Abstract

Objective: To assess the association between social participation and health-related quality of life (HRQOL) of children with special health care needs (CSHCN) and to investigate covariates of social participation of these CSHCN.

Methods: The present cross-sectional study is embedded in the cluster-randomized stepped wedge study PART-CHILD. In 14 social pediatric centers, 628 parents of CSHCN (aged 3-18 years) were interviewed before the intervention phase via paper or online questionnaires, about their child's HRQOL and social participation. HRQOL is investigated through the DISABKIDS Chronic Generic Measure (DCGM-12) and social participation through the Child and Adolescent Scale of Participation (CASP). Multilevel models were used (1) to examine the association between social participation and HRQOL of CSHCN while controlling for potential confounders (sex, age, migration background, education, indication) and (2) the association between social participation of CSHCN and covariates (sex, age, migration background, education, indication).

Results: Social participation of 357 CSHCN was positively associated with HRQOL. Lower levels of social participation were shown for 409 CSHCN without migration background or with higher levels of disability compared to CSHCN with migration background or lower levels of disability, respectively. Older CSHCN (aged 5-15 years) showed higher levels of social participation compared to younger CSHCN (aged 3-4 years).

Conclusion: Social participation is a contributor to HRQOL of CSHCN, and hence should be more focused on in health care and society. Moreover, child- and parent-related factors that might influence social participation should be considered more on an individual basis in health care in order to achieve a higher social participation of CSHCN.