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Agreement in quality of life assessment between adolescents with intellectual disability and their parents



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ABSTRACT

Intellectual disability affects different aspects of functioning and quality of life, as well as the ability to independently assess the quality of life itself. The paper examines the agreement in the quality of life assessments made by adolescents with intellectual disability and their parents compared with assessments made by adolescents without intellectual disability and their parents.

Participants included 67 adolescents with intellectual disability and the same number of their parents. Control group consisted of 122 typically developed adolescents and an equal number of their parents. In order to assess the quality of life we used The PedsQL 4.0 Generic Core Scale questionnaire, for adolescents aged between 13 and 18 and their parents. Agreement in assessing quality of life between adolescents and parents was analyzed using *t*-test, Kappa Statistics and Pearson correlation.

The agreement between adolescents with intellectual disability and their parents was found to be acceptable ($k = 0.43$), while the agreement between adolescent from control group and their parents was judged to be good ($k = 0.84$). Correlations between adolescents with intellectual disability and their parents varied across subscales from weak ($r = 0.31$) on the physical health subscale to moderate ($r = 0.56$) on the social subscale. Adolescents with intellectual disability were less satisfied with their social functioning. The highest agreement, as well as the lowest means value was found on the social agreement scale.

Assessment of the quality of life by both adolescents and their parents provides a comprehensive insight into functioning and different aspects of quality of life in these adolescents.

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1. Introduction

Quality of life is a multidimensional construct that depends on our physical and social environment, as well as on our emotional and existential reactions to the environment (Cummins, 2005; Fairclough, 2010). Renwick and Brown (1996) considered that quality of life should be viewed as a dynamic process that can change over time and can be assessed at any point in time (Renwick & Brown, 1996). The quality of life of persons with disabilities has been studied through the prism of rehabilitation, health and medical care, health promotion and to a lesser extent education (Brown & Brown, 2003). To date,

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researches have shown that the quality of life for children with developmental disabilities is lower than the quality of life for children without developmental disabilities, as well as that different disabilities have different effects on the quality of life in general and in specific aspects of functioning (Watson & Keith, 2002). In recent years, attention has been given to the quality of life of children with different types of disability and thus the subject of researches were children with multiple disabilities (cerebral palsy, attention deficit hyperactivity disorder, children with developmental disabilities due to cognitive and sensory impairments (Arkkila et al., 2009; Boulton, Haines, Smyth, & Fielder, 2006; Limbers, Heffer, & Varni, 2009; Rajendran & Roy, 2010; Shipman, Sheldrick, & Perrin, 2011; Tadić et al., 2010; Thurston, Paul, Loney, Wong, & Browne, 2010; Varni & Burwinkle, 2006). Results of these researches showed that the quality of life of children with developmental disabilities is lower than the quality of life for children without developmental disabilities (Arkkila et al., 2009; Boulton et al., 2006; Limbers et al., 2009; Rajendran & Roy, 2010; Shipman et al., 2011; Tadić et al., 2010; Thurston, Paul, Loney, Wong, & Browne, 2010; Thurston, Paul, Ye, Loney, Browne & Thabane, 2010; Varni & Burwinkle, 2006). The quality of life of children has declined in proportion to the severity of impairment, as well as the presence of related disorders or other chronic diseases. Also, the quality of life decreased with the age of children and the older children had lower quality of life than younger children (Thurston, Paul, Ye, et al., 2010). A number of studies have shown that the psycho-social aspects of life were more in danger than physical aspects. Due to the inability to obtain an adequate response of children with developmental disabilities, assessment was most often made by their parents, teachers, educators and therapists (Limbers et al., 2009; Thurston, Paul, Loney, et al., 2010). A certain number of researches have taken into account the self-assessment of a child with developmental disabilities and the assessment of his/her parents, thus gaining a holistic picture of the child's quality of life (Eiser & Morse, 2001; Shipman et al., 2011; Varni & Burwinkle, 2006; Varni, Limbers, & Burwinkle, 2007). In some studies where assessments were made by the children and their parents, there was a low to moderate agreement between the responses, especially when it comes to children with intellectual disability (Janssen, Schuengel, & Stolk, 2005; McVilly, Burton-Smith, & Davidson, 2000). Parents tend to assess the quality of life of their children lower than do children (Shipman et al., 2011; Varni & Burwinkle, 2006). Although self-assessment is seen as the standard for measuring quality of life, in some cases, when a child is too young, with developmental and cognitive disability, too sick or exhausted, it is necessary to take into account the assessment of the quality of life of the child performed by a parent, guardian, educator, teacher and so on. In order for a child to be eligible to perform the assessment of his/her quality of life, he/she needs to reach a certain developmental level, which includes competency in verbal comprehension, understanding and use of the concepts of time, differences in developmental milestones and identification of the quality of life domains and important milestones (Wallander, Schmitt, & Koot, 2001). Taking into account the specificities of certain types of disabilities, as well as the individual needs of children and their parents should serve the process of making a plan to provide developmental disability services, programs, individual interventions and treatments, monitoring the effects of new strategies (guidelines) in practical work with these children, with the aim to establish an optimal quality of life for children with developmental disabilities. The main objective of this study was to determine whether there is an agreement in the quality of life assessments made by adolescents with intellectual disability and their parents compared with assessments made by adolescents without intellectual disability and their parents.

2. Materials and methods

2.1. Participants

The study included 189 adolescents aged 13–18 years and the same number of parents. The sample was divided into two groups. Group I comprised 67 adolescents, of which 35 (52.24%) boys and 32 (47.76%) girls with intellectual disability, with the mean age of 15 years and 10 months ($SD = 14.74$) and 67 parents of adolescents with intellectual disability. Based on data from school records on intellectual functioning level, in this group of adolescents 62 (92.54%) were students with the mild intellectual disability and 5 students (7.46%) were adolescents with moderate intellectual disability. All the participants in this group were recruited from special schools. The mean age of the parent/guardian/other person who completed the questionnaire related to the quality of life of the child was 44.3 years.

Criteria for inclusion in the study were: intellectual disability without comorbidities, 13–18 year age range, knowledge of Serbian language and that participants lived with their parents or guardians. We obtained parent or guardian consent forms. Exclusion criteria included presence of hearing and visual impairments orthopedic, neurological, and severe behavioral disorders. These criteria were chosen in order to maintain homogeneity of the samples. Group II was the control group and comprised 122 adolescents with typical development and their 122 parents. Regarding gender this group comprised 62 (50.82%) boys and 60 (49.18%) girls, with the mean age of 15 years and 6 months. ($SD = 15.70$). Control group participants were selected from schools located in the same area as those attended by participants with ID. The mean age of the parents who completed the questionnaire was 43.55 years. Criteria for participation in the study were: parents or guardians consent form, children aged 13–18 years, knowledge of Serbian language and that children live with their parents or guardians.

2.2. Instruments

The PedsQL 4.0 Generic Core Scale for adolescents aged 13–18 years has been used to assess the quality of life in this research (Varni, Seid, & Rode, 1999).

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