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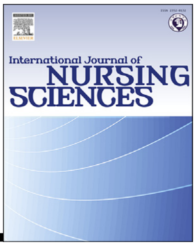

Psychometric properties of the Chinese version of the Parent Perception of Uncertainty Scale (PPUS) among parents of children with cancer diagnosis

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ABSTRACT

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.

1. Introduction

Approximately 25,000 children (0–14 years) were diagnosed with cancer in 2016 in China [1]. Although medical developments have improved the survival rate of children with different cancers, the disease is still the second most common cause of mortality children aged 0–14 years next to accidents [1]. When their child is diagnosed with cancer, parents experience considerable stressful events and are haunted by disbelief, emotional distress (e.g., anxiety and depression), and shock throughout the cancer treatment [2]. In addition, they experience high levels of illness uncertainty (IU), particularly in the first three months of the cancer treatment. IU is defined as a sense of loss of control and a perceptual state of doubt that changes over time [3]. Persistent uncertainty becomes a source of chronic stress that can interfere with parents' normal functions and intensify negative moods. IU was originally proposed to understand the patients' adjustment to acute illness [4] and was later used in cancer to explain the relationships between IU, maladaptive copings, and psychological distress [5]. The Mishel Uncertainty in Illness Scale and some revised versions, including a 31-item Parent Perception of Uncertainty Scale (PPUS) assessing uncertainty among parents, have been developed to measure the levels of IU among patients and their relatives [6,7]. However, the original PPUS was validated within a sample of parents or grandparents of hospitalized children with different acute or chronic disease (e.g., those under surgical, rehabilitative, and neonatal

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Abbreviations: CNS-tumor, Central Nervous System Tumor; EFA, Exploratory Factor Analysis; CFA, Confirmatory Factor Analysis.

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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 (P_c) on the I-CVI [$P_c = n!/(A!\ x(n\text{-}A)!] \times 0.5^n$, n = the number of professor participated, A = the number of professor regarding the item as important; K = [I-CVI- P_c)/(1- P_c)] [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.

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