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Original article

Lower limb functioning and its impact on quality of life in ambulatory children with cerebral palsy



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ABSTRACT

Background: Children with cerebral palsy (CP) are confronted on a daily basis with their motor problems affecting gait, which might impact on their quality of life (QOL).

Aim: The goal of this study was to evaluate the impact of gross motor and gait function on QOL in ambulatory children with CP attending regular school.

Methods: A condition-specific questionnaire (CP QOL-Child), including a parent/proxy and child self-report, was used to assess the relation between patient characteristics, lower limb impairments and functioning, and the different aspects of the child's QOL. Data on therapy management, lower limb impairments, and gross motor and gait function was collected for 81 children with CP (10.5 \pm 3.0 years). CP QOL-Child questionnaires were completed by a parent/proxy for all 81 children and by 39 of the children over 9 years.

Results: The mean self-reported QOL score (78.2 \pm 9.6) was significantly higher than the mean parent/proxy reported score (73.9 \pm 10.2). Lower limb spasticity and higher frequency of BTX-A injections correlated with worse scores for the pain and impact of disability domain. Results further showed the adverse impact of the severity of gait pathology on QOL perception for the parents/proxy and the child self-report. Gait speed was an important factor for the parents/proxy, though correlated less with self-perceived QOL for the children.

Conclusions: Children and parents identified similar factors that adversely affect QOL, whereby the amount of gait pathology was shown to play a crucial role. Only gait speed seemed to be of higher importance for the parents compared to the children.

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1. Introduction

Cerebral palsy is the leading cause of childhood physical disability, with a prevalence of 2 per 1000 living births.¹ Children with CP are faced with various motor and sensory impairments that contribute to perturbations of posture and movement. This in turn hinders proper performance of daily life activities and compromises the child's independence and quality of life (QOL).

Treatment planning in children with CP is focused on improving underlying primary and secondary motor impairments, whereby the ultimate goal is to improve function related QOL.² QOL is a multidimensional concept, defined by the WHO as "an individual perception of your position in life in the context of the culture and value systems in which you live, and in relation to your goals, expectations, standards and concerns".³ As such, QOL not only pertains to motor impairments, but also to e.g. psychosocial wellbeing, or the impact of pain or disability in daily life. The multicenter SPARCLE study has indeed described a reduced QOL and participation in children with CP aged 8–12 years, whereby the adverse impact of various environmental factors, pain and parental stress was shown.^{4,5} However, results are based on a heterogeneous group of children with CP, including both ambulatory and non-ambulatory children.

Adequate assessment of QOL requires the use of standardized and validated tools to as certain a comprehensive assessment of the child's QOL across multiple domains.6 Despite the availability of numerous pediatric QOL questionnaires,⁷ not all are suited to assess QOL in children with CP. Generic questionnaires are non-specific for neuromuscular diseases, though often used in CP, and focus on functioning rather than psychosocial wellbeing. These include the Child Health Questionnaire (CHQ),8 the Pediatric Quality of Life Inventory[™] (PedsQL[™])⁹ and the KIDSCREEN.¹⁰ Conditionspecific questionnaires are believed to be more sensitive and relevant to the nuances of the particular condition.⁷ The Cerebral Palsy Quality of Life Questionnaire for Children (CP QOL-Child)¹¹ is a condition-specific questionnaire that assesses several aspects of the child's QOL, including psychosocial and physical wellbeing, functioning at school, access to services and acceptance by others. It comprises a primary parent/proxy report (for children age 4-15 years) and a child's self-report (for children age 9-15 years). Recently, this questionnaire has been translated in Dutch.¹²

However, given the multidimensionality of QOL, various factors may impact on how parents or children perceive QOL. Factors such as type of CP,^{13,14} surgery,^{15,16} pain,^{4,17} or gross motor functioning^{18–20} have been put forward to impact on QOL. Other factors such as the impact of gait pathology, lower limb orthotic management or other interventions have not yet been explored.

The goal of this study was first to assess QOL in ambulatory children with CP attending regular school using the conditionspecific CP QOL-Child, including the parent/proxy and child self-report. Secondly, the relation between various factors, i.e. patient characteristics, physiotherapy frequency, orthotic management, treatment history, lower limb impairments and gross motor and gait function of the child, and the different aspects of the child's QOL were explored.

2. Methods

2.1. Participants

Children from the database of the CP-reference center of the University Hospital Pellenberg (Belgium) were screened, retrospectively, for entry in the study during a period of 8 months. Inclusion criteria were: (1) diagnosis of CP; (2) age 4-15 years; (3) complete 3D gait analysis available; (4) attending regular school. Children unable to walk independently without walking aids were excluded. Due to the higher levels of reported pain, anxiety and stress following botulinum toxin-A or surgery and the subsequent followup treatment (physiotherapy, casts, prolonged hospital stay),^{15,16} children were also excluded in case of botulinum toxin-A injections 6 months prior to or surgery 1 year prior to the QOL assessment. Including children in this period of their life would not be an adequate representation of their quality of life on a daily base. Lastly, children were also excluded when the time-interval between the 3D gait analysis and the QOL assessment had exceeded 9 months.

2.2. Assessments/procedure

The QOL was assessed using the Dutch version of the CP QOL-Child.¹² This questionnaire comprises a child selfreport (children aged 9–15 years) and a parent/proxy report (children aged 4–15 years). All questions contained in the CP QOL-child were scored on a 9-point rating scale. For the domains of social wellbeing and acceptance (SWA), participation and physical health (PPH), functioning (FU), emotional wellbeing (EWB), family health (FH), and access to services (AS), a score of 1 indicated very unhappy, a score of 3 unhappy, a score of 5 neither unhappy or happy, a score of 7 happy and 9 very happy. For the domains of pain and impact of disability (PI), a score of 1 indicated no pain/not concerned at all; a score of 9 indicated a lot of pain/very concerned. Following the guidelines of the CP QOL-Child manual, all scores were converted to a scale from 0 to 100.

General data on patient characteristics (age, sex, diagnosis), physiotherapy (frequency), lower limb orthotic management (day/ night orthoses) and lower limb treatment history (frequency of serial casting and BTX-A injections; type and frequency of surgery) were obtained from the child's clinical file at the Clinical Motion Analysis Laboratory of the University Hospital Pellenberg (CMAL-P).

Lower limb impairments of the child included lower limb measures of spasticity (modified ashworth scale²¹), muscle strength (manual muscle testing²²) and femoral anteversion (measured according to Ruwe et al.²³ in prone position, reported in degrees). Spasticity and strength were expressed as the sum of scores for the flexors and extensors at the ankle,

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