Predictors of parent-reported quality of life of adolescents with cerebral palsy: A longitudinal study

Marion Rapp a, Nora Eisemann b, Catherine Arnaud c, Virginie Ehlinger d, Jérôme Fauconnier e, Marco Marcelli f, Susan I. Michelsen g, Malin Nystrand h, Allan Colver i, Ute Thyen a,∗

a Department of Pediatrics, University of Luebeck, Ratzeburger Allee 160, 23538 Luebeck, Germany
b Institute of Cancer Epidemiology, University of Luebeck, Ratzeburger Allee 160, 23538 Luebeck, Germany
c INSERM, UMR 1027, Paul Sabatier University, Purpan, Clinical Epidemiology Unit, Toulouse, France
d INSERM, UMR 1027, Paul Sabatier University, Toulouse, France
e UJF-Grenoble 1/CNRS/CHU de Grenoble/TIMC-IMAG UMR 5525/Themas, Grenoble F-38041, France
f USL Viterbo, Via Enrico Fermi 15, 01100 Viterbo, Italy
g National Institute of Public Health, University of Southern Denmark, Oster Farimagsgade 5, 1353 Copenhagen, Denmark
h Gothenburg University, The Queen Silvia Children’s Hospital, S-41685 Gothenburg, Sweden
i Institute of Health and Society, Newcastle University, Royal Victoria Infirmary, Newcastle upon Tyne NE1 4LP, UK

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A B S T R A C T
Aim: Parent-reporting is needed to examine Quality of Life (QoL) of children with cerebral palsy (CP) across all severities. This study examines whether QoL changes between childhood and adolescence, and what predicts adolescent QoL.

Method: SPARCLE is a European cohort study of children with CP, randomly sampled from population databases. Of 818 8–12-year-olds joining the study, 594 (73%) were revisited as 13–17-year-olds. The subject of this report is the 551 (316 boys, 235 girls) where the same parent reported QoL on both occasions using KIDSCREEN-52 (transformed Rasch scale, mean 50, SD 10 per domain). Associations were assessed using linear regression.

Results: Between childhood and adolescence, average QoL reduced in six domains (1.3–3.8 points, p < 0.01) and was stable in three (Physical wellbeing, Autonomy, Social acceptance). Socio-demographic factors had little predictive value. Childhood QoL was a strong predictor of all domains of adolescent QoL. Severe impairments of motor function, IQ or communication predicted higher adolescent QoL on some domains; except that severe motor impairment predicted lower adolescent QoL on the Autonomy domain. More psychological problems and higher parenting stress in childhood and their worsening by adolescence predicted lower QoL in five and eight domains respectively; contemporaneous pain in seven domains. The final model explained 30%–40% of variance in QoL, depending on domain.

Interpretation: In general, impairment severity and socio-demographic factors were not predictors of lower adolescent QoL. However, pain, psychological problems and parenting stress were predictors of lower adolescent QoL in most domains. These are modifiable factors and addressing them may improve adolescent QoL.

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Abbreviations: CP, Cerebral Palsy; GMFCS, Gross Motor Function Classification System; PSI, Parenting Stress Index Short Form; QoL, Quality of Life; SDQ, Strength and Difficulties Questionnaire; SPARCLE, Study of PARticipation of Children with cerebral palsy Living in Europe.
∗ Corresponding author.
E-mail addresses: marion.rapp@gmx.de (M. Rapp), nora.eisemann@uksh.de (N. Eisemann), catherine.arnaud@univ-tlse3.fr (C. Arnaud), virginie.ehlinger@insERM.fr (V. Ehlinger), jerome.fauconnier@imag.fr (J. Fauconnier), marco.marcelli@asl.vt.it (M. Marcelli), sim@si-folkesundhed.dk (S.I. Michelsen), malin.nystrand@vgregion.se (M. Nystrand), allan.colver@ncl.ac.uk (A. Colver), ute.thyen@uksh.de (U. Thyen).

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What this paper adds
- There was a small reduction in average QoL between the childhood and adolescence of individuals with cerebral palsy.
- Quality of life predicted adolescent quality of life on all domains.
- Severity of impairment and socio-demographic factors had little predictive value.
- Contemporaneous pain predicted lower adolescent quality of life.
- The modifiable factors psychological problems and parenting stress in childhood and their worsening predicted lower adolescent quality of life.

1. Introduction

Quality of life (QoL) is defined as ‘the individual’s perception of their position in life in the context of the culture and value system in which they live, and in relation to their goals, expectations, standards, and concerns’ (WHOQOL, 1995). Thus, QoL is a subjective concept and should be self-reported whenever possible. Capturing such perspectives is a key expectation of Articles 13 and 14 of the UN Convention on the Rights of the Child (United Nations, 1989).

Cerebral palsy (CP) can serve as an exemplar condition of disability (Janssen, Voorman, Becher, Dallmeijer, & Schuengel, 2010; Rosenbaum, Livingston, Palisano, Galuppi, & Russell, 2007; Young et al., 2010) because the severity of CP and the patterns of its motor involvement and associated impairments show much variation and persist across the life course (Nystrand, Beckung, Dickinson, & Colver, 2014).

Children and adolescents with CP who can self-report do not cover all those with CP. Usually those with severe intellectual impairment cannot self-report, and therefore proxy reports are needed to describe QoL. (Arnaud, White-Koning, & Michelsen, 2008; Rosenbaum et al., 2007; Young et al., 2010). The proxy should be close to the child or adolescent (Pickard and Knight, 2005). Although a child’s and their parents’ view of their child’s QoL differ, (White-Koning, Arnaud, & Dickinson, 2007) parent reports are closer to those of their children than those of teachers (White-Koning, Grandjean, Colver, & Arnaud, 2008), or therapists (Pickard and Knight, 2005). Interpretation of parent-proxy reports requires information about child factors like impairments (Badia, Riquelme, & Orgaz, 2014), pain or psychological problems and parent factors like stress or life circumstances (Davis, Davies, Waters, & Priest, 2008; Pickard and Knight, 2005; White-Koning et al., 2007). As there are differences between mother and father responses, longitudinal studies should ensure the continuity of one respondent (Davis et al., 2008).

Little is known about the QoL of children with CP across all severity groups as they move from childhood to adolescence. The few studies undertaken have methodological weaknesses: a short time span (van Buuren, 2007; Livingston and Rosenbaum, 2008), a wide age frame from toddlers to adults (Vargus-Adams, 2006), small sample sizes (Janssen et al., 2010) or reporting a mixture of self- and proxy reports in one analysis (Livingston and Rosenbaum, 2008; Vargus-Adams, 2006).

The ongoing Study of Participation of Children with cerebral palsy Living in Europe (SPARCLE) is therefore the first large multi-centre European cohort study of children with cerebral palsy.

The objectives of this report are to examine, whether:
1. parent-reported QoL of adolescents with CP changes as young people move from childhood to adolescence
2. QoL in adolescence is predicted by:

a) childhood factors (impairment, pain, psychological problems),
b) family and personal factors of the reporting parent (socio-economic and parenting stress),
c) changes in pain, psychological problems and parenting stress between childhood and adolescence.

2. Method

2.1. Study design and participants

The methods of the SPARCLE study, described in detail elsewhere (Colver, 2006; Colver and Dickinson, 2010), are summarised below. Children born between 31/07/1991 and 01/04/1997 were randomly sampled from population-based registers of children with CP in eight European regions that share a standardised definition of CP. 743 (63%) of 1174 target families identified from registers joined the study. One further region (Northwest Germany) ascertained 75 cases from multiple sources. The 818 children who entered the study were interviewed in 2004/5 aged 8–12 years (SPARCLE1), and then again in 2009/10 aged 13–17 years (SPARCLE2) when 594 (73%) remained in the study. Drop out was associated with lower parental educational qualification, higher parenting stress and not being married at time 1 (Dickinson, Rapp, & Arnaud, 2012). These factors were introduced to our regression models.

The 551 (67%) children, where the same parent reported QoL in SPARCLE1 and SPARCLE2, comprised the longitudinal sample of this report (Fig. 1).
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