



A new scale for the measurement of quality of life in children with intellectual disability



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ABSTRACT

Background: Children and adolescents with intellectual disabilities make up a group which is in urgent need of an adequate operationalisation of the quality of life construct, not only to improve individual personal outcomes but also to develop and implement evidence based practices. For that reason, and with the aim of answering the growing demand for an adequate evaluation instrument for this group, the KidsLife scale was developed.

Method: This research provides evidence of the reliability and validity of the scale, which is composed of 96 items spread over eight subscales, and completed by a third-party respondent. The validation sample comprised 1060 people with intellectual disability, with ages ranging from 4 to 21 years old ($M = 13.51$; $SD = 5.04$).

Results: The results suggest that the eight quality of life domains assessed on the scale are reliable (Cronbach's alpha ranging from 0.812 to 0.949). The evidence of the validity of the construct provided by Confirmatory Factor Analysis also demonstrated adequate indexes of fit for the eight-domain model.

Discussion: Future lines of research which may use the KidsLife Scale are suggested and discussed.

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What this paper adds?

This study contributes by providing a valid and reliable scale to assess quality of life in the field of intellectual and developmental disabilities by filling the gap regarding assessment instruments in infancy and adolescence. This tool allows assessing quality of life-related personal outcomes through eight domains: material wellbeing, physical wellbeing, emotional wellbeing, personal development, self-determination, rights, social inclusion, and interpersonal relationships. This new instrument provides helpful information to improve personal outcomes and some guidance to be taken into account in the development of person-centered and individualized support planning. At the organizational level, the aggregated data may help in the implementation of quality of life enhancement strategies. Finally, at the macrosystem level, aggregated results may guide social and human policies to ensure human rights, empowerment, and inclusion.

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1. Introduction

The importance and rise of the Quality of Life (QoL) concept lies in the fact that, due to its many uses, it has become an integral reference point for the improvement of people's subjective and psychological wellbeing. Nowadays it is used widely for, amongst other things, the objective evaluation of people's needs and subjective levels of satisfaction, the evaluation of results of programs, strategies, and activities aimed at quality improvement carried out by social and welfare services, the collection of relevant information to guide service provision, and policy formulation and planning aimed at the improvement of QoL and people's rights (Bigby, Knox, Beadle-Brown, & Bould, 2014; Brown, Hatton, & Emerson, 2013; Buntinx & Schalock, 2010; Claes, van Hove, Vandeveld, van Loon, & Schalock, 2010; Gómez, Arias, Verdugo, & Navas, 2012; Luckasson & Schalock, 2013; Schalock, Gardner, & Bradley, 2007; van Loon et al., 2013; Verdugo, Navas, Gómez, & Schalock, 2012).

Children and adolescents with intellectual disabilities form a group whose need for an operational model of QoL is especially important, urgent, and widely recognised in the scientific literature (Arnaud et al., 2008; Dickinsson et al., 2007; Kalay et al., 2010; Townsend-White, Pham, & Vassos, 2012), as it is the basis for the concept's application (Schalock, Verdugo, Gómez, & Reinders, 2016). There are a number of models which aim to operationalise the QoL construct in order to be able to evaluate it. In the field of intellectual disability (ID) there are distinct conceptual frameworks which have garnered most attention and acceptance from the scientific community (e.g. Cummins, 2005; Felce & Perry 1995; Gardner & Carran, 2005; Petry, Maes, & Vlaskamp, 2005; Petry, Maes, & Vlaskamp, 2007; Renwick, Brown, & Raphael, 2000; Schalock & Verdugo, 2002, 2012). In this study we have used the eight-domain model proposed by Schalock & Verdugo because it is one of the most frequently cited in the literature and one which has better empirical evidence of validity (Gómez, Verdugo, Arias, & Arias, 2011; Jenaro et al., 2005; Schalock et al., 2005; Wang, Schalock, Verdugo, & Jenaro, 2010), as well as being the most often used in the Spanish context by social and educational service providers. In this model, QoL is regarded as a desired state of personal wellbeing which: (a) is multidimensional (comprising eight domains: emotional wellbeing, physical wellbeing, material wellbeing, social inclusion, interpersonal relationships, self-determination, rights, and personal development); (b) has universal and cultural properties; (c) encompasses objective and subjective components; and (d) is influenced by individual characteristics and environmental factors (Gómez, Peña, Arias, & Verdugo, 2016; Schalock, Verdugo, & Gómez, 2011).

In Spain there are various useful instruments for the evaluation of QoL in people with intellectual disability in adulthood and in old age, for example the GENCAT scale (Verdugo, Arias, Gómez, & Schalock, 2010), the FUMAT scale (Verdugo, Gómez, & Arias, 2009), the Quality of Life scale for elderly people with disabilities (Alcedo, Aguado, Arias, González, & Rozada, 2008), the INICO-FEAPS scale (Gómez, Verdugo, & Arias, 2014; Verdugo, Gómez, Arias, Santamaría, Clavero et al., 2013), the San Martín scale (Verdugo, Gómez, Arias, Navas, & Schalock, 2014; Verdugo, Gómez, Arias, Santamaría, Navallas et al., 2013) and the Personal Outcomes Scale (Carbó-Carreté, Guàrdia-Olmos, & Giné, 2015). However, to our knowledge, for infancy and adolescence there are only the CVI-CVIP (Sabeh, Verdugo, Prieto, & Contini, 2009) and the CCVA (Gómez-Vela & Verdugo, 2009). Both have limitations in that they are aimed only at those who are high functioning, and despite having been developed from an eight-domain model, that internal structure has never been demonstrated. Because of that, professionals and families in the area of disability in Spain have voiced the need on various occasions for an evaluation with adequate psychometric properties, which would allow the development of evidence-based practices to improve QoL in this group in the same way as in later stages of life (Gómez, Verdugo, Arias, Navas, & Schalock, 2013). In light of this, and with the aim of catering for the growing demand for an appropriate evaluation instrument for this group, the KidsLife scale was developed.

The development of this instrument began with a thorough literature review about the evaluation of QoL for people with intellectual disabilities in infancy and adolescence. Following that, a Delphi study (Gómez, Peña, Alcedo et al., 2014) was performed with the aim of operationalising the concept through a search for central indicators and items for each of the eight domains of the QoL model. Fourteen expert judges with significant experience in the field of disability participated in the Delphi study. They were asked to evaluate more than 200 proposed items – gathered from the literature review –, organised in eight domains (i.e. 25 items per domain). The evaluation was according to four criteria: suitability (were the items appropriate for the evaluation of the corresponding domain), importance (relevance of the items in the evaluation of QoL in children and adolescents with intellectual disability), sensitivity (the level to which the item content reflects aspects which can be altered via services and support that organisations for people with disability are able to provide), and observability (the level to which each item can be observed or evaluated by another person through systematic observation). The experts were also asked to suggest additional items if they felt that there were further aspects of the construct that needed to be represented. The criteria used to assess whether an item was valid were based on the mean, standard deviation and the percentage agreement. Following three rounds in which the experts evaluated and discussed the suitability of the items, an initial bank of 167 items remained (including original, reformulated, and new items). Of those, 11 were eliminated for being redundant, and so the field-test version of the KidsLife scale comprised 156 items with sufficient evidence of content validity.

Following on from that preliminary operationalisation of the concept, the main objective of this study was to evaluate the psychometric properties of the field-test version of the KidsLife Scale with a large sample of children and adolescents with intellectual disability. To that end, the study provides evidence of reliability (via Cronbach's alpha, ordinal alpha, and theta coefficients, and polychoric correlations) and validity based on the internal structure of the scale (through confirmatory factor analysis), convergent validity, and discriminant validity.

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