Determinants of Life Quality in School-Age Children with Cerebral Palsy

Annette Majnemer, PhD, OT, Michael Shevell, MD, CM, Peter Rosenbaum, MD, CM, Mary Law, PhD, OT, and Chantal Poulin, MD

Objective To characterize the quality of life of children with cerebral palsy from the parents' and children's perspectives.

Study design Ninety-five children were recruited; a parent, and when feasible, the child also completed the Child Health Questionnaire and Pediatric Quality of Life Inventory. A range of predictor variables was measured relating to impairments, activity limitations, personal and environmental factors.

Results Mean age was 9.3 ± 2.1 years; 63.2% were male, and almost half had mild motor impairment (47% Gross Motor Function Classification System level I). Mean physical well-being (Child Health Questionnaire) was 39.6 ± 16.9 with 50% <40; and mean psychosocial well-being was 43.0 ± 11.3 with 53.8% <40. Similarly, with the Pediatric Quality of Life Inventory, 61% had summary scores <1 SD. Scores of parents and their children were significantly correlated (physical: r = .59, $P <$ .0001; psychosocial: r = .39, P = .01); however, children rated themselves higher.

Conclusions Results indicate that quality of life is highly variable in children with cerebral palsy, with about half experiencing a life quality similar to typically developing children. Motor and other activity limitations are indicators of physical but not psychosocial well-being. Family functioning, behavioral difficulties, and motivation are important predictors of social-emotional adaptation. Determinants of life quality may guide resource allocation and health promotion initiatives to optimize health of the child and family. *(J Pediatr 2007;151:470-5)*

Children with cerebral palsy (CP) experience difficulties associated with limitations in everyday activities. Children with CP are at risk for lower participation in social and leisure activities.[1,2] Nonetheless, few studies have described their quality of life (QOL)—defined as a person's perception of their well-being and satisfaction with life.[3,4] This multidimensional construct includes elements about general functioning, as well as the person's appraisal of their life experiences and social/emotional well-being. Use of generic QOL measures provides information that is not specific to the disease process and enables one to compare perceived QOL with universal values.[5] Liptak et al[6] described the QOL of children and youth with moderate to severe CP with the Child Health Questionnaire[7] (CHQ). Mean scores were not provided, and no predictor variables were identified. Z scores above the normative mean occurred for Behavior and Mental Health subscales, whereas Physical Summary score and Impact on Parents-Time subscale were below −1 Z score. In a study by Wake et al,[8] mean CHQ scores were significantly lower than the norm of 50 ± 10. Severity of CP was predictive of physical well-being only. Cognitive level and epilepsy were not predictive of CHQ scores. Houlihan et al[9] assessed children and youth with Gross Motor Function Classification System (GMFCS) levels III-V also with the CHQ; however, scores were not described. There was a modest association between pain and the Parental Impact–Emotional subscale (r = .38, $P <$ .001). Another study of children with CP also identified lower CHQ scores, with better psychosocial scores compared with physical well-being scores. Consistent with previous studies, level of motor function was associated with physical well-being and parent impact domains.[10] Kennes et al[11] evaluated children with CP using the Health Utilities Index (HUI-3). Severity of CP was variably associated with most components of the HUI but not with pain or emotion. One study

See editorial, p 448 and related article, p 463

CHQ	Child Health Questionnaire	HUI-3	Health Utilities Index
CP	Cerebral palsy	PedsQL	Pediatric Quality of Life Inventory
DMQ	Dimensions of Mastery Questionnaire	QOL	Quality of life
GMFCS	Gross Motor Function Classification System	SD	Standard deviation
GMFM	Gross Motor Function Measure	VABS	Vineland Adaptive Behavior Scale

From the School of Physical & Occupational Therapy (A.M.), Departments of Neurology & Neurosurgery and Pediatrics (A.M., M.S., C.P.), McGill University, Montreal, Quebec; School of Rehabilitation Science (M.L.), Department of Pediatrics (P.R.), McMaster University, Hamilton, Ontario, Canada.

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Reprint requests: Annette Majnemer, PhD, OT, Montreal Children's Hospital, Division of Pediatric Neurology, 2300 Tupper Street, Room A-509, Montreal, Quebec, H3H 1P3. E-mail: Annette.majnemer@mcgill.ca.

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sought the perspective of children and youth with CP. QOL scores were lower than typically developing peers but similar to children with other chronic health conditions.[12] More than half of individuals with disabilities report a good to excellent life quality, whereas outside observers assume such lives to be undesirable.[13] Clarification is needed with respect to the perceived QOL of children with CP. Reported studies had samples with a wide age range (eg, 5-18 years); however, it may be important to differentiate children from adolescents.[14] With one exception,[15] studies to date have exclusively used parents as proxy respondents. The objectives of this study were to (1) characterize QOL of school-aged children with CP from the perspectives of the parents and the children themselves, and (2) evaluate biomedical, functional, and contextual factors as possible determinants of QOL. We hypothesized that contextual factors would be significantly positively associated with quality of life, whereas impairments and activity limitations would be less predictive, particularly of psychosocial well-being.[3,13,16-19]

METHODS

Design

In this historical cohort study, a sample of children diagnosed with CP by a single pediatric neurologist was recruited at school age (6-12 years) to ascertain health-related QOL. In this community, all children suspected of having CP are referred to a neurologist for diagnostic confirmation, etiologic determination, and medical management. Therefore this sample is believed to be representative of the population of children with CP. All files in the neurologist's database within July 1991-June 2001 with a diagnosis of CP were reviewed. Files that met the selection criteria were sent a letter and consent form, outlining the study aims and procedures.[20] Families who did not respond were called by the project coordinator to clarify procedures and determine whether they wished to participate. Once consent was obtained, an appointment was made for an evaluation at the Montreal Children's Hospital. A neurologist examined all children to verify the diagnosis of cerebral palsy. An occupational therapist interviewed the families using the Vineland Adaptive Behavior Scale[21] and carried out the Gross Motor Function Measure.[22] A psychologist performed the Leiter Intelligence Test.[23] While the child was assessed, parents completed questionnaires (see below). When feasible (determined by parent and interviewer, based on the child's cognitive abilities and concentration), children also completed the QOL measures. Parents completed a brief questionnaire on demographic data, type of schooling (segregated, integrated), and current rehabilitation services provided to their child. All evaluators were blinded to medical history and each other's findings. The study took 2.5 to 3 hours to complete, and rest periods were provided as needed. All measures selected were age-appropriate, standardized, with very good reliability and validity. Questionnaires were available in English and in French.

Subjects

The initial cohort in the database included 217 children with CP, and those who were school age during recruitment (2003-2005) were approached. Progressive disorders and disorders of non-cerebral origin were not included as per the definition of CP. Disorders not traditionally categorized as CP in spite of clinical presentation were excluded.[24]

Measures of QOL

A parent served as a proxy respondent for their child's perception of QOL using self-administered questionnaires. One tool was the Child Health Questionnaire (CHQ),[7] a generic health-related QOL measure that quantifies the physical and psychosocial well-being of children >5 years. It provides detailed information on 14 multidimensional health concepts. This scale was rigorously developed[3] and has excellent internal consistency and discriminant validity. The CHQ-PF50 (Parent Form-50 item) was used, which has a reliability of 0.93 (.66-.94 for subscales).[7] Scores were transformed to T-scores (mean 50 ± 10) for the physical and psychosocial well-being summary scores, with higher scores indicating better QOL. The Pediatric Quality of Life Inventory (PedsQL 4.0) is another health-related QOL measure. It is a brief, generic scale with child self-reports (>5 years) and parent proxy-reports. The advantage of including this additional QOL measure was that it is more likely to be completed by the children themselves, given that it's short and the forms are developmentally appropriate. Therefore only the PedsQL was completed by the children, if feasible. The PedsQL evaluates physical, emotional, social, and school domains. It has excellent validity, responsiveness, and reliability.[25] This user-friendly generic measure was selected as a summary assessment of overall well-being. A 5-point scale is used per item, and items are reverse-scored and transformed (0-100 scale), with higher scores indicating a better QOL. Two summary scores may be derived (physical and psychosocial). Normative means are available for total and subscale scores.

Determinants of Quality of Life

Body Structures and Functions. We examined whether certain biomedical exposures documented at diagnosis were associated with worse outcomes. Type of CP was noted on neurologic examination, and the larger subgroups (hemiplegia, diplegia, and quadriplegia) were compared. A history of neonatal difficulties (necessitating neonatal intensive care) was examined as a predictor variable. Gestational age and presence of microcephaly (<2nd percentile) were also evaluated as risk factors. Behavior and cognition may influence QOL; therefore behavioral difficulties were measured with the Strengths & Difficulties Questionnaire,[26] completed by parents. The psychologist evaluated intelligence with the Leiter Intelligence Scale,[23] suitable for children with motor impairments.