and "I am afraid of my feelings", on a 5-point Likert scale. A higher score indicates a higher level of psychological inflexibility. The AFQ-Y has demonstrated excellent internal consistency, temporal stability and convergent, discriminant and construct validity. The short version of eight items was used, AFQ-Y8, which correlates positively with child-reported anxiety, physical symptoms and problem behavior and negatively with general quality of life.[50,51] The psychometric properties of the AFQ-Y8 were investigated and supported in the larger project to which the current study pertains and hence for the population at hand, children and adolescents with cancer.[62] The score range of the AFQ-Y8 is 0–24.

Statistical analyses

All statistical analyses were performed in IBM SPSS Statistics, version 24.[63] Principal component analysis (PCA) was used to investigate factor structure. The correlation matrix revealed a high proportion of correlation coefficients above 0.30, Bartlett's test of sphericity was significant, and the Kaiser–Meyer–Olkin index (KMO) was 0.80, supporting the factorability of the data set. The Kaiser's criterion and the scree plot were assessed to determine the number of factors to extract. Preliminary analyses indicated interdependence between the factors and oblique rotation was used. Cronbach's alpha was calculated to assess internal consistency. The intraclass correlation coefficient (ICC) was calculated to assess test–retest reliability, which is the recommended method.[64,65] A two-way random Model assessing the single measures value was used.[66] A value <0.40 indicates poor inter-rater-agreement, between 0.40 and 0.59 fair, between 0.60 and 0.74 good and >0.75 excellent.[67] Correlation with the AFQ-Y8 was performed to assess convergent validity. The data on both scales were normally distributed and Pearson correlation was used. Correlation coefficients were interpreted in accordance with the guidelines by Cohen,[68] where r=0.10–0.29 small, 0.30–0.49 medium and 0.5–1.0 large. Descriptive statistics were used with regard to background data and to calculate norm values. Independent samples t-test was performed to compare the means between genders and age groups, respectively.

Results

Descriptives

Sixty-one children were included in the statistical analyses. The mean age of the participants was 12.7 years (SD=3.4), the age ranged from 7 to 18 years and 33 (54%) were boys and 28 (46%) girls. The diagnoses were leukemias (23), brain tumors (13) and solid tumors (25). The means (SDs) of the children's current and average level of pain during the last week were 1.1 (1.6) and 1.4 (1.5), respectively. The means (SDs) of the children's current and average level of discomfort during the last week were 1.0 (1.7) and 1.5 (2.0), respectively.

Factor analysis

The PCA revealed three factors with eigenvalues above 1, explaining 42.4%, 11.7% and 8.8% of the variance, respectively. The scree plot revealed a distinct break after the first and another more subtle break after the second factor. Hence, the results were ambiguous with regard to number of factors to retain. Inspecting the different rotation solutions, they yielded very similar results. In the three-factor solutions, factor 3 was comprised of only item 8, "When I have pain, I want pain to go away". A factor with only one item would be far too unstable and a three-factor solution would hence not be appropriate according to the data set. The analyses were, therefore, run again forcing a two- and one-factor solution, respectively. Item 8 did not reach a factor loading of 0.4, which is recommended, in either of these solutions and its communality value was low (0.156 and 0.155, respectively). Item 8 was therefore removed from the analyses. Without item 8, the analyses revealed two factors with eigenvalues exceeding 1, accounting for 44.9% and 12.6% of the variance, respectively. The result from scree plot was somewhat ambiguous, with a distinct break after factor 1 and yet another clear break after factor 2. The different two-factor solutions yielded similar results, with one more dominant factor of eight–nine items and a second factor

with three-four items. Item 3 loaded quite similarly on both factors; slightly stronger on factor 1 in the Oblimin solution and slightly stronger on factor 2 in the Promax solution. Communalities were all above 0.3 (lowest 0.460). In the one-factor solution, the factor loading for item 12 was low, 0.139. For the rest of the items, factor loadings ranged from 0.448 to 0.804. The communalities for three items (7,12 and 13) were low (0.019–0.233). Taken together, the results suggested that a 2-factor solution excluding item 8 best represented the data. The factor loadings for a two-factor solution were somewhat higher with the Promax rotation. Factors, items, factor loadings and communalities for this solution are presented in Table 1.

Reliability and convergent validity

Internal consistency, test–retest correlation coefficients and correlation coefficients for the validation with the AFQ-Y, including and excluding item 8 respectively, are presented in Table 2. The internal consistency of the scale was good, the test–rest reliability was excellent and the correlation with the AFQ-Y8 was medium, regardless of inclusion or exclusion of item 8.

Norm values

Mean values, standard deviations (SDs), standard errors (SEs), confidence intervals (CIs) for means, trimmed means and medians, score ranges and total (possible) ranges for the total scale and the subscales, excluding item 8, are presented in Table 3. Including item 8 the mean (SD) was 22.5 (9.5); SE 1.3; 95% CI for means (19.9–25.1); 5% trimmed mean 22.4; median 22.0; score range 4–45 and total range 0–52. With regard to gender, the mean (SD) for girls (n=25) was 22.3 (8.6) and for boys (n=29) 16.2 (8.9), a statistically significant difference (t (52)=2.54, p=0.01, two-tailed). With regards to age, the mean (SD) for children 7–12 years of age (n=23) was 19.5 (9.1) and for adolescents 13–18 years (n=31) 18.7 (9.4), a nonsignificant difference (t (52)=0.32, p=0.75, two-tailed). Both gender- and age-specific means were calculated excluding item 8.

Table 2 Internal consistency, test–rest correlation coefficients and Pearson's *r* correlation coefficients for validation with the AFQ-Y

The PCS-C	Cronbach's α	Test–retest (ICC)	Correlation with the AFQ-Y8 (*r*)
… with item 8	0.87	0.76	0.42
… without item 8	0.87	0.75	0.46

Abbreviations: PCS-C, the Pain Catastrophizing Scale for Children; AFQ-Y8, the Avoidance and Fusion Questionnaire for Youth; ICC = intraclass correlation coefficient.

Discussion

The aim of the study was to validate a Swedish version of the PCS-C for children and adolescents with cancer reporting pain. The results of the current study did not support the original three-factor structure of the PCS-C, but suggested that a two-factor structure excluding item 8 best represented

Table 1 Factors, items, factor loadings and communalities of a two-factor solution with Promax rotation for the PCS-C, with item 8 ("When I have pain, I want pain to go away") excluded

Factor	Item When I have pain, …	Factor loading	Communality
1	9 … I can't keep it out of my mind	0.839	0.711
	10 … I keep thinking about how much it hurts	0.794	0.674
	11 … I keep thinking about how much I want the pain to stop	0.777	0.620
	2 … I feel I can't go on	0.767	0.589
	6 … I am afraid that pain will get worse	0.739	0.583
	5 … I can't stand it anymore	0.738	0.544
	1 … I worry all the time whether pain will end	0.713	0.640
	4 … it's awful and I feel it takes over me	0.707	0.509
2	13 … I wonder whether something serious will happen	0.740	0.547
	7 … I keep thinking of other painful events	0.671	0.460
	12 … there's nothing I can do reduce pain	0.639	0.502
	3 … it's terrible and I think it's never going to be better	0.616	0.515

Abbreviation: PCS-C, the Pain Catastrophizing Scale for Children.

Table 3 Mean, standard deviation (SD), standard error (SE), confidence interval (CI) for mean, trimmed mean, median, score range and total (possible) range for the PCS-C, excluding item 8

The PCS-C	Mean (SD)	SE	95% CI for mean	5% trimmed mean	Median	Score range	Total range
Total scale	19.1 (9.2)	1.3	16.5–21.6	19.0	19.0	2–41	0–48
Factor 1	14.0 (7.3)	1.0	12.1–16.0	14.0	14.0	0–28	0–32
Factor 2	4.9 (3.2)	0.4	4.0–5.7	4.8	4.0	0–13	0–16

Abbreviation: PCS-C, the Pain Catastrophizing Scale for Children.

the data. Previous results regarding the factor structure of the PCS-C have been inconsistent. Two studies, by Solé et al[42] and Parkerson et al,[39] have supported the three-factor structure of the original version by Crombez et al.[38] Two other studies, by Kröner-Herwig et al[40] and Pielech et al,[41] have previously found no support for the three-factor model even though a one-factor solution best represented the data in those studies. In the Pielech study,[41] items 7 and 8 were found problematic due to floor/ceiling effects. Although the Solé study[42] and the Parkerson study[39] found support for the original factor structure, items 8 and 12 were found problematic due to low factor loadings in both of these studies, and Solé recommended exclusion of item 8. Hence, as to factor structure, the results of the current study are partly consistent with previous studies. With regard to the composition of the two factors of the current study, factor 1 consisted of all items, except item 8, of the rumination scale, one item of the magnification subscale and four items of the helplessness subscale. Factor 2 consisted of three items of the magnification subscale and one item of the helplessness subscale. Hence, the composition of the subscales is not consistent with the original version. The internal consistency, test–rest reliability and convergent validity were calculated both including and excluding item 8, for which both solutions showed good internal consistency, excellent test–rest reliability and a medium correlation with the validation measure indicating convergent validity. These results are in line with previous studies supporting the psychometric properties of the scale.[38–42] The mean (SD) for the PCS-C in the sample was 22.5 (9.5) including item 8. This is higher than the mean reported in Crombez et al[38] and Parkerson et al[39] studies for community samples (16.85–17.20), but lower than the mean reported in the Kröner-Herwig et al study[40] for children and adolescents with recurrent headaches and chronic pain (26.44–33.35). The fact that the mean is higher than in community samples is expected. However, that the mean is lower in our sample compared to a sample of children and adolescents with recurrent headaches and chronic pain is somewhat surprising. One may assume that the levels of pain catastrophizing would be higher in a sample of children and adolescents with cancer given the nature of the disease. Clinical reference points were provided by Pielech et al,[41] suggesting that a mean of 17.6 corresponds to a low level of catastrophizing, 21.8 of a moderate level and 25.6 of a high level. Hence, the current sample seems to report moderate levels of pain catastrophizing. This result may be explained by the low levels of current and average pain ratings (1.1 and 1.4, respectively) in our sample. (In the Kröner-Herwig et al study[40] the pain ratings were relatively high, 4.54–6.18.) Given that exclusion of item 8 has been recommended by previous studies and the current one, it is important to note the number of items when comparing means between samples henceforth. A statistically significant difference was shown between genders, where girls reported a higher level of pain catastrophizing than boys. This is in line with the results of the Kröner-Herwig et al study,[40] although Parkerson et al[39] did not find any difference between genders. No difference was found with regard to age, which is in line with the results of the Parkerson study, although a trend was found between younger and older children in the Kröner-Herwig study (where the younger children reported higher levels of catastrophizing). Taken together, the results of the present study support the psychometric properties of the PCS-C and are mainly consistent with previous studies with regards to norm values.

All children, 7–18 years of age, who were being treated for cancer in Sweden at the time of the study were invited to participate in the study. Many respondents reported previous but not current pain. This may explain the low mean pain level. The fact that respondents could report pain retrospectively is a limitation of the study, which may have affected the reports of pain catastrophizing. Furthermore, there was no control question asking the respondent if he/she had any experience of pain during their cancer trajectory. This may have inferred that children or adolescents who had not experienced any pain participated in the study. Pain is, however, reported by

children and adolescents with cancer as one of the most frequent adverse symptoms during their cancer trajectory[44] and is likely to affect all children and adolescents with cancer, to some extent, at one time or another. In addition, the patient information specified that the study addressed children and adolescents with cancer and pain. The risk of including participants without pain experience is therefore considered small. Twenty-seven percent of the children participated in the study. Even though this response rate is realistic given the average proportion of participants in survey research nowadays and the difficult situation that these patients are in, this still limits the generalizability of the results of the study. Furthermore, the sample size is particularly low with regard to factor analysis, and the study should be seen as a preliminary validation of the PCS-C for the population. The participants were evenly distributed across the age span, showing that younger children participated in the same extent as older adolescents. A Swedish version of the PCS-C was used, which has been available and used frequently but has not been validated previously. In order to assess if and how this version differs from the original version in any cultural or linguistic aspect, it remains to be validated in equivalent samples as well.

Gender- and age-specific norm values for the PCS-C are now available for children and adolescents with cancer. Pain catastrophizing has been shown to predict pain and disability in pain and community samples. For children with cancer, the role of pain catastrophizing may be even more pronounced, given the implicit threat of the disease. Validated instruments and population-specific norm values in pediatric oncology enable identifying patients likely to benefit from therapeutic interventions as well as screening for patients at risk of developing more prolonged pain conditions, and hence the possibility to offer them preventive interventions. The psychometric properties of the PCS-C were supported. The factorial validity of the PCS-C does, however, deserve more investigation, including optimal number of items. Given the small sample of the study, the results should be seen as preliminary.

Acknowledgments

We would like to thank the Swedish Childhood Cancer Registry for identifying participants for our study. We would also like to thank the research nurses of the pediatric oncology centers in Sweden for your cooperation to ensure that no families with children who had gone into palliation or died were contacted. Lastly, we would like to thank our participants for taking the time to fill out the questionnaires. This work was supported by grants from the Swedish Childhood Cancer Foundation [PR2013-0058] and the Swedish Cancer Society [CAN2013/749].

Disclosure

Dr Jenny Thorsell Cederberg reports grants from Swedish Childhood Cancer Fund and grants from Swedish Cancer Society, outside the submitted work. The authors report no other conflicts of interest in this work.

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