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## Quality of life in adolescents and adults with autism spectrum disorder: Results from a nationwide Danish survey using self-reports and parental proxy-reports

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### ABSTRACT

**Background:** Quality of life (QoL) in individuals with autism spectrum disorder (ASD) is essential to investigate with regard to knowledge about factors of importance for QoL and concordance between self-reported and parental proxy-reported QoL.

**Aims:** This study investigated QoL in adolescents and adults with ASD using both self-reports and parental proxy-reports.

**Methods:** From a nationwide survey, 1738 individuals diagnosed with ASD in childhood, were included for this study. The individuals themselves and/or their parents completed the INICO-FEAPS scale. Concordance between self-reports and proxy-reports were examined, and factors associated with QoL were explored via linear regression models.

**Results:** Compared to proxy-reported QoL scores, self-reported QoL scores were significantly but only slightly higher and not in every QoL domain. Independent of respondent type it was found that psychiatric comorbidity, sleeping difficulty, intellectual disability, maladaptive behavior, adaptive functioning, autism symptomatology, main daytime activity and residence were associated with QoL.

**Conclusion:** Proxy-reported QoL is different from self-reported QoL and should be considered as an alternative source of information. QoL might be enhanced when factors associated with QoL are improved. However, large variations in QoL were found for most factors, suggesting the need to involve the individuals with ASD and/or their families when improving their QoL.

### What this paper adds

Knowledge about factors of importance of Quality of life (QoL) in adolescents and adults with autism spectrum disorder (ASD) is emerging but still needs further investigation. Furthermore, the concordance between self-reported QoL and parental proxy-reported QoL is not well-investigated for adolescents and adults with ASD, however about to gain insight into. In this study it was found that psychiatric comorbidity, sleeping difficulty, intellectual disability, maladaptive behavior, adaptive functioning, autism symptomatology, main daytime activity and residence were associated with QoL, independent of respondent type. Importantly, large variations in QoL were found for most factors suggesting individual differences within the sample, which should be taken into account when

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planning intervention. Furthermore, differences between self-reported QoL and parental proxy-reported QoL were found indicating that parental proxy-reported QoL constitute an alternative source of information on an individual's QoL.

## 1. Background

The assessment of quality of life (QoL) as an outcome measure for individuals with autism spectrum disorder (ASD) was suggested by Burgess and Gutstein (2007) a decade ago. Further, Jonsson et al. (2017) emphasized the importance of including the subjective perspective of wellbeing in addition to the assessment of symptom severity and adaptive functioning in individuals with a mental or behavioral disorder. Recently, QoL research involving children, adolescents and adults with ASD has been published, as well as comprehensive reviews and a meta-analysis (Ayres et al., 2017; Chiang & Wineman, 2014; Ikeda, Hinckson, & Krägeloh, 2014; Van Heijst & Geurts, 2015), which indicate, with few exceptions (Hong, Bishop-Fitzpatrick, Smith, Greenberg, & Mailick, 2016; Moss, Mandy, & Howlin, 2017), that individuals with ASD have lower levels of QoL compared to typically developing individuals. This finding is valid for different informants reporting on QoL; however, there is a tendency for self-reports to result in a higher QoL score compared to parental proxy-reports or standard parental reports (Ikeda et al., 2014).

Whether individuals with ASD can rate their own QoL, due to language difficulties, for example, has been questioned (Persson, 2000). However, increasing evidence supports the idea that individuals with ASD, children as well as adults, can rate their own QoL reliably (Hong et al., 2016; Shipman, Sheldrick, & Perrin, 2011; Stokes, Kornienko, Scheeren, Koot, & Begeer, 2017) when essential modifications are made to the actual QoL scale and/or to the administration of the scale (Hong et al., 2016; Shipman et al., 2011). Since QoL by definition involves a subjective perspective, the use of proxy-reports to determine QoL has also been questioned, and it has been concluded that self-reports cannot simply be replaced by proxy-reports (Verdugo, Schalock, Keith, & Stancliffe, 2005). However, proxy-reports should not necessarily be discarded but rather employed as an alternative source of information on an individual's QoL (Clark, Magill-Evans, & Koning, 2015; Egilson, Ólafsdóttir, Leósdóttir, & Saemundsen, 2017).

Several scales for measuring QoL exist, and even though no consensus has been reached in the area of ASD for the optimal estimation of QoL, the WHOQOL-BREF scale (The WHOQOL Group, 1998) is often applied in studies of QoL in adults with ASD (Bishop-Fitzpatrick, Mazefsky, & Eack, 2017; Hong et al., 2016; Jennes-Coussens, Magill-Evans, & Koning, 2006; Kamio, Inada, & Koyama, 2013; Kamp-Becker, Schroder, Remschmidt, & Bachmann, 2010; Lin, 2014; Moss et al., 2017) and recently, nine additional ASD specific items was developed to the WHOQOL-BREF (McConachie et al., 2017). While WHOQOL-BREF produces comparable QoL results across countries, the scale is only usable for self-administration, if the individuals have the ability to do this; otherwise assistance is recommended in terms of, for example, carrying out an interview (World Health Organization, 1996). Accordingly, the WHOQOL-BREF may not be easily self-administrated by individuals with ASD and intellectual disability (ID). Instead, the INICO-FEAPS scale<sup>1</sup> (Gomez, Verdugo, & Arias, 2015) was chosen to investigate QoL in the present study. The INICO-FEAPS scale is based on the theoretical framework of QoL by Schalock and Verdugo (2002). It consists of two forms (self-report and report of others) and is specifically developed for adolescents and adults with ID and/or developmental disabilities. Hence, applying a customized scale may facilitate a larger group of individuals with ASD to self-report, including individuals with ID in addition to ASD.

Growing interest in and increased research on the factors important for the QoL of individuals with ASD in all age groups have developed. For adolescents and adults, factors such as symptoms of ASD, psychiatric comorbidity, adaptive behavior, and employment status have been investigated for their associations with QoL. However, contradicting results for these factors have been found, with some studies finding associations with QoL whereas others did not (Clark et al., 2015; Helles, Gillberg, Gillberg, & Billstedt, 2017; Hong et al., 2016; Kamp-Becker et al., 2010; Lin, 2014; Moss et al., 2017; Saldana et al., 2009). Therefore, more studies are needed to investigate which specific factors are associated with QoL.

The aim of this study was to explore QoL in a large and nationwide sample of adolescents and adults with ASD by applying the INICO-FEAPS scale. First, concordance in ratings of QoL across self-reports and parental proxy-reports will be examined, as well as levels of QoL in different domains in accordance with the INICO-FEAPS scale. Second, different factors will be investigated for potential associations with QoL when measured via self-reports as well as parental proxy-reports. A wide range of external factors, such as current main daytime activity, current residence, and age of diagnosis of ASD, and internal factors such as psychiatric comorbidity, sleeping difficulty, ID, maladaptive behavior, adaptive functioning, and autism symptomatology will be explored and might thereby contribute to the emerging knowledge about which factors are associated with QoL.

## 2. Method

### 2.1. Study population

A total of 1738 individuals with ASD were included in this study. For 710 individuals, both self-reports and parental proxy-reports on the QoL questionnaire were available. For 165 individuals with ASD, self-reports only were available, and for 863 individuals with ASD, only parental proxy-reports were available. Parents were allowed to assist their son/daughter in completing the QoL questionnaire, but it was emphasized that the individuals with ASD should decide how to rate the items themselves. Of the 875 self-

<sup>1</sup> The name of the scale, INICO-FEAPS, is explained in the manual of the INICO-FEAPS scale: "The University Institute on Community Integration (INICO) of the University of Salamanca and of the Spanish Confederation of Organisations in Favour of Individuals with Intellectual or Developmental Disabilities (FEAPS)" (Verdugo Alonso et al., 2013) (p. 9).

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