

Summary

C. Petersen

The growing interest of health care providers and researchers in valid and sensitive HRQOL measurement has been a driving force for the development of such instruments in the paediatric area. Historically, HRQOL has been used as a synonym for a subject-centred perspective on health. Recently, researchers started to address the relationship between HRQOL and the way of how children deal with their disease. Coping strategies may play an important role for the adaptation process and for a better HRQOL. Within the 5th Framework Programme on "Quality of Life and Management of Living Resources" the European Commission funded a project for three years starting February 1st, 2001. The aim of the project is to enhance HRQOL of children and adolescents with disabilities and their families by developing, testing, and implementing European instruments for the assessment of HRQOL. The current thesis was connected to this project and focussed on the development of two measures: a chronic generic HRQOL as well as a coping questionnaire. Using literature searches, expert consulting and focus groups with the children/ adolescents and families, items of the instruments were developed and translated into the respective languages. A pilot test with 380 children and adolescents was conducted. Children and adolescents (8-12,13-16 years) with different chronic health conditions (asthma, epilepsy, diabetes, arthritis, atopic dermatitis, cerebral palsy, and cystic fibrosis) as well as their families were included. Data was analysed according to predefined psychometric and content criteria. Analyses resulted in a 56-item version of the chronic generic HRQOL questionnaire with six domains ("Treatment", "Physical", "Emotion", "Independence", "Social Inclusion", "Social Exclusion"). The final coping questionnaire CODI contains 29 items and six coping strategies ("Emotional Reaction", "Cognitive-Palliative", "Acceptance", "Distance", "Wishful Thinking", "Avoidance"). The results of the thesis will be helpful in discussing challenges and possible solutions of European cooperation within the HRQOL field. The thesis has provided sound measures for the assessment of chronic generic HRQOL and coping. The potential implementation of the new tools in the clinical settings has to be planned, tested, and evaluated in the near future.