

Validating the Cerebral Palsy Quality of Life for Children (CPQOL-Child) Questionnaire for Use in Sri Lanka

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Abstract : Background: The potentially high level of physical need and dependency experienced by children with cerebral palsy could affect the quality of life (QOL) of the child, the caregiver and his/her family. Poor QOL in children with cerebral palsy is associated with the parent-child relationship, limited opportunities for social participation, limited access to healthcare services, psychological well-being and the child's physical functioning. Given that children experiencing disabilities have little access to remedial support with an inequitable service across districts in Sri Lanka, and given the impact of culture and societal stigma, there may be differing viewpoints across respondents. Objectives: The aim of this study was to evaluate the psychometric properties of the Tamil version of the Cerebral Palsy Quality of Life for Children (CPQOL-Child) Questionnaire. Design: An instrument development and validation study. Methods: Forward and backward translations of the CPQOL-Child were undertaken by a team comprised of a physiotherapist, speech and language therapist and two linguists for the primary caregiver form and the child self-report form. As part of a pilot phase, the Tamil version of the CPQOL was completed by 45 primary caregivers with children with cerebral palsy and 15 children with cerebral palsy (GMFCS level 3-4). In addition, the primary caregivers commented on the process of filling in the questionnaire. The psychometric properties of test-retest reliability, internal consistency and construct validity were undertaken. Results: The test-retest reliability and internal consistency were high. A significant association ($p < 0.001$) was found between limited motor skills and poor QOL. The Cronbach's alpha for the whole questionnaire was at 0.95. Similarities and divergences were found between the two groups of respondents. The child respondents identified limited motor skills as associated with physical well-being and autonomy. Akin to this, the primary caregivers associated the severity of motor function with limitations of physical well-being and autonomy. The trend observed was that QOL was not related to the level of impairment but connected to environmental factors by the child respondents. In addition to this, the main concern among primary caregivers about the child's future and on the child's lack of independence was not fully captured by the QOL questionnaire employed. Conclusions: Although the initial results of the CPQOL questionnaire show high test-retest reliability and internal consistency of the instrument, it does not fully reflect the socio-cultural realities and primary concerns of the caregivers. The current findings highlight the need to take child and caregiver perceptions of QOL into account in clinical practice and research. It strongly indicates the need for culture-specific measures of QOL.

Keywords : cerebral palsy, CPQOL, culture, quality of life

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