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Polish translation and cross-cultural adaptation of the Caregiver Priorities and Child Health Index of Life with Disabilities questionnaire

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Abstract: The aim of this study was to translate and adapt the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD) questionnaire into the Polish language, and to test the reliability and validity of CPCHILD scores of children with cerebral palsy (CP). Methods: This study consisted of two parts: the translation and transcultural adaptation of the English version of the CPCHILD into Polish language and the validity testing of the Polish version of the CPCHILD. Patients: Parents of non-ambulatory children with CP aged between 5 and 18 years. All of the 25 children with cerebral palsy were classified using the Gross Motor Function Classification System as level V. Results: The Polish version of CPCHILD yielded similar test-retest reliability and score distributions across the GMFCS level as the original version. The best correlations were observed for domains that are close to the functional deficits. Conclusion: This study shows that the Polish version of CPCHILD, the same as English version, is a disease specific measure of the caregivers' perspective, is reliable and internally consistent, and can be reliably used to evaluate the health-related quality of life in Polish patients with CP from the caregivers' perspective.

Key words: Caregiver Priorities and Child Health Index of Life with Disabilities, transcultural adaptation, validation

Introduction

Cerebral palsy (CP) is the most common cause of chronic childhood disability, and occurs in 2.0 children per 1000 live births (1-4). CP is a group of permanent disorders of the development of movement and posture, causing limitations of activity, arising from an injury to the developing brain (5). Non-ambulatory children (25% up to 35%) are classified as levels IV and V in the Gross Motor Function Classification System (6). In these children reduced activity may lead to a reduced quality of life, compared to their typically developing peers (7-9). Recently the measures of health-related quality of life in patients with CP were of much interest, and various assessment tools and questionnaires have been developed. The Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD) was developed in 2006, to assess the health-related quality of life of children with severe developmental disabilities from the perspective of caregivers for population for Canadian children (3). It consists of 37 items over seven domains: Personal care/Activities of Daily Living, Positioning, Transferring and Mobility; Comfort and Emotions; Communication and Social Interaction; Health; and Overall Quality of Life. The aim of this study was to translate and adapt the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD) questionnaire into the Polish language, and to test the reliability and validity of CPCHILD scores of children with cerebral palsy (CP).

Methods

This study consisted of two parts: the translation and transcultural adaptation of the English version of the CPCHILD into Polish language and the validity testing of the Polish version of the CPCHILD.

Translation and transcultural adaptation were conducted according to published international recommendations (7,10). Permission was obtained from the developer to use and translate the

CPCHILD into Polish using the international guidelines. The original CPCHILD questionnaire and manual were translated and back translated. Inter-rater reliability was assessed by comparing the CPCHILD-scores of two parents for the same child who independently completed the CPCHILD on the same day.

Data on sex, age, type of limb involvement and Gross Motor Function Classification System (GMFCS) level were obtained. Participants were invited for the retest of reliability of the Polish CPCHILD 4 weeks after initial assessment.

Participants

Parents of non-ambulatory children with CP aged between 5 and 18 years. All of the 25 children with cerebral palsy were classified by neurologist, using the Gross Motor Function Classification System as level V. All of these children were diagnosed as having spastic quadriplegic CP.

All participating parents gave a written informed consent. Interviews were conducted face-to-face in the caregivers' homes.

The inclusion criteria were: primary caregiver – the most responsible for the day-to day caring of the child and who must have lived with the child for at least the previous 6 months.

This study received ethical approval from the local Ethics Committee.

Parents (mostly mothers) of 25 children participated in the study. The total score of the CPCHILD was approximately normally distributed. None of the participants achieved the lowest or highest possible score.

Statistics

Data were analyzed using SPSS for Windows (version 17). Test-retest and inter-rater reliability was estimated by using the Intraclass Correlation Coefficient including 95% confidence intervals. An ICC of >0.70 was regarded as indicative of good reliability.

Results

Primary caregivers of 25 children with CP, completed the questionnaire. Mean total CPCHILD score across GMFCS level was 49.8 (SD 11.1) for level V (Fig. 1).

Content validity of the CPCHILD was assessed by the parents' rating of the importance of each item's contribution to their child's quality of life on a 6-point scale from 1 (least important) to 6 (most important). The threshold value was set at a median of 3. There were no floor and ceiling effects, which indicate that this measure is appropriate for the target population. Parents rated all items more than slightly important, thereby confirming the test validity (Fig. 2). The mean importance rating for all items was 3.95. None was rated below the threshold value of 3 (slightly important). Test-retest reliability was assessed for all 25 caregivers of children with severe CP, who participated in the study, who completed a second administration of the CPCHILD 4 weeks after the first. Test-retest and inter-rater reliability was fairly good - all parents reported no change in health status during given interval.

Therefore, our study showed that the items in Polish version of CPCHILD are relevant to Polish caregivers, and rated as important for the assessment of quality of life of children with severe CP.

Discussion

The main rule of the long-term care of children with chronic incurable diseases, is to improve the quality of life of the whole family, through the interventions that maximize their independence, and ease the performance in activities of daily living. Measuring quality of life of non-ambulatory children with CP is challenging. Researchers assessing quality of life in children with CP, should have a valid, reliable, easy to administer, low cost instrument, suited to the cultural and societal background of the children involved. Although the primary lesion in the brain is non-progressive, the pathology is permanent and many of the secondary clinical consequences are acquired and progressive over time. CP has a substantial lifelong impact not only on the children, but also on their caregivers and families (3). Condition specific measures of quality of life, are needed for children with CP, to include all domains unique to the population group, such as physical functioning, adaptive equipment as well as psychosocial domains (11). Such instruments as the Child health Questionnaire (CHQ) and the pediatric Quality of Life Inventory (PedsQL), do not adequately represent quality of life in non-ambulatory children with CP, and CHQ has been shown to have significant floor effects (12-14). Other instruments e.g. cerebral Palsy Quality of Life (CPQOL), Pediatric Outcome data Collection Quality of Life (PODCI) also assume higher intellectual or motor abilities. Because most non-ambulatory children with CP are unable to express their perception of their health-related quality of life, clinicians have to rely on the caregivers perceptions of their children's quality of life (15,16). Adequate measures and questionnaires should focus on the areas, that are most important for child and family functioning, and should help to evaluate the patients' response to interventions or alteration in management, while also being easy to complete, analyze and access (3,17). Condition specific measures are preferable to a generic measures, because it address the aspects of life which are unique to a given population group.

The CPCHILD is specifically focused on children with greater physical impairment (children with GMFCS classifications III to V) and relies on parents' report of their child's quality of life (1,3). The outcome of CPCHILD can be used on an individual level to guide treatment, or to assess the effects of daily care, and on a group level, to establish the effects of interventions. The original version of CPCHILD, showed excellent test-retest reliability of the CPCHILD for the total, and for each of the domain scores (3). A systematic review found that the CPCHILD was one of the strongest measures of QOL in children with CP (18).

In order to have worldwide application of the assessment tools and questionnaires, translation and transcultural adaptation from the original version is necessary, while maintaining the original meaning (18,19). In addition, validity testing is necessary for the adapted version. Recently, translation and transcultural adaptation of the CPCHILD have been performed for the German and Brazilian Portuguese languages. Validity testing of the German CPCHILD showed relevant known-group validity, and test-retest reliability (19). In our study, the Polish version of CPCHILD yielded similar test-retest reliability as the original version, so it can be reliably used in clinical and research settings, to evaluate the health-related quality of life in Polish patients with severe CP.

Because of the wide age range that was used in our study, questions of validity of our results may arise. We believe that some further considerations of the appropriateness of questions across the spectrum of age is needed, as there may be variations in life experiences, present between children of different ages.

Conclusion

This study shows that the Polish version of CPCHILD, the same as English version, is a disease specific measure of the caregivers' perspective, is reliable and internally consistent, and can be reliably used to evaluate the health-related quality of life in Polish patients with CP from the caregivers' perspective.

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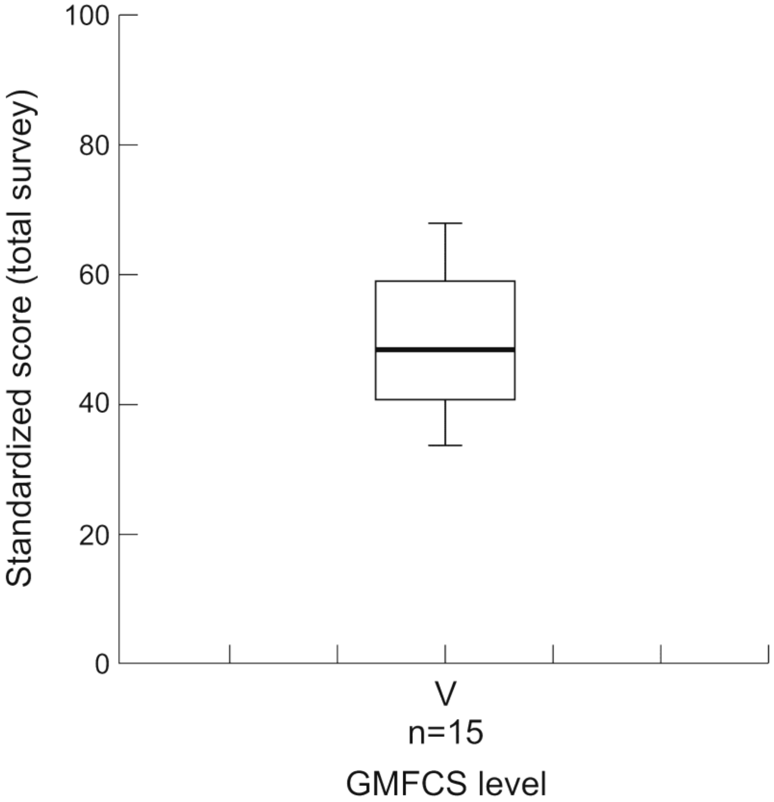

Figure 1. Box plot of median standardized total survey score for GMFCS level V. Box include median within interquartile range, whiskers illustrate range

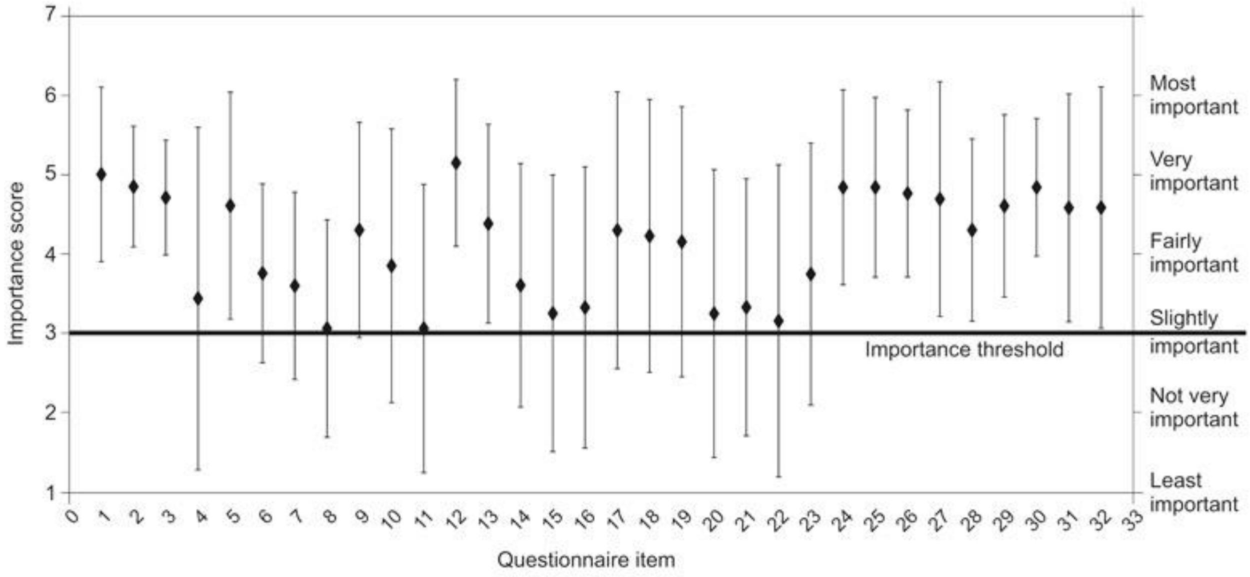

Figure 2. Mean importance scores with standard deviations. Importance scores of 3 (slightly important) was arbitrary chosen as threshold level of importance, below which items would be dropped or modified