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Evaluating the Reliability and Validity of the Arabic Version of the Parents Perceptions of Uncertainty Scale (A-PPUS)



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ABSTRACT

Background: Uncertainty often accompanies illness and may be a major aversive component of the patients' treatment process. There is evidence that parental uncertainty has a negative impact on their own and on their child's coping strategies and may affect family functioning. Key to the provision of competent care, to address uncertainty, is the use of an appropriate validated assessment tool to understand key parental concerns. The 'Parent Perception of Uncertainty Scale' (PPUS) has been widely used for this purpose.

Aim: This study reports on the validity and reliability testing of the Arabic version of the Parents Perception of Uncertainty Scale (A-PPUS).

Methods: The scale was translated to Arabic using the translation-back-translation method. Appropriate statistical tests were performed including measurements of internal consistency, item to total scale correlation, and univariate and multivariate analyses.

Results: The study included 240 parents of children with chronic illnesses. Cronbach's alpha coefficient of the whole scale was 0.93. All the items were positively correlated to the total score. The univariate and multivariate analysis supported the previous tests and the assertion that the Arabic version of the PPUS provided a relevant measure of the uncertainty level.

Conclusion: This study has identified that the A-PPUS is a reliable tool for parent report of their uncertainty, in the UAE and Arabic population.

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Introduction and Background

Linguistically, uncertainty is the state of being unsure, not fully decided, or in doubt (Meriam-Webster, 2015). Uncertainty in illness, on the other hand, is the inability to comprehend illness-related events and their outcomes. Illness times are transitional in nature; illness can be unpredictable, variable in course of development and may involve complex treatment regimens, especially chronic illness. Therefore, uncertainty often accompanies illness and may be a major aversive component of the patients treatment process (Bailey et al., 2011; Mishel, 1983a,b; Mishel, 1988; Sajjadi, Rassouli, Abbaszadeh, Alavi Majd, & Zendehdel, 2014).

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Uncertainty in illness has been shown to have a negative impact on the life of adult patients (Bailey et al., 2010; Carroll & Arthur, 2010; Hagen et al., 2015; Mauro, 2010), parents of children who are unwell (He, You, Zheng, & Bi, 2016; Kerr & Haas, 2014; Lin, Yeh, & Mishel, 2010; Page et al., 2012; Stewart, Pyke-Grimm, & Kelly, 2012), and child and adolescent patients (Boyse, Gardner, Marvicsin, & Sandberg, 2014; Hommel et al., 2003; Ju et al., 2011; Van Pelt, Mullins, Carpentier, & Wolfe-Christensen, 2006). This uncertainty can be heightened, and is associated with worse outcomes, in patients with chronic health conditions (Hoth et al., 2015). In fact, adapting to life during illness and negotiating the associated uncertainty has been identified as a major concern for patients, something which was possibly a source of more stress than the illness itself (Perrett & Biley, 2013; Walsh & Hegarty, 2010).

In adult patients, various negative consequences of increased uncertainty were reported in the literature, including: high levels of anxiety and distress (Carroll & Arthur, 2010; Mauro, 2010; Wolfe-Christensen,

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Isenberg, Mullins, Carpentier, & Almstrom, 2008); lower quality of life, depressive symptoms, fatigue, and increased perceptions of pain (Bailey et al., 2009); reduced motivation to seek and adhere to treatment (Apostolo, Viveiros, Nunes, & Domingues, 2007); avoidant, passive coping, and affective disturbances during stressful times (Reich, Johnson, Zautra, & Davis, 2006); and deterioration of psychological, physical and functional status in patients with critical conditions (McCormick, Naimark, & Tate, 2006).

Parents of children with complex chronic illnesses described unique types of uncertainty relevant to them, including: uncertainty regarding their child's ability to be "normal" in the future; the "parental proxy uncertainty" which denotes their obligation to act on behalf of their child; and the "social stigma uncertainty" which refers to the potential effect of social stigma on their child in the future (Kerr & Haas, 2014; Stewart et al., 2012). There is evidence that parental uncertainty has a negative impact on their own and on their child's coping strategies and may affect family functioning (Brenner et al., 2016; Lin et al., 2010; Page et al., 2012; Ryan et al., 2011; Steele, Aylward, Jensen, & Wu, 2009). It is acknowledged in the literature that parents go through a process of reordering of their life priorities to accommodate the needs arising from their child illnesses (He et al., 2016) and early studies in this field suggest a potential link between parental uncertainty and the occurrence of posttraumatic stress in such parents (Santacroce, 2003).

The negative effects of uncertainty have also been reported in, and associated with, the younger population. For example, in adolescents with a chronic condition uncertainty has been associated with an increased tendency to self-focus and heightened levels of psychological distress (Hommel et al., 2003; Van Pelt et al., 2006). This is often manifested by anxiety and panic (Ju et al., 2011) health communication problems, inability to determine an appropriate healthcare provider, and a desire for extra social and professional support to make care decisions and choices (Boyse et al., 2014).

To address this uncertainty, and to support parents and children, a number of interventions and strategies have been suggested in the literature. For example, the provision of adequate information and health education for parents and children is widely reported as a critical component to addressing this issue (Alligood & Tomey, 2013; Brashers, 2007; Brashers & Hogan, 2013; Komatsu & Yagasaki, 2014; Mishel, 1983a,b; Mishel, 1997; Mishel et al., 2009). It is important however that any intervention should take place in a timely, planned, structured, individualised and family-centered method to be most efficient (Boyse et al., 2014; Hagen et al., 2015; Komatsu & Yagasaki, 2014; Mishel et al., 2009; Mishel, 1988; Mitchell & Courtney, 2004; Walsh & Hegarty, 2010). Key to the provision of such individualised care is an appropriate validated assessment of the needs of the family in the first instance and the 'Parent Perception of Uncertainty Scale' (PPUS) (Mishel, 1983a,b) has been widely used for this purpose. This tool was developed from the original 'Mishel Uncertainty in Illness Scale' (MUIS) which was developed in 1980 and both assessment tools have been widely used and translated in to many languages.

Study Purpose

This study reports on the validity and reliability testing of the Arabic version of the Parents Perception of Uncertainty Scale (A-PPUS), it also describes the general uncertainty levels of parents of children with a chronic illness.

Design and Methods

Parents Perceptions of Uncertainty Scale (PPUS) Translation and Pilot Study

The PPUS is a self-administered questionnaire for parents of children with a spectrum of health problems, and is of particular relevance for parents of children with a chronic illness. The questionnaire consists of 31 questions which are designed to measure four sub-aspects of uncertainty: illness ambiguity, lack of clarity, lack of information, and unpredictability. Each question is rated by respondents on a 5-point Likert scale ranging from 1, strong disagreement, to 5, strong agreement with the item statement.

There is no Arabic version of the PPUS questionnaire; therefore it was translated by a professional translation service and a bilingual member of the research team. The Arabic translated questionnaires were then compared and agreement was reached on the final Arabic version. Discussions also took place between the translation team and the team member who was bilingual about the suitability of the language and the terms used for the local Arabic culture and the local healthcare system. The Arabic version was then back translated into English by another bilingual healthcare professional and a professional translator. A comparison between the English versions was then performed to ensure no major discrepancies existed. Fig. 1 highlights the process of questionnaire translation.

The clarity and readability of the translated questionnaire was examined during an initial pilot study which involved purposefully recruiting 25 parents who were visiting the Out Patient Department (OPD) with their children. A content validity questionnaire was developed, using all the items that would formulate the final questionnaire. Participants were asked to read each item and to rate it on a fourpoint scale for clarity, readability and appropriateness of the wording used, the threshold to consider an item as valid was based on that item achieving a score above 3 based on established criteria. No modification was required based on the results of the pilot study.

Study Participants

Two hundred and forty participants were recruited for this study using a convenience sampling strategy. The sample size was calculated to give a 95% power level, a medium effect size (0.3), and 0.05 α value. This calculation was done using the G*Power software V 3.0.10. The sample size also met the criteria set out by Streiner and Norman (2003), which recommends approximately 8–10 participants per item in validity studies. As the PPUS questionnaire contains 31 items, a



Fig. 1. The translation process of the questionnaire.

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