HEALTH-RELATED QUALITY OF LIFE IN CHILDREN AND ADOLESCENTS WITH CEREBRAL PALSY

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Abstract

Introduction. In a cross-sectional cohort study, health-related quality of life of Slovenian children and adolescents with cerebral palsy was examined, and factors associated with it have been identified.

Methods. Caregivers of 122 children and adolescents with cerebral palsy were addressed to fill out proxy versions of HRQoL questionnaires (DISABKIDS generic and cerebral palsy module). Children and adolescents without cognitive deficit were asked to fill out the self-report versions.

Results. Ninety-one families of 43 children (the mean age is 10 years, 6 months, SD 1.2; 26 males and 17 females) and 48 adolescents (the mean age is 14 years, SD 0.9; 23 males and 25 females) completed proxy-reports. Forty-eight individuals were able to self-report (26 children and 22 adolescents). Health-related quality of life was perceived as good. Self-reporting participants scored higher than their caregivers (mean score 75.6, SD 15.9 versus mean 72.3, SD 17.9; p=0.048). Adolescents scored lower than children in all domains (mean score 69.4, SD 19.4 versus mean 80.8, SD 10.0; p=0.01). Higher age (p<0.001), pain (p<0.001) and disturbed sleep (p=0.002) were strong predictors of worse health-related quality of life. Social Inclusion and Independence domains received the lowest scores.

Conclusions. Slovenian children and adolescents with cerebral palsy have a good health-related quality of life, with Social Inclusion and Independence being the weakest domains. Children reported higher scores than adolescents or their caretakers. Pain was the strongest predictor of poor health-related quality of life.

Keywords: cerebral palsy, children, adolescents, quality of life, self-reports, proxy-reports

Uvod. V luči vse večjega trenda k celostnemu pristopu obravnave otrok s cerebralno paralizo se poleg dobrega poznavanja in vrednotenja otrokove oviranosti med glavna orodja, ki so v pomoč pri načrtovanju obravnav, uvrščajo vprašalniki za oceno z zdravjem povezana kakovosti življenja. Cilja raziskave sta bila pridobiti vpogled v z zdravjem povezana kakovost življenja pri skupini slovenskih otrok s cerebralno paralizo in najti morebitne povezave z njihovimi demografskimi in kliničnimi podatki.

Metode. V okviru presečne kohortne raziskave je bilo iz Slovenskega registra otrok s cerebralno paralizo naključno izbranih 122 družin. Skrbniki otrok so bili pozvani k sodelovanju z izpolnitvijo proxy različice vprašalnika o z zdravjem povezani kakovosti življenja. Otroci brez kognitivne okvare so bili izpolnili vprašalnik za samostojno oceno. Skrbniki so ocenili otroke vso različico vprašalnika (proxy različica). Ocenjena z zdravjem povezana kakovost življenja je bila dobna. Otroci so ocenili bolje kot njihovi skrbniki (povprečno 80.8, SD 10.0 proti povprečno 69.4, SD 19.4; p=0.01). Preiskovanci so ocenili bolje kot njihovi skrbniki (povprečno 75.6, SD 15.9 proti povprečno 72.3, SD 17.9; p=0.048). Višja starost (p<0.001), prisotnost bolečine (p<0.001) in motnje spanja (p<0.001) so bili močni napovedni dejavniki za slabše z zdravjem povezane kakovosti življenja. Socialna vključenost in samostojnost sta bili najslabše ocenjeni domeni. Vprašalnik DISABKIDS se je izkazal za dobro orodje za oceno z zdravjem povezane kakovosti življenja otrok s cerebralno paralizo.

Sklep. Slovenski otroci s cerebralno paralizo ocenjujejo svojo z zdravjem povezana kakovost življenja kot dobro. Otroci ocenjujejo bolje kot njihovi skrbniki. Bolečina je najmočnejši napovedni dejavnik slabše z zdravjem povezane kakovosti življenja.

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1 INTRODUCTION

Cerebral palsy (CP) is a diverse condition with various levels of reduced motor function, often accompanied with cognitive deficit, epilepsy, vision or hearing impairment, orogastrointestinal malfunction and skeletal problems (1). All CP definitions share the fact that the injury to the immature brain results in a life-long disability (2-4). Current therapeutic interventions, focused on alleviating physical dysfunctions, can only offer limited relief and can cause additional pain (4, 5). Psychological problems and needs of CP patients are much less obvious and are usually poorly understood and tended by healthcare practitioners. Evidence shows that CP patients do not primarily search for physical improvement as much as they crave for social inclusion (5, 6).

QoL is a broad concept defined by the World Health Organization as “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” (7). Health-Related Quality of Life (HRQoL) represents the QoL in the view of an individual’s health status (8). When managing chronic conditions, such as CP, it is an important marker of the efficacy of clinical interventions. It is, however, a complex, hard-to-define term and controversies exist about its detailed definition and appropriate measuring tools (8).

Studies that examined HRQoL of children and adolescents with CP showed scores similar to aged-matched general population with the exceptions in social participation and motor functioning (5, 6, 9, 10). In longitudinal studies, HRQoL in childhood correlated well with HRQoL in adolescence (5). Pain, parenting stress and psychological problems were identified as predictors of worse HRQoL (5, 10, 11). Although motor impairment influenced functioning and participation, it affected psychosocial wellbeing to a much lesser extent (9).

Not all existing HRQoL measuring tools actually measure HRQoL (a subjective perspective), but rather an objective interaction between body structure, function and participation (12). The weakness of many HRQoL measures is the lack of indicators that measure wellbeing (positive emotions and satisfaction about daily activities, relations and life overall), while being oriented towards asking how often patients feel sad and unsatisfied with their involvement in daily tasks (13).

We chose DISABKIDS questionnaires for their recognition as good HRQoL measuring tools (12). Generic and various disease specific modules enable a comparison between children with different chronic conditions (14, 15). A good correlation with KIDSCREEN measures (developed by the same group of professionals) offers an opportunity for comparing QoL of aged-matched general population. DISABKIDS questionnaires show good linkage with the International Classification of Functioning, Disability and Health (ICF) (16).

The objective of our study was to assess HRQoL of Slovenian paediatric patients with CP, identify possible underlying factors that are associated with it, and find potential differences in scoring between caregivers and children.

2 METHODS

2.1 Participants

At the time of data collection in July 2014, the Slovenian National Cerebral Palsy Registry (SRCP) included 371 children of all ages. They were registered through neurodevelopmental paediatricians in regional outpatient clinics covering around 90% of Slovenian paediatric CP population. Out of original 150 children aged 8-16 years, randomly selected from the SRCP, contact data for 122 families were available; 91 caregivers (of 43 children aged 6-12 years and 48 adolescents aged 13-16 years) were willing to cooperate. Children with tested IQ score >70 or attending regular school were considered cognitively able to self-report, and 48 of them (26 children and 22 adolescents) agreed to do so.

2.2 The Procedure

The caregivers of 122 children with CP were contacted by telephone at one or (in the case of first call non-responders) at two occasions by a single physician. Study aims were explained to them and caregivers were invited to participate. Questionnaires were sent to 103 caregivers who accepted the invitation, together with written instructions and informed consent form.

2.3 Measures

DISABKIDS instruments were used to assess HRQoL. DISABKIDS Chronic Generic Measure - long version (DCGM-37) - contains 3 domains (Mental, Social and Physical) that
The partial and final scores of self-reports and proxy-reports were compared using Pearson’s Product Moment Correlation coefficient (Pearson’s r).

The partial and final scores of self-reports and proxy-reports were also compared to subscales and the total score of PedsQL measure, where Pearson’s r was used again.

All the analyses were conducted with the SPSS (Statistical Package for Social Sciences Program) version 20.0.

3 RESULTS

Out of 122 parents of children with CP invited to partake in the study, 91 were willing to participate (the response rate was 75%). The main reason for refusal came from parents of children with very mild disability, as they considered their children healthy (not having cerebral palsy) and were concerned that the questionnaire would disturb them. In the initial sample, there were 60 families with cognitively intact children, among which 48 were willing to self-report (the response rate was 80%). The remaining 43 families with more severely affected children filled out only the proxy-reports. DISABKIDS final scores (transformed to a scale of 1-100) by different modules, items and demographic properties are presented in Table 1.
3.1 Sample Characteristics

The mean age of all participants with CP was 12 years and 4 months (SD 2.02); 43 (48%) were children (the mean age is 10 years, 6 months, SD 1.2) and 48 (53%) adolescents (the mean age is 14 years, SD 0.9). The sample consisted of 53 (58%) males and 38 (42%) females.

Among 48 self-reporting participants, there were 26 (54%) children (the mean age is 10 years 8 months, SD 1.1) and 22 (46%) adolescents (the mean age is 13 years, 11 months, SD 0.8). Gender distribution across the self-reported sample was balanced with 23 (48%) males and 25 (52%) females.
Table 2. Demographic and health-related data of 91 participants.

| Age (mean) | Gender | CP classification | GMFCS | IQ | Epilepsy | Speech disorder | Attention disorder | Visual impairment | Hearing impairment | Reporting pain | Disrupted sleep | Gastrostomy | Reduced bone density |
|------------|--------|--------------------|-------|----|----------|-----------------|-------------------|-------------------|-------------------|----------------|----------------|-----------|---------------------|
| 10 y 6 mo, SD 1.2 | male 26 (23.3%) | spastic 35 (81.4%) | 18 (41.9%) | 25 (58.1%) | 15 (34.9%) | 19 (44.2%) | 14 (32.6%) | 15 (34.9%) | 4 (9.3%) | 7 (16.3%) | 8 (18.6%) | 1 (2.3%) |
| 14 y, SD 0.9 | female 26 (23.3%) | unil 14 (33%) | uni 43 (89.6%) | 10 (20.8%) | 11 (22.9%) | 22 (45.8%) | 11 (22.9%) | 19 (39.6%) | 2 (4.2%) | 14 (29.2%) | 12 (25.0%) | 5 (10.4%) |
| 12 y 4 mo, SD 2.02 | dyskinetic dystonia 35 (81.4%) | unil 11 (23%) | uni 25 (27%) | 10 (20.8%) | 11 (22.9%) | 46 (95.8%) | 11 (22.9%) | 34 (67.4%) | 7 (14.6%) | 14 (29.2%) | 12 (25.0%) | 5 (10.4%) |
| 10 y 8 mo, SD 1.1 | dys.choreoathetosis 35 (81.4%) | / | / | 10 (20.8%) | 11 (22.9%) | / | / | 34 (67.4%) | / | 10 (20.8%) | 12 (25.0%) | / |
| 13 y 11mo, SD 0.8 | ataxic 35 (81.4%) | / | / | 10 (20.8%) | 11 (22.9%) | / | / | / | / | 10 (20.8%) | 12 (25.0%) | / |
| 12 y 2 mo, SD 1.9 | | | | 10 (20.8%) | 11 (22.9%) | / | / | / | / | 10 (20.8%) | 12 (25.0%) | / |

Abbreviations: the number of cases (N); years (y); months (mo); unilateral (uni); Gross Motor Function Classification Scale (GMFCS); intelligence quotient (IQ)
Table 3. Implemented interventions and socio-economic data of 91 participants.

| All participants - proxy reports | Self-reported participants |
|---------------------------------|---------------------------|
| **Interventions:**              |                           |
| Neurodevelopmental th.          |                           |
| age at onset                    |                           |
| Physiotherapy                   |                           |
| Occupational therapy            |                           |
| Speech-language therapy         |                           |
| Special pedagogy                |                           |
| Hypo therapy                    |                           |
| Hydrotherapy                    |                           |
| Psychological therapy           |                           |
| Social pedagogy                 |                           |
| Complementary methods           |                           |
| Orthopedic therapy              |                           |
| Typhlopedagogy                  |                           |
| Surdopedagogy                   |                           |
| **Education (stage):**          |                           |
| - mother (N)                    |                           |
| (%)                             |                           |
| - father (N)                    |                           |
| (%)                             |                           |
| **Unemployment:**               |                           |
| - mother (N)                    |                           |
| (part time)                     |                           |
| - father                        |                           |
| - both                          |                           |
| **Financial support**           |                           |
| - lost income substitute        |                           |
| - child care support            |                           |
| **Child residence**             |                           |
| - home                          |                           |
| - day care centre               |                           |
| - 24h centre                    |                           |
| **Schooling:**                  |                           |
| - regular                       |                           |
| - adjusted program              |                           |

Abbreviations: the number of cases (N); years (y)
3.2 Proxy-Reports
Caregivers rated their children's HRQoL as 'good' (DCGM-37 mean total transformed score 66.9, SD 18.2). The worse scored domains were Social Inclusion (mean 53.2, SD 24.5) and Independence (mean 58.1, SD 24.4). The highest rated were Emotion (mean 78.3, SD 20.4) and Medication (mean 79.8, SD 21.0). HRQoL of children was scored higher than HRQoL of adolescents (mean 75.1, SD 12.5 versus mean 60.5, SD 19.5; mean difference 14.64, 95% CI 7.21 - 22.07; p<0.001). The largest differences were for Independence (mean 67.79, SD 20.84 versus 50.34, SD 24.54; mean difference 17.45, 95% CI 7.36 - 27.54; p<0.001), Social Inclusion (mean 65.23, SD 19.17 versus 44.02, SD 24.34; mean difference 21.21, 95% CI 11.40 - 31.02; p<0.001) and Social Exclusion domains (mean 82.52, SD 13.65 versus 71.74, SD 22.76; mean difference 10.78, 95% CI 2.23 - 19.34; p=0.014). There were some missing data for each item, and 5 items had a missing data rate equal to 10% or more. In nine questionnaires, scoring was not possible due to too many missing values (>20% of unanswered items).

Seventy-nine DCSM-CPM completed proxy reports with more. In nine questionnaires, scoring was not possible due to too many missing values (>20% of unanswered items).

Only 6 children and adolescents able to self-report had concomitant epilepsy. They scored their HRQoL through DCSM-EM as very good (80.4, SD 24.1).

3.3 Self-Reports
Among DCGM-37 self-reporters, HRQoL was perceived as ‘good’ (the mean total transformed score is 75.6, SD 15.9). The worse scored subscales were, as in proxy-reports, Social inclusion (mean 65.7, SD 19.5) and Independence (mean 70.4, SD 20.1). The highest score was given to the sub-scale Emotion (mean 85.3, SD 17.7). Children rated their HRQoL better than adolescents (mean 80.8, SD 10.0 versus mean 69.2, SD 18.6) compared to caregivers of children (mean 76.8, SD 13.6), but the difference was borderline statistically important (p=0.050).

Nineteen DCSM-EM proxy reports were valid and gave the total transformed score of mean 89.3, SD 14.3.

3.4 Proxy and Self-Reports Comparison
The correlation between DCGM-37 proxy and self-reports was good (Pearson r=0.80 for total scores and r=0.59 - 0.80 for separate domains, where only Social Inclusion and Social Exclusion domains resulted in r<0.70). The absolute difference between proxy and self-reported scores was significant, self-reporting participants rating their HRQoL higher than caregivers (mean 75.6, SD 15.9 versus mean 72.3, SD 17.9; the mean difference 3.23, 95% CI 0.03 - 6.43; p=0.048). The same was found for DCSM-CPM measure with the total transformed score r=0.76 and r=0.73 and r=0.81 for Impact and Communication subscales. There was no difference between proxy and self-reported DCSM-CPM scores (p=0.97).

3.5 PedsQL Reports
The mean total score of 78 PedsQL - proxy measures - was 61.5, SD 21.4, and of 41 PedsQL self-reported measures 75.6, SD 19.6. The correlation between DISABKIDS and PedsQL total transformed scores was very good (Pearson r=0.81 for self-reports and r=0.86 for proxy reports). Domains measuring similar concepts showed high correlation as well: r=0.70 for physical domains (self) and r=0.81 for physical domains (proxy), r=0.74 for emotional domains (self) and r=0.64 for emotional domains (proxy) and r=0.75 for social domains (self) and r=0.80 social domains (proxy).

3.6 Factors Influencing HRQoL
DCGM-37 proxy reports: lower age was found a strong single predictor of better HRQoL (mean 75.1, SD 12.5 versus mean 60.5, SD 19.5; the mean difference 14.64, 95% CI 7.21 - 22.07; p<0.001). There was a negative correlation between HRQoL and disease severity. GMFCS level alone, tested with one-way ANOVA, was negatively associated with HRQoL. More concomitant epilepsy. They scored their HRQoL through DCSM-EM as very good (80.4, SD 24.1).
and the strongest standardised regression coefficient was found for pain -0.47, p=0.001. No correlation was found between the number of implemented therapeutic interventions and HRQoL, nor for comorbidities, such as epilepsy, and language, speech and attention disorders. There was also no HRQoL association with parents’ education, employment status, financial support, child cognitive abilities and schooling type.

DCGM-37 self-reports: in the single variable analysis, besides higher age (the mean difference 11.37, 95% CI 2.57 - 20.17; p=0.012), the main factors reducing HRQoL were pain (the mean difference 18.57, 95% CI 6.03 - 31.11; p=0.005) and comorbidities (the mean difference 9.56, 95% CI 0.24 - 18.88; p=0.045). In the multivariable model using these variables, the adjusted r score was 0.27, and the strongest standardised regression coefficient was found for pain (-0.39, p=0.009), whereas age was only borderline significant (p=0.059).

DCSM-CPM proxy reports: in the multivariable model using variables that tested significant in univariate models (pain, disturbed sleep, GMFCS, cognitive impairment, speech impairment and epilepsy), pain was the only factor negatively influencing HRQoL (adjusted r score 0.34, standardized regression coefficient -0.30, p=0.009). DCSM-CPM self-reports: pain was the only significant single factor related to a lower perception of HRQoL (p=0.027).

3.7 Additional Questions
The caregivers needed, on average, 13.6 minutes to fill out DCGM-37 and DCSM-CPM proxy modules. Forty-six caregivers (54%) thought they were useful and 40 (47%) interesting. Eighty-three (87%) would potentially fill them out again, 50 (58%) would do that gladly.

The self-reported children and adolescents needed, on average, 14.5 minutes to fill out both questionnaires. Twenty-one (48%) of them found the questionnaires interesting and 16 (36%) useful. Only 3 participants (7%) considered the questionnaires stupid. The items made 2 participants (5%) feel uncomfortable, 12 (27%) felt a bit embarrassed, but were not bothered by them, and 30 (68%) were not bothered by them not at all. Forty-one (93%) individuals would potentially fill out the questionnaires again, 20 (45%) would do that gladly.

4 DISCUSSION
This is the first study that assessed HRQoL of Slovenian children and adolescents with CP. Overall, their self- and proxy reported HRQoL is good, which is similar to the findings in studies evaluating similar patient populations in other countries (5, 10, 11, 18).

Recently published data about HRQoL in children and adolescents with CP (SPARCLE I and II studies) convincingly show scores similar to the general age-matched population, with the exception of social support and peers domains (5). In these studies, HRQoL of children was a good predictor of HRQoL later in adolescence (5). In the present study, we compared HRQoL of children and adolescents in cross-sectional cohorts simultaneously and with the same HRQoL tool. We found significantly lower HRQoL scores in adolescents, as compared to those in children. QoL issues tend to change over time, as independence, relationships, sexuality and acceptance of disability increasingly gain importance in adolescence (20). This could potentially explain lower self- and proxy-perceived HRQoL scores in adolescents. However, our sample of self-reporting participants was small, and we did not include a control group of healthy children.

Pain is a well-recognized predictor of decreased participation and poor HRQoL (5, 10, 11, 21). In our study, it was related to lower scores in all groups. Disturbed sleep negatively associated with proxy-reported HRQoL, but it was a rare complaint with no impact in the self-reporting group. Our study was unable to show the impact of therapeutic interventions on HRQoL. This could be explained by a well-organized Slovenian neurodevelopmental network that enables all children with developmental delay to start a specific neurodevelopmental treatment at an early age, most of them within the first 6 months of life (19). Whereas most interventions aim to improve physical independence, most have a limited effect on HRQoL. It is therefore very important to design accessible interdisciplinary therapeutic approaches, which would better address HRQoL issues.

Children and adolescents rated their HRQoL higher than their caregivers in all domains, which is similar to the findings of other studies (11, 22). One reason for that could be that children focus on their abilities, as their disability has always been a part of their functioning, while caregivers tend to compare the abilities of their children to those of healthy children (23). Regardless of their level of disability, almost all children in our study resided at home, which indicates a high level of family engagement. It is possible that lower proxy scores reflect caregivers’ psychological burden. It has been recognized that caregivers’ well-being is significantly impaired, compared to matched adults from the general population (24). No proper supportive family-centred services or parent networks currently exist in Slovenia. Surprisingly, despite various unfavourable socio-economic factors, such as high maternal unemployment rate, none of them were significantly associated with HRQoL (20).
Consistent with other studies, there were limitations regarding Social Inclusion and Independence, which are, to some extent, expected due to the nature of the disease (5, 9). Whereas most interventions aim to improve physical independence, a lot more could be done in the wider society to improve social inclusion of children with CP.

This study has some limitations: The number of patients in subgroups was relatively small, there was no comparative sample of healthy children and adolescents, a non-personal approach was used, and a generic questionnaire was selected as a primary assessment tool.

5 CONCLUSIONS

This was the first study to assess HRQoL of children with CP in Slovenia. It is important to follow HRQoL of CP patients closely throughout their childhood and adolescence, and pay attention to the factors that might be negatively associated with it, such as pain. It is also important that therapeutic interventions are well-balanced and use integrated multidisciplinary approach to improve participation and social inclusion of individuals with CP.

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CONFLICTS OF INTEREST

The authors declare that no conflicts of interest exist.

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ETHICAL APPROVAL

The study was approved by the Slovenian National Ethics Committee, application number: 122/05/13. After receiving verbal and written information about the study, all caregivers signed written consent.

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