A comparison of self-reports and parent-proxy reports on Health related quality of life (HRQoL) of children and adolescents with Diabetes and Epilepsy

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The prevalence of chronic physical health conditions has increased over the past decades and is still rising (Perrin et al., 2007; Van Cleave et al., 2010). Approximately 10-20% of the child population in the western world are suffering from chronic conditions, of which 1-2% are of such severity that they may cause ongoing problems for the child (Wallander & Varni, 1998) and have a negative impact on their health-related quality of life (HRQoL). HRQoL has been defined by Ebrahim (1995) as those aspects of self-perceived well-being that are related to, or affected by the presence of disease or treatment. Children with chronic diseases have a distinct perspective on their own lives as a result of numerous complex social, economic, and medical variables (Ingerski et al., 2010; McDougall et al., 2011). However, there may be circumstances where children and adolescents with chronic diseases are unable to report on their perceived HRQoL, for example due to very young age, cognitive impairment, severe disease or fatigue, and in such instances researchers must rely on reliable and valid parent proxy-measurements (Varni et al., 2007). A cooperation by seven European countries led to the development of The DISABKIDS questionnaires for assessment of HRQoL of children with chronic conditions (Bullinger et al., 2002), and it includes both a self-report questionnaire and a parent-proxy questionnaire. The main objectives of its development were fourfold: (1) The development and promotion of standardized measure of HRQoL for children with heterogeneous chronic health conditions; (2) enabling comparisons of HRQoL internationally across Europe; (3) addressing the needs for care based on the patient´s points of view and (4) enhancing the HRQoL and the independence of children with chronic health conditions. Assessment and monitoring of HRQoL may then facilitate the creation of successful intervention strategies by enabling the identification of unmet health care requirements (Bullinger et al., 2002).