Children and adolescents with cerebral palsy have reliable knowledge about their own condition - Self- and parent reported quality of life

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Abstract

Background: to assess health related quality of life (HRQoL) of children (8–12 years) and adolescents (13–18 years) with cerebral palsy (CP) and to compare it with age-matched healthy control children from the general population (GP). Methods: prospective cohort study. HRQoL was self-reported by KIDSCREEN questionnaires. 99 families with children with CP and 237 children from the GP and their parents were enrolled. Collected data were evaluated and compared to each other across all dimensions of KIDSCREEN: European values compared to our GP’ groups, scores of children with CP and of their parents with general population groups (both children and parents); parents’ reports with childrens’, child and adolescent reports, age, sex, special features of CP on HRQoL. Results: patients with CP and their parents rated their HRQoL as poorer than their GP counterparts did, except for the parent relation/home life and social support/peers dimensions. Reports given by children and their parents were correlated. Children and adolescents had similar scores. Assessments of children and their parents were in a medium-strong positive relationship regarding psychological well-being, moods/emotions, self-perception, autonomy, parent relation/home life dimensions (0.552<r<0.747). The correlations were stronger than medium, also in a positive direction, in financial resources, social support/peers and school environment dimensions (0.771<r<0.792). With the severity of CP, not only the assessment of physical well-being diminishes remarkably, but financial resources, social support/peers, and social acceptance dimensions were evaluated on lower levels as well. The lowest HRQoL scores were measured in children with unilateral spastic CP. Female sex, poorer gross motor function and comorbidities (epilepsy, incontinence and intellectual impairment) had
negative impacts on HRQoL. Conclusions: our study is based not only on the assessments of parents, but on the opinions of children and adolescents with CP as well. The study highlighted that children with CP have reliable knowledge about their own condition.

Background

Cerebral palsy (CP) is a set of signs and symptoms in which motor disability dominates. Its general prevalence is between 2–4 ‰, in Hungary it is 2.1‰. The main risk factors of CP are prematurity and low birth weight (1-7). Children who suffered from birth asphyxia are found in 10–20 % of CP cases (7). The most frequent sign of CP is spasticity. Comorbidities such as epilepsy, intellectual disability or incontinence can accompany CP. Less frequent disorders involve e.g. attention deficit or speaking and learning difficulties. Each comorbidity can decrease the quality of life of children with CP (8–13).

In the last 60 years medical treatment of newborns, especially premature infants, has improved greatly as new drugs and modern techniques have become available. The chance of the survival of these very sick babies has improved considerably, but some children have severe or less severe motor and/or mental disability. Health related quality of life (HRQoL) refers to the assessment of various aspects of health from the patient’s point of view. Several studies have been published about HRQoL of children with chronic neurological diseases, but these are mainly based on parental reports of their child’s HRQoL, rather than self-reported HRQoL. In recent years there has been much work studying the impact of CP on HRQoL.(14-29) However the results of these studies are not unified, but sometimes contradictory and they are usually based only on the opinions of the parents of children with CP.

We aimed to investigate whether HRQoL of children with CP differed from that in the general population of children and adolescents in the same age range. We wanted to study what factors are likely to affect the HRQoL of children and adolescents with CP. Our null hypothesis was that the HRQoL of children and adolescents with CP and their self-report abilities and those in the general population are similar and independent from other variables such as age, sex and other characteristics of CP. We planned to involve a large number of applicants to gain statistically sufficient data. Similar studies have been done in many countries (14–29), but not yet in Hungary.

Methods

We administered the KIDSCREEN-52 questionnaire, which is a generic, validated paediatric HRQoL instrument designed for healthy and chronically ill children and adolescents (30, 31). General population (GP) data from some different European
countries are also available from the developers; however, we were interested in the Hungarian general population data, so we decided to collect the assessments of Hungarian children without any chronic diseases. Parents of both populations (CP and GP) were also requested to fill in their versions of the questionnaires.

Patient and general population

The planned population was 100 families with children with cerebral palsy (CP) and 200 from the general population (GP). 493 (268 GP and 225 CP) KidScreen-52 Children & Adolescents and Parental questionnaires were issued.

Two different age-group populations were studied: 8–12-year-old children and 13–18-year-old adolescents. Throughout this paper, when children and adolescents are considered together, they are collectively called ‘children’. Families with children with cerebral palsies are abbreviated as CP families or CP children, healthy control children from the general population are called GP children or GP parents.

Participants were recruited from two geographical regions of Hungary through following sources:

databases of the Department of Paediatrics of the University of Pecs and of Borsod County Hospital,
neurological, rehabilitation and special nephrological (incontinence care) services and consultations at Pecs University Hospital and at Borsod County Hospital,
special and/or mainstream schools and institutions for disabled children in both regions, early intervention centres located in these two districts.

Participants from the general population were recruited from the same two regions, from urban and rural primary and high schools of Borsod County and catchment areas of the Pecs University Hospital (Baranya, Tolna, and Somogy Counties). Data were collected between November 2012 and February 2016.

Parents and children with CP were asked to fill in the questionnaires during follow-up visits at the hospitals. We strived to have personal contacts with all families.
Most children were able to complete the questionnaires independently. Where motor impairment hindered them, physical help was given. Children with learning difficulties were not excluded, but it was essential that a child could understand the questions and answer them clearly.

Data were collected about the different characteristics of the chronic disease: type of CP, level of motor disability. The proposed SCPE classification scheme was used considering the different types of CP: unilateral or bilateral spastic, ataxic, dyskinetic, dystonic, choreo-athetotic and non-classified CP (32). The five levels of the Gross Motor Function Classification System (GMFCS) were used to determine the level of gross motor function of children with motor disability:

Level I: walks without restriction, limited by more advanced gross motor skills.
Level II: walks without assistive devices, limitations when walking outdoors or in the community.
Level III: walks with assistive device, limitations when walking outdoors or in the community.
Level IV: limited self-mobility, going outdoors or about the community requires transportation or powered device.
Level V: self-mobility severely limited even with assistive device(s), totally dependent; mobility severely limited. (33)

Not only the motor status of the children was evaluated but in every case other comorbidities (intellectual status, epilepsy, incontinence, etc.) were assessed as well. If the children had not only pure motor disability but other associated disorders (for example active epilepsy or intellectual disability IQ 50-70) we classified them as mild (CP plus one other disability) or severe CP (CP plus 2 or more other disabilities).

Statistical analysis

Collected data were evaluated and compared to each other across all 10 dimensions of KidScreen:
KIDSCREEN European values compared to our general populations’ groups, scores of children with CP and of their parents with general population groups (both children and parents), parents’ reports with childrens’ ones for the CP group, scores of 8-12-year-old children and 13-18-year-old adolescents (child and adolescent reports) for the CP group, opinions of boys and girls for the CP group, influence of type and severity of CP, gross motor function scores (GMFCS) and comorbidities (e.g. epilepsy, intellectual disability, incontinence) on HRQoL.

The statistical analysis was performed using SSPS-19 statistical software. Where KidSCREEN items were negatively formulated, they were recoded, as was recommended by the developers, so that higher values indicated higher HRQoL.

Questionnaires with more than 10% missing values were omitted. The items were summed and averages were calculated for each dimension score and for total score.

To compare the HRQoL of children with CP and without any chronic disease (GP) the age and the sex-adjusted means were compared with a covariance analysis (ANOVA). We used ANOVA descriptive statistics to investigate significant differences between mean scores of different groups and paired sample t-test. The Chi-square probe shows whether significant correlation exists between variables. Confidence index (CI) was =95%. Strength of correlation (r) was rated as weak = 0-0.25, medium weak = 0.25-0.5, medium strong = 0.50-0.75 or strong = 0.75-1. For establishing statistical significance p<0.05 was used. For measuring effect sizes (ES) Cohen’s d was used, which defines the difference between two means divided by standard deviation for the data. ES was rated as very small d=0.01; small 0.2; medium 0.5; large 0.8; very large 1.2 and huge 2.0.

Ethics
Approval was obtained from the Regional Science Ethical Committee of the University of Pecs and from the Regional/Local Committee of Science and Research Ethics of Borsod-Abauj-Zemplen, Heves and Nograd Counties. Informed consent was obtained from the children and their parents.

Results
Demographic data
Fewer CP and more GP questionnaires were given back than had been expected. Completed questionnaires were received from 99 CP families (44%). The mean age of the children with CP was 12 years 3 months, 46/99 were younger than 13 years. Kidscreen-52 questionnaires were given to 268 families from the general population, 237 (88.4%) were completely filled in and returned (237 parents and 236 children). The children’s average age was 12 years 11 months, 113 (47.7%) of them were under 13 years. 115 males (48.5%), 121 females (51.1%), 1 whose gender was unknown. Parental questionnaires were completed mainly by mothers (69.7% CP; 87.3% GP) (Table1).
The main features of cerebral palsy
Half of our patients (51; 51.5%) had the spastic bilateral type of CP and a quarter of them had (26; 26.3%) spastic unilateral CP. 55/99 children had moderate or mild intellectual disability (IQ = 50-70), 16/99 had active epilepsy at the time of completing the questionnaire, and 15 % of children had incontinence; 39.4 % of the children with CP had more than 2 comorbidities. 47.5% of children with CP walked without assistive device (GMFCS Level 1–2) (Table 1).

Validation of the General Population for KIDSCREEN
The data given by the general population were validated for the KIDSCREEN values. The values of GP parents did not differ practically from those of KIDSCREEN. Interestingly, the social acceptance (bullying) values of the Hungarian GP children were higher than the European average. Bullying was less common in both the general and the CP population than in the KIDSCREEN European population (EU: 71.35 %; GP: 95 %; CP: 90.8 % of available scores; p<0.05, ES=1.1) (Table 2).

HRQoL of children with CP compared to the General Population
Table 2 gives the mean KIDSCREEN scores and their standard deviations of children and parents of both the CP and GP groups. Similarities were found between self-reports of children and parental reports. Assessments of children with CP and of their parents differed from the values given by the children and their parents from the general population. Considering the summary of the ten KIDSCREEN dimensions, all children with CP and their parents rated their HRQoL as significantly poorer than children and their parents from the general population (p<0.001). Physical well-being, moods/emotions, financial resources, social support/peers and social acceptance/bullying were rated as significantly poorer by the children with CP and their parents compared to the assessments given by the GP children and their parents (Table 2).

Agreement of self- and parents’ proxy-reports in the CP population
Assessments of children and their parents were in medium strong positive relationship regarding the psychological well-being, moods/emotions, self-perception, autonomy, parent relation/home life dimensions (0.552<r< 0.747). The correlations were stronger than medium, also in a positive direction, in the financial resources, social support/peers and school environment dimensions (0.771<r<0.792). In the other domains no significant relationship was found. It seems that self-perception, school environment and social acceptance have larger effects on HRQoL as reported by parents than children.(p<0.001) (Tables 2–3)

Self-reports of children and adolescents with CP
No significant difference was found considering HRQoL of children according to age. Only the financial resources are near to significance (p<0.051, ES:-0.45). (Table 3)

Sex
Significant sex differences were found. Girls rated their total HRQoL as poorer than boys at p: 0.025, with three of ten dimensions being given lower assessments: psychological well-being, moods/emotions and autonomy (p: 0.002–0.029, ES: medium strong, 0.52–0.76) (Table 3). In addition, parents of CP girls felt their financial status was worse than parents of boys (p: 0.006–0.033).

Other variables
The severity of disability
With the severity of CP, not only the assessment of physical well-being remarkably diminishes, but financial resources, social support/peers, and social acceptance dimensions were evaluated as poorer as well. There is also a measurable difference in the friendship, school environment and social acceptance dimensions (p: 0.003–0.004, ES: medium -0.6–0.69). Compared to the GP population both family life (parent relation/home life) and school environment were evaluated better, receiving higher scores for all three severity groups of CP (Figure 1).

HRQoL by types of CP
Patients with CP were ranked into 3 groups according to the types of their motor disabilities: unilateral spastic CP, bilateral spastic CP and other. Physical well-being was assessed as worst in the bilateral spastic CP group (ES related to unilateral and other CP-s: 0.5;-1.7). Although values for unilateral spastic CP were consistently lower than the other types of CP groups, no significant difference was found among the three groups. All CP types differed significantly from GP except for parent relation/home life and school environment domains (p< 0.05 significance level) (Figure 2).

GMFCS level
The more severe the motor disability based on GMFCS was, the lower physical well-being was assessed (p:0.029, ES: medium, 0.5). (Figure 3)

Intellectual disability
More than half of patients with CP had a mild to moderate degree of intellectual disability (ID). ID clearly negatively influenced only the social support/peers dimension according to the assessments of both children and their parents (p=0.019–0.007, ES: medium 0.61–0.51). Parents of children with ID are at risk of perceptions of stigma (Figure 3).

Epilepsy
Considering epilepsy as an associated disorder of CP, both parents and their children with CP evaluated the school environment (p=0.012, ES: 0.55) and social acceptance as significantly lower (p=0.048-0.003, ES: 0.63-0.99), than the GP population. (Figure 3)

Incontinence
Incontinence primarily affects social life. The parents of children with CP considered their financial situation, their children’s autonomy, friendly relations and school environment significantly worse when their children had associated incontinence (p=0.001-0.023, ES: 0.71-0.95). Assessments of the children with CP and incontinence were very similar to those of their parents (p=0.022, ES: 0.71-0.95). (Figure 3)

Discussion
Children with CP have differing ranges of physical, orthopedic and cognitive impairments. They have varying degrees of limited mobility and self-care capability and therefore they have also restrictions in participation. Traditional medical treatment primarily focuses on the physical symptoms of patients. In our study we wanted to examine not only the physical and mental health status of children with CP but to reveal how this disability influences their HRQoL.

Recent studies measured self-reported quality of life of 8-12-year-old children with CP in six Western European countries, and they found that children with CP had similar QoL to children in the general population with the exception of schooling and physical well-being (24). In our country, similar studies have not been yet carried in children with CP, so our study compensates this deficit.

We assessed HRQoL of children with CP with a validated questionnaire in comparison with general population (control) children. KIDSCREEN-52 children and adolescents and parental HRQoL tests were improved and validated by a project of the European Union (30–31). A total of 99 children with CP and 237 children from the general population were participated in the study. Children’s quality of life was self-reported with the KIDSCREEN-52 questionnaire, while parents filled in the parental form. QoL scores of 10 dimensions were compared between the CP and general population, between children and parents, and between children and
adolescents with CP. The data of general population were quite homogeneous. The focus was directly on the views of children and adolescents, but we obtained valuable proxy data from parents, too.

We found that parent-reported scores were similar to the child-reported ones in both groups (CP and GP). Parent proxy reports were complementary to children reports in situations that are well-known for parents, e.g. physical and psychological states, but gave different scores for self-perception and school environment question groups.

Not surprisingly QoL scores were lower in the CP group than in the general population; all children with CP and their parents assessed their total HRQoL as significantly poorer than children and their parents from the general population (p<0.001). Similar results were published in other studies (18-20). Children with CP and their parents rated their family life (parent relation/home life) and school environment dimensions as more interesting and pleasant than the GP children and their parents did. This suggests that cohesion in families with disabled children may be stronger than in other families from the general population. The fact that both children with CP and their parents assessed the school environment with better scores than the “control” families did is encouraging, especially for the present school system for disabled children.

In our study the age-specific self-reported HRQoL of children with CP was similar to each other, but the older children had a more realistic and informed view of their financial situation. Age-specific differences have been found in other publications (21,24), but with the exception of the financial resources dimension, we did not see any significant difference between the assessments of the children and adolescents. The financial situation of the family or the mother’s occupation influenced the socio-economic environment and long-term outcomes (25). Adult examinations suggest that quality of life is best characterised by interpersonal relationships, personal development, and social inclusion rather than in case of physical or material well-being (26).

Both children’s and parents’ perspectives were essential to understand the impact of a condition on a child’s HRQoL. (25, 26) The strength of correlation of answers of children-adolescents and their parents provides vital information (27). In the investigated sample, family cohesion was reflected in the strongly correlated answers of the CP children-adolescents and their parents. In previous studies, parent perception of HRQoL in the CP group was lower level. (20, 21). In our study we observed significant differences compared to the general population (p< 0.000) and despite the correlation, significant differences were detected in six domains between children and parents with CP. These differences show that both disease and environmental factors change the HRQoL. (22-24)

The emotional life of the girls with CP was rated lower compared to the boys, as also found in (23), probably due to the higher value placed on bodily appearance or body image.

Our findings regarding degree of severity of CP confirm those of some earlier studies. Lower functional ability has been associated with higher GMFCS scores and lower levels of physical and psychological HRQoL (25–27). Comorbidities (e.g. epilepsy, mental impairment, incontinence) impair the psychosocial HRQoL (26–28). Family and friend domains directly affected others, which would improve with early interventions. (29) Adult examinations suggest that quality of life is best characterised by interpersonal relationships, personal development, and social inclusion rather than physical or material well-being (26).

We found that the severity of CP had a very remarkable impact not only on the physical well-being but also on financial resources, social support/peers, and social
acceptance dimensions as well. Power et al. reported that children with CP from low- and middle-income countries had significantly poorer HRQoL in all dimensions compared to age-matched controls. They found physical well-being to be the poorest dimension (34). We have to take into consideration that the expenses of the families (transport, nutrition, drugs, diapers, etc.) increase with the severity of CP. Besides that, it is clearly evident that families whose child has severe CP need more social acceptance and support. Our findings correlate well with the results of Colver et al. (24). Studying adolescents with CP, they also found that the severity of impairment was significantly associated (p<0.01) with reduced quality of life in three domains (moods/emotions, autonomy, and social support/peers). Adolescents with CP had a significantly lower quality of life than those in the general population in only one domain (social support/peers; mean difference -2.7 (0.25 SD), 95% CI -4.3 to -1.4).

Importantly, the types or distribution of CP did not significantly influence the total HRQoL of children, but we found that HRQoL was generally rated lower in the group with unilateral type CP than in the bilateral and other CP types. Based on this finding, we can assume that the difference between the two sides of the body can be very disturbing for these children. We have not found any other data to confirm this assumption; further studies are indicated on a larger group of different types of CP.

We found that associated intellectual disability negatively influenced only the social support and peers dimension. Children with CP and epilepsy and their parents assessed their HRQoL as being significantly poorer comparing to the GP population only in the school environment and social acceptance (bullying) dimensions. This means that epilepsy is still a stigma, children with epileptic seizures are bullied by their classmates, and their teachers are also negatively influenced by the presence of epilepsy. Associated incontinence deteriorates the HRQoL of children; not only their autonomy but their peer relations diminish as well. Our findings confirm the importance of peer relations and friendships in children with CP.

Strengths
We studied not only children with CP but we had an age-matched comparison group as well. Sample size was relatively high in both groups. The main strength of our study that it is based not only on the assessments of the parents but that children’s opinions were asked as well. In the majority of the published studies there is a lack of age-matched healthy control general population group and only the parents of the disabled children are involved.

Considering the relatively wide age range and number of the participants we were able to compare the reports of children and adolescents. Children with CP and with slight-to-moderate intellectual disabilities were not excluded, meaning that their views were being heard.

Limitations
Weaknesses were that our CP population was not quite homogenous considering the type of CP and GMFCS levels. Most of the patients had severe co-morbidities, which negatively influenced the HRQoL. We could only ask the opinions of the children who were able to answer the questions, so the results reflect the self-reported assessments of children who are not very seriously impaired. Those children with CP who were not able to fill in the tests alone needed a longer time to fill them in than those from the general population.

Conclusion
Chronic disability has a negative impact on the HRQoL of children and adolescents with CP. The age, GMFCS status, and co-morbidities were in negative correlation with each other and with many domains of HRQoL. Significant gender differences were found, the girls with CP rated their psychosocial HRQoL lower than the boys did. All patients with CP had higher T-values in the parental and school environment domains than the GP children. This is an important factor, it means that disabled children and adolescents are more attached to their parents and teachers. The analysis revealed that the severity of CP influenced the QoL of children and their parents to a large degree.

This study helped identify the psychosocial care needs of parents and children with CP. Based on our results, psychosocial care is needed not only for CP patients but also for their family members. Therapeutic recreation programs have been reported to improve the HRQoL of chronically ill patients (35-36), and adolescents have reported a need to participate in age-appropriate and leisure activities (37). Family-centered care would help these families and it would improve the integration processes. Living standards would improve for families with children with disabilities if they had a higher income.

The clinical significance of this study is that reported negative factors can be influenced and medical doctors, nurses and policy makers have to try to make a positive impact. CP is a life-long disorder, it influences the employment, marriage, and socio-economic status of the patients with CP in adulthood. There is a need to improve the negative impacts of CP. The gap between self-reported and parent-reported HRQoL scores is well-known in chronic diseases.

We concur with (38) in urging pediatricians, pediatric neurologists, rehabilitation specialists and family doctors to take into consideration the different perceptions of HRQoL between children and parents and to consider the child’s own perspective whenever feasible. Our study highlighted that children with CP have reliable knowledge about their own condition. We hope that this analysis aids in understanding the relationship between HRQoL and different variables of children and adolescents with CP. There is a need for further HRQoL studies directly focusing on the views of patients.

Abbreviations

HRQoL: health related quality of life, CP: cerebral palsy, GMFCS : Gross Motor Function Classification System, CI :Confidence index, GP :general population, ES: effect size, ID :intellectual disability, SD: Standard Deviation, T: mean T-value, P: parents, PID: parents with intellectually disabled child, C: child, CID: child with intellectual disability, E: epilepsy, INC: incontinence

Declarations
Ethics approval and consent for publication

Approval was obtained from the Regional Science Ethical Committee of the University of Pécs (2012.03.31. Number: 4416) and from the Regional/Local Committee of Science and Research Ethics of Borsod-Abauj-Zemplen, Heves and Nógrád Counties. Informed consent was obtained from the children and their parents.

Consent for publication

The manuscript does not contain data from any individual person, it is not applicable.

Availability of data and material

The original database is available at M.F, the questionnaires and parental informed consents are at M.F. and K.H. Results of statistical probes are at B.V. and M.F. The original database has personal data.

Competing interest

The authors declare that they have no competing interest.

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Authors’ contributions

K.H. had the original idea. K.H., M.F collected the dates. Data entry was done M.F., B.V. The statistics analysis was made by M.F, B.V. All authors contributed to the data interpretation and to writing the manuscript. All authors read and approved the final manuscript. A native English reviewer checked the grammar and the composition.

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Tables

Table 1 Descriptive information of groups of Cerebral Palsy (CP) and general population (GP)
| Variable                  | CP (N°/%) | GP (N°/%) |
|---------------------------|-----------|-----------|
| **Total**                 | 99/100    | 237/100   |
| 8-12 years                | 46/46.5   | 113/47.7  |
| 13-18 years               | 53/53.5   | 124/52.3  |
| Age (mean±SD)             | 12 y 3 mo ± 7.5 mo | 12 y 11 mo ±7 mo |
| **Sex**                   |           |           |
| - Male                    | 42/42.4   | 115/48.5  |
|   - Female                | 57/57.6   | 121/51.1  |
|   - Unknown               | 0/0       | 1/0.4     |
| Parental tests filled by %|           |           |
| Mother                    | 69/69.7   | 207/87.3  |
| Father                    | 17/17.2   | 22/9.3    |
| Other relatives           | 9/9.1     | 6/2.5     |
| Unknown                   | 4/4.0     | 2/0.9     |
| Types of CP               |           |           |
| Spastic Unilateral        | 26        | 26.3      |
| Spastic Bilateral         | 51        | 51.5      |
| Dystonic                  | 5         | 5.0       |
| Choreoathetotic           | 1         | 1.0       |
| Ataxic                    | 7         | 7.1       |
| Non-classified            | 6         | 6.1       |
| Unknown                   | 3         | 3.0       |
| Comorbidities             |           |           |
| Intellectual disability   | 55        | 55.6      |
| Active epilepsy           | 16        | 16.2      |
| Incontinence              | 15        | 15.2      |
| Severe disabled*          | 39        | 39.4      |
| GMFCS level               |           |           |
| 1                         | 21        | 21.2      |
| 2                         | 26        | 26.3      |
| 3                         | 15        | 15.2      |
| 4                         | 12        | 12.1      |
| 5                         | 20        | 20.2      |
| Unknown                   | 5         | 5.0       |

**Abbreviations:** N°: Number of patients, SD: Standard Deviation, %:percent, y: year, mo: month. GMFCS: Gross Motor Function score, *severely disabled: >2 comorbidities
Table 2 Mean T-values and their standard deviation of GP and CP parental and child population with Cohen effect size (ES) calculations between groups

| Questions                              | Children GP       | Children CP       | Parents GP       | Parents CP       |
|----------------------------------------|-------------------|-------------------|------------------|------------------|
| Sum                                    | T ±SD ES-1        | T ±SD ES-2        | T ±SD ES-3       | T ±SD            |
| Sum                                    | 51.7 8.6 0.17     | 50.6 10 0.08*     | 54.1 8.60 0.06   | 51.2 1           |
| Physical Well-being                    | 52.9 14.4 0.29    | 35.7 27.6 1.32*   | 52.3 12.2 0.03   | 40.7 1           |
| Psychological Well-being               | 53.6 13.8 0.36    | 52.5 16 0.08      | 59.0 11.2 0.12   | 52.7 1           |
| Moods & Emotions                       | 55.3 10.6 0.53    | 53.3 13.2 0.15*   | 53.2 8.60 0.04   | 51.4 1           |
| Self-Perception                        | 46.2 4.2 -0.38    | 44.1 4.8 0.16     | 52.6 11.2 0.03   | 54.0 1           |
| Autonomy                                | 52.2 17 0.22      | 51.5 17.8 0.05    | 50.6 15.2 0.01   | 50.2 1           |
| Parent Relation & Home Life            | 53.4 12.6 0.34    | 54.7 12.6 -0.10   | 53.6 12.4 0.05   | 55.2 1           |
| Financial Resources                     | 52.9 21.6 0.28    | 42.7 27.2 0.78*   | 54.0 20.4 0.05   | 46.7 2           |
| Social Support & Peers                 | 53.8 16.8 0,8     | 48 19.8 0.44*     | 54,90 15.0 0.05  | 48.8 6           |
| School Environment                     | 55 15.8 0.5       | 58,9 13.6 -0.8    | 54,0 13.0 0.06   | 55.1 1           |
| Social Acceptance                      | 61 9.6 1.1*       | 51.7 14.6 0.6*    | 53.0 9.0 0.5     | 51.3 4           |

Abbreviations: SD: Standard Deviation, GP: General Population, CP: children with cerebral palsy, T: mean T-value ,*: p< 0.05, **p<0.001, Sum: summary of the ten KIDSCREEN dimensions. ES-1: Cohen effect sizes between KIDSCREEN and GP, ES-2:
Cohen effect sizes between GP and CP children, ES-3: Cohen effect sizes between KIDSCREEN and GP, ES-4: Cohen effect sizes between GP and CP parents.
Table 3 Agreement of child and parent assessments in the CP population and KIDSCREEN HRQoL scores according to age and sex
| Dimensions | Child-Parent | Age | Sex |
|------------|--------------|-----|-----|
|            | r  | ES-5 | 8-12 years | 13-18 years | Male | Female |
|            |    |      | T- value ±S D | T- value ±S D | ES-5 T- value ±S D | ES-5 T- value ±S D | ES-5 T- value ±S D | ES-5 T- value ±S D |
| Sum        | .83 | -0.01 | 50. 10 75 | 50. 10 45 | 0.0 2 94 | 0.0 51. 48 | 0.0 | 10. 48. 48 |
| Physical Well-being | .27 | -0.02 | 44. 18 14 | 42. 15. 8 8 | 0.2 16. 48 | 0.1 62. 42 | 0.1 | 7. 42. 42 |
| Psychological Well-being | .74 | -0.00 | 53. 12 28 | 51. 17. 8 8 | 0.2 13. 7 | 0.5 26. 50 | 0.5 | 7. 50. 50 |
| Moods & Emotions | .71 | 0.02 | 54. 13 48 | 52. 13 3 | 0.2 11. 55 | 0.6 11. 55 | 0.6 | 6. 50. 50 |
| Self-Perception | .55 | -0.15 | 42. 4.8 93 | 44. 4.8 81 | 0.04 * 4.4 73 | 0.4 44. 63 | 0.4 | 3. 42. 42 |
| Autonomy | .70 | 0.01 | 48. 13. 82 | 53. 17. 4 | -0.2 8 | 0.7 17. 49 | 0.7 | 6. 46. 46 |
| Parent Relations & Home Life | .61 | -0.01 | 53. 12 96 | 55. 12 3 | 0.0 9 | 0.1 53. 72 | 0.1 | 5. 73. 73 |
| Financial Resources | .77 | -0.01 | 38. 28 25 | 45. 25 88 | -0.45 * | 29 | 56 | 29. 56 |
| Social Support & Peers | .77 | -0.00 | 47. 19 2 | 48. 20 46 | -0.0 8 | 0.3 45. 83 | 0.3 | 4. 45. 45 |
| School Environment | .79 | 0.03 | 57. 12 59 | 59. 14 27 | 0.0 6 | 0.2 59. 68 | 0.2 | 4. 68. 68 |
| Social Acceptance | .70 | -0.00 | 51. 13 68 | 50. 15 65 | 0.1 2 | 0.1 50. 41 | 0.1 | 3. 51. 51 |

Abbreviations: r: Pearson correlation, significance *p<0.05, **p<0.001, SD: standard deviation, mean: mean KIDSCREEN scores, Sum: summary of the ten KIDSCREEN scores ES: Cohen effect sizes. ES-5: child-parent effect sizes, ES-6: child-adolescent effect sizes, ES-7: male-female effect sizes.
Figures

Figure 1

Relationship of HRQoL T-values to CP severity (GP mean score=50, SD=10) Abbreviations:
- GP: General Population
- CP: Cerebral Palsy
- Mild: CP+1 comorbidity
- Severe: CP+2 or more comorbidities
- 1: GP score
- 2: Total CP score
- 3-12: Several domains

Figure 2

Types of cerebral palsy (CP) and the HRQoL T-values related to the general population
HRQoL assessments of CP patients with comorbidities (intellectual disability, epilepsy, incontinence, severe or mild motor disability) and their parents.