

ORIGINAL ARTICLE

# Long-Term Trajectories of Health-Related Quality of Life in Individuals With Cerebral Palsy: A Multicenter Longitudinal Study



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## Abstract

**Objectives:** To (1) determine the long-term trajectory of health-related quality of life (HRQOL) for the dimensions of physical complaints and motor, psychological, and social functioning for groups of individuals with cerebral palsy (CP) aged 1 to 24 years; (2) assess the variability in HRQOL within individuals with CP over time; (3) assess the variability in HRQOL between individuals with CP; and (4) compare the HRQOL in individuals with CP to reference data of typically developing individuals.

**Design:** Multicenter prospective longitudinal study.

**Setting:** Rehabilitation departments of 3 university medical centers and various rehabilitation centers in The Netherlands.

**Participants:** Dutch individuals with CP (N=424; age, 1–24y).

**Interventions:** Not applicable.

**Main Outcome Measures:** The HRQOL dimensions of physical complaints and motor, psychological, and social functioning. Each individual visited the rehabilitation department for 3 or 4 measurements. The time between measurements was 1 or 2 years.

**Results:** Individuals with CP experience an HRQOL that, on average, remains fairly stable over time. Variability in HRQOL within individuals with CP was similar to that within typically developing individuals. Variability between individuals with CP could be explained by type of CP (motor functioning), Gross Motor Function Classification System level (physical complaints and motor and social functioning), and intellectual disability (physical complaints and social functioning). Finally, individuals with CP experienced a lower HRQOL than did typically developing individuals, especially for the dimensions of motor and social functioning.

**Conclusions:** Many changes take place in the psychosocial development of the individual with CP, which accordingly change their expectations and those of their caregivers, peers, and professionals. As a result, perceived physical complaints and motor, psychological, and social functioning remain fairly stable over many years.

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Children are entitled to a full and decent life, and their views must be taken into account in all matters concerning them.<sup>1</sup> Therefore, there has been growing interest in concepts associated with quality of life (QOL). QOL is a multidimensional construct reflecting subjective perceptions of the individual's position in life in the context of the culture and value systems in which he or she lives and in relation to the individual's goals, expectations, and concerns.<sup>2,3</sup> QOL refers to the notion of holistic well-being, whereas *health-related quality of life* (HRQOL) specifically focuses on health-related aspects of well-being.<sup>3,4</sup> HRQOL includes elements about physical and mental functioning, as well as the person's appraisal of their effect on daily life and social functioning. In the present article, we focus on HRQOL, addressing the dimensions of physical complaints and motor, psychological, and social functioning.<sup>5,6</sup>

For individuals with disabilities, HRQOL may be restricted. With a prevalence of about 2 per 1000 live births, cerebral palsy (CP) is one of the most common childhood-onset disabilities.<sup>7,8</sup> The severity of CP ranges substantially from subtle motor impairment to involvement of the whole body. Owing to improved medical care, the life expectancy of individuals with CP has substantially increased during the past decades and is currently nearly comparable to that of typically developing individuals.<sup>9</sup>

Although little is known about the long-term consequences of HRQOL in individuals with CP,<sup>10,11</sup> many studies have assessed HRQOL for specific age groups of individuals with CP.<sup>11-15</sup> Their HRQOL was, on average, fairly stable over the course of 1 to 3 years, but much variation was found within and between individuals.<sup>14-16</sup> Type of CP and level of gross motor function were among the most studied factors to explain variability in HRQOL between individuals with CP. Furthermore, the HRQOL of individuals with CP was reported to be lower than that of typically developing individuals,<sup>14,15</sup> particularly for the dimension of physical functioning.<sup>12,13</sup>

Because existing knowledge on the consequences of CP on HRQOL is restricted to specific age groups, it has been argued that longitudinal studies over a longer time period are needed to provide evidence on long-term outcomes.<sup>4,6,10</sup> The Pediatric Rehabilitation Research in the Netherlands (PERRIN) program, a national consortium of the rehabilitation departments of 4 university hospitals and several rehabilitation centers ([www.perrin.nl](http://www.perrin.nl)), examined activities and participation for 4 age groups of individuals with CP over time: toddlers, children, adolescents, and young adults.<sup>14,15,17,18</sup> For the total sample of individuals with CP aged 1 to 24 years, we have recently described long-term

trajectories of *objective* functioning, that is, performance of physical activities and social participation.<sup>19-21</sup> These trajectories show that the level of objective functioning increased toward adult age. It might be questioned whether *subjective* functioning in individuals with CP will also increase toward adult age or will stay stable over many years. Therefore, the present study aimed to (1) determine the long-term trajectory of HRQOL for the dimensions of physical complaints and motor, psychological, and social functioning for groups of individuals with CP aged 1 to 24 years; (2) assess the variability in HRQOL within individuals with CP over time; (3) assess possible sources of variation in HRQOL between individuals with CP; and (4) compare the HRQOL in individuals with CP to reference data of typically developing individuals.

## Methods

This study was performed as part of the Dutch longitudinal PERRIN program, which started in 2000 as a collaboration between various rehabilitation centers and departments of rehabilitation medicine in The Netherlands. The centers served most of the eligible individuals with CP in their areas. For the current study, data on 424 individuals with CP were combined from the 4 age groups in the PERRIN program: toddlers (aged 1 and 2y at baseline; n=97), children (aged 5 and 7y at baseline; n=116), adolescents (aged 9, 11, and 13y at baseline; n=108), and young adults (aged 16–20y at baseline; n=103). The recruitment process has been described in detail elsewhere.<sup>14,15,17,18</sup> In short, eligible individuals had a clinical diagnosis of CP. Individuals were excluded when they were diagnosed with additional disorders affecting motor functioning or when they or their caregiver lacked the basic knowledge of the Dutch language. Young adults with intellectual disability were also excluded. For this age group, the PERRIN program investigated activities and participation during their transition to independent adulthood, thus focusing on those without intellectual disability who were expected to be capable of living an independent adult life.<sup>22</sup> Each individual visited the rehabilitation department for 3 (children and young adults) or 4 (toddlers and adolescents) measurements. The time between measurements was 1 year (for toddlers, children, and adolescents) or 2 years (for young adults). Toddlers, children, and adolescents were accompanied by their caregivers. A trained researcher conducted a face-to-face semistructured interview, including the Dutch language version of the caregiver-reported Netherlands Organisation for Applied Scientific Research-University Hospital Leiden (TNO-AZL) Preschool Children Quality of Life Parent Form (TAPQOL-PF) for toddlers,<sup>23</sup> TNO-AZL Children's Quality of Life Parent Form (TACQOL-PF) for children and adolescents,<sup>24</sup> and the self-reported TNO-AZL Children's Quality of Life Child Form (TACQOL-CF) for adolescents<sup>24</sup> or the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) for young adults.<sup>25</sup> Thus, for adolescents both caregiver-report and self-report data were used.

## Health-related quality of life

The TAPQOL-PF, TACQOL-PF, and TACQOL-CF measure the frequency of difficulties experienced in the previous weeks and accompanying subjective perception and have been shown to be reliable and valid standardized instruments to assess HRQOL in toddlers, children, and adolescents.<sup>23,24</sup> The generic 43-item TAPQOL-PF questionnaire comprises 12 domains: sleeping (4 items), appetite (3), lung problems (4), stomach problems (2), skin

### List of abbreviations:

CP	cerebral palsy
GMFCS	Gross Motor Function Classification System
HRQOL	health-related quality of life
PERRIN	Pediatric Rehabilitation Research in the Netherlands
QOL	quality of life
SF-36	Medical Outcomes Study 36-Item Short-Form Health Survey
TACQOL-CF	TNO-AZL Children's Quality of Life Child Form
TACQOL-PF	TNO-AZL Children's Quality of Life Parent Form
TAPQOL	TNO-AZL Preschool Children Quality of Life
TAPQOL-PF	TNO-AZL Preschool Children Quality of Life Parent Form
TNO-AZL	Netherlands Organisation for Applied Scientific Research-University Hospital Leiden

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