Psychometric properties of the INICO-FEAPS scale in a Danish sample with autism spectrum disorders

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ABSTRACT

Background: There is a need to evaluate subjective perspectives of outcomes, such as quality of life (QoL), in individuals with autism spectrum disorders (ASD), but to date, there is no specific instrument available to assess this population. While the INICO-FEAPS scale is customized for studying QoL in adolescents and adults with intellectual and/or developmental disabilities, this scale has not been previously evaluated in an ASD population.

Aims: To examine the usability of the INICO-FEAPS scale in a Danish population of adolescents and adults with ASD.

Methods: In a nationwide survey, 875 adolescents and adults with ASD and 1573 parents completed the INICO-FEAPS scale. Internal consistency was evaluated through several indices. Confirmatory factor analysis (CFA) was conducted to investigate the fit of the model with eight correlated first-order factors, and convergent validity was explored comparing the results of different QoL measures through correlation analysis.

Results: Internal consistency was adequate for the indices applied, and the CFA model tested indicated an acceptable fit to the data. Generally, comparisons of results of different QoL measures resulted in moderate to high correlations.

Conclusion: Overall, it was concluded that due to the psychometric properties found, the INICO-FEAPS scale is applicable for use in ASD populations.

What this paper adds

The INICO-FEAPS scale is a recently developed scale for assessing quality of life (QoL) in individuals with intellectual and/or developmental disabilities. The scale is based on Schalock and Verdugo’s theoretical model of QoL that is comprised of eight domains: self-determination, rights, emotional wellbeing, social inclusion, personal development, interpersonal relationships, material wellbeing and physical wellbeing. This model is sparsely investigated in the ASD population. This study contributes to the literature by administering the INICO-FEAPS scale to a large Danish population comprised of adolescents and adults with ASD, following an investigation of the psychometric properties of the scale. Statistical analyses of internal consistency, internal structure and convergent validity suggest acceptable psychometric properties of the INICO-FEAPS scale for both self-reporting and parental reporting.
1. Background

Investigating quality of life (QoL) has become significantly important in both research and clinical practices as the last several decades have emphasized the importance of the individual’s perspective regarding values in life and, more importantly, have acknowledged that everyone, regardless of the presence of disabilities, should be included in efforts to enhance their QoL (Schalock, 2004; Schalock, Verdugo, Gomez, & Reinders, 2016). Even though no single definition of QoL exists, most QoL researchers agree on the specific characteristics of the QoL construct, for instance, with respect to the importance of the person’s perception of personal satisfaction (i.e., subjectivity) with life in the different domains, such as the physical, psychological, and social spheres (i.e., multidimensionality) (World Health Organization, 1995).

Robert L. Schalock and Miguel Á. Verdugo have developed a model of QoL that is comprised of eight domains, namely, self-determination, rights, emotional wellbeing, social inclusion, personal development, interpersonal relationships, material wellbeing and physical wellbeing (Schalock & Verdugo, 2002; Schalock et al., 2016). The importance of the eight domains has been empirically and transculturally validated in several studies (Gomez, Verdugo, Arias, & Arias, 2011; Jenaro et al., 2005; Schalock et al., 2005; Wang, Schalock, Verdugo, & Jenaro, 2010), and although the model has been applied primarily in the field of intellectual and developmental disabilities, it is not limited to this field (van Hecke et al., 2017). Based on Schalock and Verdugo’s model of QoL, several instruments using different methods of collection of information have been developed to assess QoL, including the Personal Outcome Scale (Van Loon, Van Hove, Schalock, & Claes, 2008), the San Martin Scale (Verdugo, Gomez, Arias, Navas, & Schalock, 2014), the INTEGRAL scale (Gómez, Arias, Verdugo, & Navas, 2012), the GENCAT Scale (Verdugo, Arias, Gómez, & Schalock, 2010), and the INICO-FEAPS scale (Gomez, Verdugo, & Arias, 2015).

Recent reviews of QoL studies (Ayres et al., 2017; Chiang & Wineman, 2014; Ikeda, Hinckson, & Krägeloh, 2014) and a meta-analysis (Van Heijst & Geurts, 2015) of QoL in individuals with autism spectrum disorders (ASD) illustrate well the range of different instruments in operationalizing QoL. However, to date, no specific QoL instrument for individuals with ASD has been developed, and there is no consensus about which of the existing instruments best capture the important aspects of QoL in the ASD population. Plimley (2007) suggested transferring the knowledge from research in the field of QoL, particularly research based on Schalock and Verdugo’s QoL model, to individuals with ASD. Yet, to date only one study with an ASD study population has reported psychometric properties of a QoL scale based on Schalock and Verdugo’s model comprised of the eight QoL domains (Arias et al., 2017).

The INICO-FEAPS scale consists of two forms, the self-report form and the report of others form (Gomez et al., 2015), and is the instrument chosen for the present study. Originally, the INICO-FEAPS scale was developed to assess QoL in individuals with intellectual/developmental disabilities who receive different types of support. Even though not all individuals with ASD are suffering from intellectual disability (ID), and they are not all receiving support, it is well known that a subgroup of individuals with ASD has ID, and an even larger group of individuals with ASD are receiving different types of support, a factor that can substantially affect self-determination. Using the INICO-FEAPS scale among an ASD population can be advantageous compared to the more generic measures of QoL since the INICO-FEAPS scale accounts for the dependency on services and support that often characterizes individuals with ASD on a group level. Furthermore, this scale can promote the self-report form for QoL by using a customized instrument that enables as large a group of individuals with ASD as possible, including those with ID, to complete the questionnaire. Hence, the application of a scale written in a plain language makes self-reporting more accessible to a larger group of the study population.

QoL researchers argue that self-reports on QoL are the only valid reports (Schalock et al., 2002). Additionally, a review addressing the assessment of QoL in children and adolescents with ASD (Ikeda et al., 2014) indicates there are considerable differences between self-reports on QoL and reports completed by others, thus emphasizing that these two sources of information are not interchangeable, and furthermore should be analyzed separately (Verdugo, Schalock, Keith, & Stancliff, 2005). Yet, research indicates that parental ratings with an instruction of rating the QoL as they think, their child would do themselves, yield results that are better aligned with the ratings the involved individuals would give compared to standard parental ratings where no such instruction were given (Hong, Bishop-Fitzpatrick, Smith, Greenberg, & Mailick, 2016; Sheldrick, Neger, Shipman, & Perrin, 2012). Further, there are individuals who are unable to self-report on their QoL, and thus, allowing the parents to report on behalf of their children may be the second-best solution. Accordingly, it is valuable to use an instrument like the INICO-FEAPS scale consisting of both a self-report form and report of others form in ASD populations.

As argued by Ikeda et al. (2014), it is important to establish the psychometric properties of the QoL scale applied in an ASD population prior to reporting the results from the specific scale. Particularly, the purpose of this study was to examine the usability of the INICO-FEAPS scale in a population of adolescents and adults with ASD. Therefore, we investigated the psychometric properties of the scale by applying the same methods used when Gomez et al. (2015) validated the original version of the scale. In addition to internal consistency, Gomez et al. (2015) explored the internal structure of the scale by testing four different models using confirmatory factor analysis (CFA) and concluded that a model with eight correlated first-order factors best fit the data. Accordingly, we aimed to investigate the fit of the same model when INICO-FEAPS was administered in an ASD population. Beyond investigating the internal consistency and internal structure, this study further compared the results for proxy-reporting and self-reporting of different QoL measures with the purpose of exploring convergent validity.

2. Method

2.1. Participants

The study population consists of 875 adolescents and adults with ASD and 1573 parents who completed the self-report or the
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امکان دانلود نسخه ترجمه شده مقالات
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امکان جستجو در آرشیو جامعی از صدها موضوع و هزاران مقاله
امکان دانلود رایگان ۲ صفحه اول هر مقاله
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