



Determinants of quality of life in children with cerebral palsy: A comprehensive biopsychosocial approach



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ARTICLE INFO

Article history:

Received 23 July 2013

Received in revised form 2 December 2013

Accepted 4 December 2013

Available online 27 December 2013

Keywords:

Quality of life
Cerebral palsy
Determinants
ICF

ABSTRACT

This study investigated the determinants of quality of life (QOL) of children with cerebral palsy (CP) considering possible variables comprehensively from a biopsychosocial perspective by adopting the International Classification of Functioning, Disability and Health (ICF) and using a CP-specific QOL questionnaire. A total of 167 children with CP (mean age 9.06 years, SD 2.61 years) and their caregivers participated in this study. Children's QOL was measured by the Cerebral Palsy Quality of Life for Children (CP QOL-Child) – primary caregiver proxy-report form. The potential determinants of QOL were collected based on all ICF dimensions. Results of seven multiple regression models showed that the determinants of QOL in children with CP were multidimensional and biopsychosocial in nature, i.e., encompassing the domains of health condition, body functions and structures, and contextual factors of the ICF. Children's behavioral and emotional problems as well as caregiver's psychological and family-related factors were important determinants of QOL in children with CP. Knowledge of the determinants of QOL could serve as a guide in a holistic approach to evaluation and intervention targeted at these determinants to improve the QOL of children with CP.

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1. Introduction

Cerebral palsy (CP) is the most common cause of chronic disability in children (Rosenbaum et al., 2007; Surveillance of Cerebral Palsy in Europe, 2000) with a prevalence of 1.5–2.5 per 1000 live births (Oskoui, Coutinho, Dykeman, Jette, & Pringsheim, 2013). CP denotes a group of non-progressive disorders in development of movement and posture, which are ascribed to disturbances occurring in the developing fetal or infant brain (Rosenbaum et al., 2007). With its accompanying disabilities, CP not only impedes children's participation in daily activities (Rosenbaum et al., 2007) but compromises their quality of life (QOL) (Maher, Olds, Williams, & Lane, 2008; Pirpiris et al., 2006; Vargus-Adams, 2005; Varni et al., 2005).

QOL is defined as “an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (The WHOQOL Group, 1998).” In health care, health-related quality of life has been coined to assess how the individual's well-being may be affected by a disease, disability, or disorder to represent specifically health aspects of well-being (Bullinger, 2003). Compared to typically developing children, children with CP have reduced QOL (Maher et al., 2008; Pirpiris et al., 2006; Vargus-Adams, 2005; Varni

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et al., 2005). In 1991, the [United Cerebral Palsy Association \(1991\)](#) adopted the mission statement: “To affect positively the QOL of persons with cerebral palsy.” Improving QOL has then become a treatment goal for children with CP.

Children’s functioning and contextual factors have been shown to be correlated with the QOL of children with CP ([Arnaud et al., 2008](#); [Beckung et al., 2008](#); [Majnemer, Shevell, Rosenbaum, Law, & Poulin, 2007](#)). The International Classification of Functioning, Disability and Health (ICF), published by the WHO in 2001, is a comprehensive classification system for how health-related conditions affect people’s life. The ICF, encompassing all biopsychosocial aspects of human health and health-relevant components of QOL, not only offers a well-integrated and standardized approach to health care but also serves as a framework for building a comprehensive picture of possible factors that may influence the QOL of children ([WHO, 2001](#)).

Although a multitude of studies investigated the determinants of QOL of children with CP, only two multivariate studies took into consideration all dimensions of the ICF ([Arnaud et al., 2008](#); [Majnemer et al., 2007](#)). In these studies, determinants of QOL in each dimension of the ICF have been identified such as severity of gross and fine motor (health condition), cognitive functioning (body function and structures), communication (activity and participation), age (personal factor), and education placement (environmental factor). Yet, these studies had some limitations: (1) using generic rather than CP-specific QOL measures; (2) adopting QOL measures focusing on a child’s capability or limitations, i.e., physical functioning, instead of a child’s subjective perception of life as defined by the WHO.

Thus, this study was to identify the determinants of QOL of children with CP, considering possible variables comprehensively from a biopsychosocial perspective by adopting the ICF framework and using a CP-specific QOL questionnaire following the WHO’s definition of QOL. Results of this study could inform assessment and guide clinical intervention for improving QOL of children with CP.

2. Method

2.1. Participants

The participants of this study were part of a psychometric study of CP QOL-Child. The recruitment of subjects has been described in detail elsewhere ([Chen et al., 2013](#)). Briefly, 167 children with CP and their primary caregivers were recruited. These children were included if they were (1) diagnosed with CP; (2) aged between 4 and 12 years; and (3) their primary caregivers gave informed consent. Children were excluded if their primary caregivers were not able to communicate in Mandarin Chinese or Taiwanese. The protocol for this study received approval from the Institutional Review Board of the National Taiwan University Hospital.

2.2. Measure of QOL

The QOL of children with CP was measured with the Chinese version of the Cerebral Palsy Quality of Life for Children (CP QOL-Child)-primary caregiver proxy-report form. The CP QOL-Child is the first condition-specific QOL questionnaire designed for children with CP ([Waters et al., 2006](#)). Two versions of the CP QOL-Child are available: a primary caregiver-proxy report version for children aged 4–12 years, and a self-report version for children aged 9–12 years. The proxy version has seven domains: Social Well-being and Acceptance, Functioning, Participation and Physical Health, Emotional Well-being, Access to Services (proxy-report form only), Pain and Feeling about Disability, and Family Health (proxy-report form only). The proxy form contains 66 items. Almost all of the items have the following item stem: ‘How do you think your child feels about...’ and a 9-point rating scale, where 1 = very unhappy to 9 = very happy. For example, the domain “Functioning” measures caregiver’s perception of how the child feels about his functioning in the areas of the ability to play on his/her own, the way he/she communicates with people they know well, the way he/she uses his/her arms, and the way he/she uses their hands. Therefore, the domain “Functioning” measures a child’s subjective feelings about his or her functioning via his or her caregiver’s perception, instead of objective capability or limitations. Few items where this stem or rating scale is not appropriate, such as pain, have the following stem and rating scale: ‘How does your child feel about the amount of pain that they have,’ where 1 = not upset at all to 9 = very upset.

The reliability and validity of the CP QOL-Child have been established ([Waters et al., 2007](#)). The CP QOL-Child was cross-culturally translated into Mandarin Chinese, and the reliability and validity of the proxy-report form have been established ([Chen et al., 2013](#); [Wang et al., 2010](#)). Internal consistency ranges from .78 to .91 and 2-week test-retest reliability ranges from .86 to .97. The factor structure of the proxy-report form has been validated with principal components analysis ([Wang et al., 2010](#)) and confirmative factor analysis ([Chen et al., 2013](#)).

2.3. Measures of determinants of QOL

Measures of the potential determinants of QOL in children with CP were described according to the ICF as follows.

2.3.1. Measures of variables related to health condition

Variables related to children’s health condition (disease or disorder) were collected as follows: type of CP (including types of tonal abnormalities and anatomic distribution), severity of gross and fine motor impairment, and other diseases. Type of CP was based on a formal assessment by a pediatrician, pediatric neurologist, or physiatrist. Severity of gross motor

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