

## Summary

### *Assessment of the quality of life in the adolescents aged 13-18 with cerebral palsy validation of the CP QOL-Teen scale*

**Introduction** Particular emphasis on patient subjectivity presented by WHO led to the creation of the concept of quality of life dependent on health (HRQOL). This made it possible to conduct research on the quality of life using standardized tools, including questionnaires with proven psychometric properties. They allow to assess the impact of the therapy on the patient' quality of life giving the opportunity to modify and improve the treatment.

**Aim:** The main aim of the dissertation was to conduct the Polish cultural adaptation and assessment of validity and reliability of the CP QOL-Teen scale. Another aim was to compare the self-assessment of teenagers' quality of life with the assessment of their quality of life by their parents. In addition, analysis of the relationship between quality of life in teenagers with CP aged 13-18 checked with CP QOL-Teen questionnaire and clinical questionnaires (GMFCS E&R, prematurity) and socio-demographic determinants (age, sex, education, family status, parents' education) of the disease.

**Material:** 84 adolescents with CP aged 13-18 and 81 parents were enrolled in the study. The group of teenagers consisted of 84 people, including 37 girls (44.05%) and 47 boys (55.95%). The mean age was 15.11 (SD-1.63). GMFCS level I had 28 subjects (33.33%), GMFCS II - 26 subjects (30.95%), GMFCS III - 11 subjects (13.10%), GMFCS IV - 16 subjects (19.05%), GMFCS V - 3 subjects (3.57%). The premature babies constituted up to 60% of the group of adolescents. The group of parents consisted of 81 people, women dominated -72 (88.89%) and 9 men (11.11%). Most parents had secondary education: 65.43%, higher 28.4%, the rest 6.17% had primary education. As in the case of adolescents, the majority of parents inhabited rural areas. 75.31% of the respondents lived in both-parent families, in single-parent-family: only mother: 20,99% only father: 1.23%, 2 adolescents lived with their legal guardians.

**Methods** In the first stage of the research, the process of translation and cultural adaptation of the Polish version of CP QOL-Teen was carried out in accordance with the authors' guidelines and based on available literature. In the next stage, psychometric properties of the Polish version of the CP QOL-Teen questionnaire were evaluated and the quality of life assessed by adolescents and their parents. The correlation between clinical and socio-demographic factors was examined, and the assessment of the quality of life by teenagers and the assessment of the

teenagers' quality of life in the parents' opinion were examined. After 4 weeks, a re-test was performed in which time coherence was assessed.

**Results** As a result of the first stage of the study, a Polish version of the CP QOL-Teen questionnaire was created. The Cronbach's alpha (internal coherence) for individual subscales was from 0.858-0.953 in the analysis of teenagers' results and from 0.824-0.937 in the analysis of parents' results. The interclass correlation coefficient (ICC) used to assess temporal coherence was for individual subscales from 0.82 to 0.889 in the analysis of teenagers' results and from 0.702 to 0.798 in the analysis of parents' results. The validity of the questionnaire was evaluated using the Spearman correlation coefficient between the results of the CP QOL-Teen questionnaire for teenagers and the results of the generic questionnaire KIDSCREEN-27. All CP QOL-Teen subscales of the teenager's version correlated moderately between 0.5-0.6 with all KIDSCREEN-27 subscales. Majority of CP QOL-Teen subscales of the parent's version correlated moderately between 0.4-0.6 with all KIDSCREEN-27 subscales.

The best quality of life for adolescents was in the domains of "social well-being": 79.48 and "feelings about functioning": 73.58, and the weakest in the domains "general well-being and participation": 68.99 and "school wellbeing": 69.5. The best results of the assessment of the teenagers' quality of life in the parents' opinion were obtained in the domains of "social well-being": 78.83, and "communication and physical health": 67.36, and the worst in the domains "family health" 64.24 and "access to services" 56.81. A correlation was found between the quality of life and adolescent age, the level of functioning assessed in the GMFCS scale as well as the way the teenager moved, the family situation and the frequency of rehabilitation. The mean value of the teenagers' quality of life measurement was 69.02, while in the parents' opinion 65.58.

**Conclusion** The Polish adaptation of the CP QOL-Teen questionnaire is a valid and reliable research tool for the assessment of the quality of life in teenagers with CP. Teenagers with CP aged 13-18 assessed their quality of life at good level which was in line with their parents' assessment. However, there were differences in individual domains. A relationship was found between the results of the quality of life assessment according to teenagers' and their parents. The assessment of the relationship between teenagers' responses and parents' ones showed that teenagers rated their quality of life significantly higher than their parents. The level of gross motor skills in GMFCS E&R has a significant impact on the quality of life of teenagers with CP in subscales related to the functioning assessed by teenagers and parents. Growing up

in a both-parent family positively influences the teenagers quality of life in two domains:  
"social well-being" and "access to services" according to parents.