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HEALTH-RELATED QUALITY OF LIFE IN CHILDREN AND ADOLESCENTS WITH STROKE, SELF-REPORT AND PARENT/PROXY REPORT: CROSS SECTIONAL INVESTIGATION

B. Neuner¹, S. von Mackensen², S. Friedfeld³, G. DeVeber⁴, U. Nowak-Göttl⁵ ¹Department of Epidemiology and Social Medicine, University of Münster, Münster, ²Institue of Medical Psychology, University Medical Center Hamburg-Eppendorf, Hamburg, Germany, ³Department of Occupational Science and Occupational Therapy, Faculty of Medicine, University of Toronto, ⁴Hospital of Sick Children, Toronto, ON, Canada, ⁵Department of Pediatric Hematology/Oncology, University of Münster, Münster, Germany Background: Aim of the present study was to assess health-related quality of life (HR-QoL) by self and proxy-parent assessment in children and adolescents who survived a first stroke episode.

Methods: We investigated HR-QoL in 133 pediatric stroke survivors (71 preschool children (G1) aged 4 to < 8 years and 62 school children/adolescents (G2) aged 8 to 21 years) and in 169 healthy controls aged 4 - 16 years. HR-QoL was assessed with the generic KINDL-R questionnaire exploring overall well-being and 6 sub-dimensions (physical well-being, psychological well-being, self-esteem, family-related well-being, friend-related well-being, and school-related well-being. Proxy-parent reports explored overall well-being and sub-dimensions. Results were compared within groups between cases and controls. In pediatric stroke survivors the neurological long-term outcome was measured with the standardized Pediatric Stroke Outcome Measure.

Results: 65% of stroke survivors exhibited at least one motor-sensor/cognitive disability. G1 and G2 stroke survivors reported lower overall well-being compared with healthy controls. In G2 stroke survivors, friend-related well-being was significantly reduced compared with healthy controls, 85.0 vs. 73.0 points, p< 0.001. Parents/proxys of both G1 and G2 stroke survivors rated the overall well-being and all sub-dimensions (except family-related and school-related well-being and in G1 stroke survivors physical functioning) lower compared with parent/proxys of healthy children/adolescents.

Inpretation: Our results suggest that the KINDL-R questionnaire is a useful tool in the assessment of HR-QoL in pediatric stroke survivors. Compared with healthy controls, all pediatric/adolescent stroke survivors are strongly affected regarding their overall well-being and older children/adolescents regarding their well-being with peers.