Original Article

Psychometric properties of the Chinese version of the Parent Perception of Uncertainty Scale (PPUS) among parents of children with cancer diagnosis

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Objective: Parents of children diagnosed with cancer often experience high levels of illness uncertainty. This study evaluated the psychometric properties of the Chinese Version of the Parent Perception of Uncertainty Scale for Childhood Cancer (PPUS-CC) in Mainland China.

Methods: Exploratory factor analysis (EFA) and confirmatory factor analysis (CFA) were performed using study population of 420 parents. The participants were also given the social support questionnaire and assessed using the Self-Rating Anxiety Scale, Zarit Burden Interview, and Self-Rating Depression Scale to test the association with PPUS-CC and obtain the cut-off of the scale.

Results: The Chinese version of PPUS-CC includes 14 items, and two factors were extracted by EFA, which could explain the 54.56% variances. The Cronbach’s α of two factors ranged from 0.830 to 0.877. The dimensions of PPUS-CC show statistical association with other scales, and the cut-off is 42.5.

Conclusion: The Chinese version of PPUS-CC, as a reliable, valid, and easy-to-use clinical tool, can be adapted in clinical settings as a screening tool to recognize parents with high-risk psychological problems.

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intensive care). Furthermore, parental experience of IU has changed due to the development of medical techniques and treatment since 1980s, and new research should be conducted to test whether PPUS can still efficiently measure the IU of parents. In addition, varying cultures may affect the understanding of the scale, and Eastern people adapt to their social environments in manners that are sometimes different from those of Western people, particularly in traumatic events. For example, many Chinese cancer patients use more distraction strategies against emotional distress and are inclined to suppress their desires or emotional needs in the process of cancer treatment, whereas Western patients tend to seek help from physicians or organizations. The associated stigma with pediatric cancer also prevents Chinese parents from explicitly seeking social support, limiting their opportunity to reduce their level of IU. To the authors' knowledge, although the relationships between IU and parental adjustment have been well established [8–11], no study has validated the Parent Perception of Uncertainty Scale for Childhood Cancer (PPUS-CC) in Mainland China. Also, only one study has examined the psychometrics of the PPUS in Western countries since its first introduction [12]. Therefore, the present study was undertaken to fill this gap and was designed to (1) evaluate the psychometrics of the Chinese version of the PPUS-CC in a sample of Chinese parents whose children were diagnosed with cancer, (2) test whether a high level of IU among the parents indicates worse psychological functions (increased levels of anxiety, and depression), and (3) obtain a cut-off of PPUS-CC to help medical staff recognize parents with high risk of emotional distress.

2. Methods

2.1. Participants and procedures

Participants were recruited from a specialist cancer hospital in Guangdong Province between September 2013 and December 2014. The participants were randomly divided into two groups: Sample 1 and Sample 2 for EFA and CFA, respectively. The inclusion criteria were: (1) children diagnosed with cancer, (2) can read and write in Chinese, (3) fluency in oral Mandarin or Cantonese, (4) the children are receiving treatment lasting for less than 1 year, and (5) only one parent is included the study if both are present. Exclusion criteria are as follows: (1) not Chinese, (2) children are in the phase of palliative treatment, and (3) unwillingness to enroll in the study. Written informed consent was obtained before the administration of the scale booklet. On average, parents took 20–35 min to finish the booklet. After four weeks, 30 of the participants completed the PPUS-CC again. This study was approved by the Ethics Committees of the hospital.

2.2. Translation and revision

According to international guidelines, the PPUS-CC was translated into Chinese version by two of the researchers fluent in English and Chinese after obtaining written permission from the original designer of the scale. The two translations were found to have many items of semantic repetition and confuse parents in Chinese context; thus, we held a meeting asking six professors majoring in psychology, including clinical psychology, oncology psychology, and psychometrics, and nine clinical nursing professors, including clinical nursing, oncology psychology, and instruments, to revise the scale. Content validity index (CVI), including item-level CVI (I-CVI) and scale-level CVI, was applied to evaluate the content validity of the revised Chinese scale [13]. Also, adjusted kappa index (K) was used to counter the effect of chance agreement (Pc) on the I-CVI: \[ K = \frac{1}{n} \left( \frac{1}{n} \sum_{i=1}^{n} (P_j - P_c)(1 - P_c) \right) \] [14]. According to statistical standard, I-CVI should be more than 0.78 if the number of participating professors exceed six, and K should be more than 0.60 (0.74 or more is better). Some results of discussion were as follows (complete results are shown in Table 1): Item 31 “The doctors and nurses use everyday language so I can understand what they are saying” was retained, whereas items 5 and 9 were deleted. In addition, item 11 “I can predict how long my child’s illness will last” was preserved, whereas items 7 and 23 were deleted accordingly. Also, item 13 “It is difficult to know if the treatments or medications my child is getting are helping” was chosen instead of item 21. Among items 3, 18, and 19, item 3 “I am unsure if my child’s illness is getting better or worse” was chosen and the other ones were deleted. Moreover, items 25, 26, 28, and 30 were merged to item 28 “My child’s diagnosis is definite and will not change.” Item 8 “My child’s symptoms continue to change unpredictably” was retained instead of item 16. All experts argued that item 29 had low associations with the whole scale; thus, this item was deleted. Finally, we ended with a 19-item revised PPUS-CC based on the professors’ suggestions in the meeting (Table 2).

2.3. Measures

2.3.1. Demographics

The questionnaire includes the parents’ demographic characteristics (e.g., age, gender, and marital status) and clinical variables about their children’s diagnosis and treatment (e.g., duration of treatment and confirmed diagnosis).

2.3.2. Parental Perception of Uncertainty Scale for Childhood Cancer (PPUS-CC)

The revised PPUS-CC is a 19-item tool examining the IU of parents about their child’s illness by reporting how they agreed to the whole 19 statements. Items are rated based on a 5-point Likert scale: 1 “strongly disagree,” 2 “disagree,” 3 “uncertain,” 4 “agree,” and 5 “strongly agree.” The score ranges from 19 to 95, and a high score suggests high level of IU.

2.3.3. Social Support Questionnaire (SSQ)

This instrument is used in this study to measure the parents’ perceived social support during the cancer treatment [15]. A high score indicates high level of social support. Previous studies reported that social support is associated with IU, and this scale was applied to test the criterion validity of PPUS-CC [9,16].

2.3.4. Self-Rating Anxiety Scale (SAS)

This scale is a 20-item tool used to assess perceived anxiety of participants [17]. A high score indicates high level of anxiety, IU is positively associated with anxiety, and SAS is used to test the criterion validity of PPUS-CC [10,18].

2.3.5. Self-Rating Depression Scale (SDS)

This scale is also a 20-item tool and is used to assess perceived depression of participants [19]. A high score indicates high level of depression. IU is positively associated with depression, and SDS was used to test the criterion validity of PPUS-CC [10,20].

2.3.6. Zarit Burden Interview (ZBI)

This scale is a 22-item analytically derived questionnaire used to assess the perceived caregiver burden among enrolled subjects [21]. A high score indicates high level of caregiver burden. According to previous studies, parents with high levels of IU have high levels of care burden [9,11]. Therefore, we used the ZBI to test the convergent validity of PPUS-CC.
Table 1
The retained and deleted items (semantic repetition) of PPUS-CC based on professors’ suggestions in the conference.

| Item in this study | Item in the original study | Original Dimension | I-CVI | \( P_e \) | K | Result |
|-------------------|----------------------------|--------------------|-------|------|---|-------|
| Cluster 1         |                            |                    |       |      |   |       |
| 5                 | Lack of Clarity            |                    | 0.47  | 2.0  | -1 | 0.34 deleted |
| 9                 | Lack of Clarity            |                    | 0.53  | 2.0  | -1 | 0.42 retained |
| 31                | Lack of Clarity            |                    | 0.53  | \( 4.6 \times 10^{-9} \) | 0.93 | retained |
| Cluster 2         |                            |                    |       |      |   |       |
| 3                 | Ambiguity                  |                    | 0.80  | \( 1.4 \times 10^{-1} \) | 0.80 | retained |
| 18                | Ambiguity                  |                    | 0.40  | 1.5  | -1 | 0.29 deleted |
| 19                | Ambiguity                  |                    | 0.47  | 2.0  | -1 | 0.34 deleted |
| Cluster 3         |                            |                    |       |      |   |       |
| 7                 | Lack of Clarity            |                    | 0.33  | 9.2  | -2 | 0.27 deleted |
| 11                | Unpredictability           |                    | 0.73  | \( 4.2 \times 10^{-2} \) | 0.72 | retained |
| 23                | Unpredictability           |                    | 0.40  | 1.5  | -1 | 0.29 deleted |
| Cluster 4         |                            |                    |       |      |   |       |
| 25                | Ambiguity                  |                    | 0.40  | 1.5  | -1 | 0.29 deleted |
| 26                | Lack of Information        |                    | 0.33  | 9.2  | -2 | 0.27 deleted |
| 28                | Lack of Information        |                    | 0.87  | \( 3.2 \times 10^{-3} \) | 0.87 | retained |
| 30                | Lack of Information        |                    | 0.27  | 4.2  | -2 | 0.23 deleted |
| Cluster 5         |                            |                    |       |      |   |       |
| 8                 | Ambiguity                  |                    | 0.93  | \(4.6 \times 10^{-6}\) | 0.93 | retained |
| 16                | Ambiguity                  |                    | 0.53  | 2.0  | -1 | 0.42 deleted |
| Cluster 6         |                            |                    |       |      |   |       |
| 13                | Ambiguity                  |                    | 0.87  | \(3.2 \times 10^{-1}\) | 0.87 | retained |
| 27                | Ambiguity                  |                    | 0.67  | 9.2  | -2 | 0.63 deleted |
| Cluster 7         |                            |                    |       |      |   |       |
| 29                | Lack of Clarity            |                    | 0.00  | 3.1  | -6 | 0.00 deleted |

\( P_e = n!(A!(n-A)!)/(A!(n-A)!)) \times 0.5^n; \ K = (I-CVI - \( P_e \))/(1 - \( P_e \)). Bolded items indicated they should be retained.

2.4. Statistical analysis

2.4.1. Critical Ratio (CR) and Popular Level (PH)

Parents with different levels of IU were classified into high and low IU groups using CR to determine whether the item has enough power of discrimination [22]. DI is equal to the value of PH in high IU group minus PH in low IU group. According to statistical standard, items with CR value lower than 3 or DI lower than 0.3 should be deleted, and CR higher than 4 and DI higher than 0.4 are recommended [22].

2.4.2. Construct validity

EFA was performed in Sample 1 (EFA group), and principal axis factoring with direct oblimin rotation was undertaken to identify derived factors. Items with factor loadings >0.40 were retained, and if an item was loaded on different factors, then theoretical understanding and parsimony should be conducted [23]. The EFA-derived structure of PPUS-CC was first investigated using Velicer’s Minimum Average Partial (MAP) Test, and a parallel analysis was performed to re-evaluate the scale structure [24,25]. CFA is conducted by structural equation modeling (SEM) technique in Sample 2 (CFA group). With all parameters appearing in order and no special problems arising during optimization, the X² test and measures for goodness of fit [e.g., comparative fit index (CFI) and goodness fit index (GFI)] are reviewed [26]. The magnitude of the standardized coefficients should be >0.40, and no item should be loaded on different factors in the model. Also, residual item between different factors is prohibited except for specific reasons.

2.4.3. Reliability

Cronbach’s α was applied to test the internal consistency of PPUS-CC. Cronbach’s α above 0.70 is acceptable, and 0.80 or more is recommended [26]. The test–retest reliability was measured via Spearman’s correlations on 30 parents with a four-week interval [27].

2.4.4. Cut-off of PPUS-CC

People (anxiety ≥40 or depression ≥41) are recommended for medical intervention in Chinese population [28]. Thus, the parents in this study were divided into two groups, namely, high-risk group (anxiety ≥40, depression ≥41, or both) and low-risk group (anxiety <40 and depression <41). Then, we drew the ROC curve by using Youden index [29].

3. Results

3.1. Sample characteristics

A total of 420 participants were approached, and 396 answered the questionnaires. Nineteen respondents were excluded because these scales had incomplete or missing identification. Therefore, 377 parents were finally analyzed, and the response rate was 88.1%. Characteristics for Sample 1 (EFA group = 191) and Sample 2 (CFA group = 186) are presented in Table 3. No statistical difference was found between Sample 1 and Sample 2 in all kinds of demographics. Lymphoma
was the most common diagnosis among the children, constituting 35.0% of all the cancer diagnoses, followed by central nervous system (CNS, 27.1%) tumor and leukemia (17.5%).

3.2. Critical Ratio and Popular Level

Items 6 (CR = 2.2204, P = 0.026), 17 (CR = 1.8173, P = 0.072), and 18 (CR = 2.7295, P = 0.007) should be deleted according to statistical standard; thus, we obtained a 16-item version of PPUS-CC. Furthermore, items 12 (DI = 0.14) and 19 (DI = 0.18) should be deleted according to statistic standard. Finally, we got a 14-item version of PPUS-CC, which was then conducted by EFA.

3.3. Construct validity

3.3.1. EFA for construct validity

The Kaiser-Meyer-Olkin statistic was 0.835, and Bartlett’s test of sphericity was significant (Chi-Square = 688.972, P < 0.001). The communalities between the 14 items and the total score were all more than 0.30, indicating that these items were suitable for factor analysis. Ambiguity, lack of information, lack of clarity, and unpredictability are the four fundamental factors of uncertainty in Mishel’s theory. Therefore, factors of PPUS-CC were increased from one to four for potential analysis (Table 4). When the number of factors was fixed to one, the 14 items could explain 31.08% of PPUS-CC, but one item (Item 5) loading was below 0.30. When the number of factors was fixed to two, the explained variances increased from 31.08% to 54.56%. The two factors “Ambiguity” and “Comprehension” consisted of nine and five items, respectively. However, items 4 and 9 exhibited cross-loadings. Several items belonging to unpredictability subscale in the original PPUS became ambiguity-related items, and the items belonging to Lack of Information or Lack of Clarity became Comprehension-related items. When the number of factors was fixed to three, the structure of PPUS-CC began to exhibit overextraction due to the items extracted with negative loadings, and this structure was not recommended according to the statistical standards. When the number of factors was fixed to four, items with significant cross-loadings were identified, and this structure could not be explained by Mishel’s theory. In addition, the four-factor-solution was clustered with few items (three to four), and this structure was unstable. Therefore, we adapted the two-factor model of PPUS-CC for the reasons mentioned above. In addition, the MAP test shows that when the root was 2, we obtained the smallest average squared partial correlation and the smallest average 4th-power partial correlation of 0.0206 and 0.0011, respectively. In the parallel analysis, the first three eigenvalues from the actual dataset of the PPUS-CC scores were 4.4284, 1.6639, and 1.1675, whereas the corresponding first three 95th-percentile random-data eigenvalues were 1.6054, 1.4491, and 1.3566, which indicate that factor number should be fixed to two. Therefore, based on the MAP test and parallel analysis, we retained the two-factor structure in PPUS-CC.

3.3.2. CFA for construct validity

The final SEM for sample 2 is presented in Fig. 1. CFA confirmed the EFA-derived two-factor structure as all the regression weights obtained exhibited positive and highly significant ones (all above 0.4) and highly satisfactory fit indexes, including Chi-square = 119.12, P < 0.001, TLI = 0.914, CFI = 0.922, GFI = 0.915, NFI = 0.832, IFI = 0.929, RFI = 0.887, RMR = 0.066, and RMSEA = 0.043. In addition, several paths of covariance between error terms were added to the SEM, resulting in an improved fitting model.

3.4. Criterion-related validity and reliability

PPUS-CC demonstrated criterion-related validity by its significant association with social support (r = 0.376, P = 0.01) and caregiver burden (r = 0.359, P < 0.01), anxiety (r = 0.382, P < 0.01), and depression (r = 0.422, P < 0.01). Correlations of the Comprehension factor were positively related to social support (P < 0.01, r = 0.371) and positively associated with emotional distress (anxiety and depression, P < 0.05), whereas the Ambiguity factor has positive correlations with caregiver burden (P < 0.01, r = 0.219) and emotional distress (anxiety and depression, P < 0.01). Cronbach’s α for the whole scale of PPUS-CC was 0.925, and the two factors ranged from 0.830 to 0.877. The test–retest correlation coefficient of PPUS was 0.880.

3.5. Cut-off of PPUS-CC to discriminate parents with different levels of emotional distress

The cut-off of PPUS-CC was 42.5 with a maximum Youden Index of 0.481, and the sensitivity and specificity of PPUS-CC were 0.708 and 0.773 respectively, suggesting that medical staff should pay more attention to parents with IU score higher than 42.5.

Table 3

| Characteristics | Total (n = 377) | EFA Group (n = 191) | CFA Group (n = 186) | X² | P |
|----------------|---------------|-------------------|--------------------|----|---|
| Age (>30)      | 234 (62.1)    | 121 (63.4)        | 113 (60.8)         | 0.2702 | 0.6032 |
| Is The Caregiver| 311 (87.8)    | 163 (85.3)        | 168 (90.3)         | 2.1835 | 0.1395 |
| Education Level(high school or more) | 249 (66.0) | 129 (67.5) | 120 (64.5) | 0.3841 | 0.5354 |
| Marital Status(married) | 315 (83.6) | 112 (58.6) | 103 (55.4) | 0.4903 | 0.5223 |
| Unemployment   | 231 (61.8)    | 114 (59.7)        | 119 (64.0)         | 0.7356 | 0.3911 |
| Residence(city dweller) | 141 (37.4) | 69 (36.1) | 72 (38.7) | 0.2688 | 0.6042 |
| Insurance(none or partial) | 158 (41.9) | 80 (41.9) | 78 (41.9) | 0.0001 | 0.9920 |
| Duration Of Treatment(/>6 Month) | 124 (32.9) | 64 (33.5) | 60 (32.3) | 0.0067 | 0.7962 |
| Religious Beliefs | 41 (10.9) | 21 (11.0) | 20 (10.8) | 0.0057 | 0.9398 |
| Confirmed Diagnosis | | | | 4.3389 | 0.5017 |
| Leukemia       | 66 (17.5)     | 36 (18.8)         | 30 (16.1)          | | |
| Lymphoma       | 132 (35.0)    | 70 (36.6)         | 62 (33.3)          | | |
| Skeletal tumor | 38 (10.1)     | 15 (7.9)          | 23 (12.4)          | | |
| Rhadomyosarcoma | 23 (6.1)     | 9 (4.7)           | 14 (7.5)           | | |
| CNS-tumor      | 102 (27.1)    | 54 (28.3)         | 48 (25.8)          | | |
| Other/unspecified | 16 (4.2) | 7 (3.7) | 9 (4.8) | | |
4. Discussion

IU is an important concept that impact pediatric cancer, but this problem has not been fully studied in Mainland China due to lack of proper tools. Although several studies explored the relationships between IU, psychological change distress, and personal growth among Chinese parents [30–32], these studies were all conducted in Taiwan, which is different compared with cities in Mainland China due to the different development of economic. Moreover, none of these studies reported specific psychometrics of the Chinese version of PPUS-CC in their English or Chinese publications. Therefore, this study is designed to translate the Chinese version of PPUS-CC and evaluate its psychometric properties because a tool suitable in one society or culture may not be appropriate in another. In this study, the translated scale was first examined by 15 professors majoring in psychology and clinical nursing, and we found repetition semantics to be cross different items in Chinese context. Then, we revised the scale and obtained a 19-item version of PPUS-

Table 4
Final item loadings for different factor models based on the 14-item version of PPUS-CC.

| Item Number | One-factor model | Two factor-model | Three factor-model | Four factor-model |
|-------------|------------------|------------------|--------------------|------------------|
|             | 1                | 1                | 2                  | 3                |
| 1           | 0.411            | 0.588            | 0.512              | -0.403           |
| 2           | 0.612            | 0.521            | 0.437              | 0.456            |
| 3           | 0.723            | 0.759            | 0.724              | -0.535           |
| 4           | 0.693            | 0.694            | 0.412              | 0.651            |
| 5           | NA               | 0.536            | 0.707              | 0.511            |
| 7           | 0.516            | 0.695            | 0.707              | 0.654            |
| 8           | 0.549            | 0.697            | 0.706              | 0.625            |
| 9           | 0.594            | 0.413            | 0.623              | 0.456            |
| 10          | 0.545            | 0.601            | 0.611              | 0.483            |
| 11          | 0.591            | 0.709            | 0.711              | 0.553            |
| 14          | 0.565            | 0.687            | 0.412              | -0.769           |
| 15          | 0.453            | 0.606            | 0.431              | -0.568           |
| 16          | 0.554            | 0.657            | 0.642              | -0.355           |
| Cumulative Variances | 31.08% | 54.56% | 60.41% | 69.59% |
| Cronbach α | 0.825            | 0.830            | 0.877              | 0.794            |
| Factor correlations | NA  | 0.388 | 0.152–0.251 | 0.203–0.291 |

Bolded item loadings indicate the factor the items loaded on. Italicized item loadings indicate cross loadings between the factors.

Fig. 1. Final CFA model of the Parental Perception of Uncertainty Scale for Childhood Cancer (PPUS-CC). IU, Illness uncertainty.
CC based on suggestions in the conference. Then, the CR, PH, DI, content validity, construct validity, reliability, and cut-off of this tool were assessed according to relevant statistical standards. The two-factor structure suited well, and the first, named “Ambiguity,” and second factors, named “Comprehension,” accounted for 54.56% of the variance in PPUS-CC. Several items belonging to unpredictability subscale in the original PPUS became ambiguity-related items, and items belonging to Lack of Information or Lack of Clarity now became Comprehension-related items. Factor structure in the original scale was also changeable in analyses conducted by Mishel at different times, suggesting that transferring these items theoretically and logically from one factor to another was alright [33–35]. The structure of PPUS-CC is different from that of PPUS developed by Mishel for some reasons. First, our study consists of homogenous parents of children with cancer, whereas Mishel’s includes parents of children both diagnosed with different acute and chronic illnesses. Second, contemporary treatments, including all kinds of surgeries, medications, and examinations, for pediatric cancer are much more advanced and complex at present than 30 years ago, possibly increasing parents’ IU. Meanwhile, parents are provided with more information from physicians than in the past years, reducing IU of parents in some way. Moreover, parents can conveniently seek additional information via the internet, which was not available in the 1990s, and dimension of “lack of information” may not be salient in such context. Third, oblique rotation was performed in this study to improve discriminate validity of the factors, whereas varimax rotation was conducted in Mishel’s study. In addition, according to previous research, the cut-off of PPUS was suggested to be 50% of the total score [36,37], but the cut-off of PPUS-CC in this study is higher at 42.5 of 70. Also, we should be cautious about this cut-off due to its low sensitivity ($\alpha = 0.708$), and further studies are warranted. Parents with low educational attainment and children with CNS tumor have the highest level of IU in this study, and this group is susceptible to emotional distress. Therefore, medical staff should pay more attention to this parent group to achieve the best effectiveness of psychological interventions.

5. Limitations

Several limitations of this study should be considered. First, the study is limited by its cross-sectional nature, and further studies are warranted to test the scalability of PPUS-CC throughout the disease trajectory. Second, all parents were recruited from one cancer hospital, and this condition may affect the generalizability of findings in this study. Third, we did not compare the IU levels of parents of children with different cancer in this study, and more studies are warranted to verify if PPUS-CC has the convergent validity to discriminate parents of children with different cancers.

6. Conclusion

PPUS-CC is an important instrument for understanding the IU of parents whose children were diagnosed with cancer and can be used as a salient indicator of parents’ emotional distress. It can be used as a quick screening tool to recognize parents with high psychological risks.

7. Implication for clinical practice

Translation and application of the PPUS-CC is the first step to manage parents’ IU. Future studies should update the content of this tool to improve application in the modern clinical settings.

Conflict of interest

The authors have no funding or conflicts of interest to disclose.

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Appendix A. Supplementary data

Supplementary data related to this article can be found at http://dx.doi.org/10.1016/j.jnss.2017.05.004.

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