

Facing the Challenge of Assessing Quality of Life of Children with Profound and Multiple Disabilities

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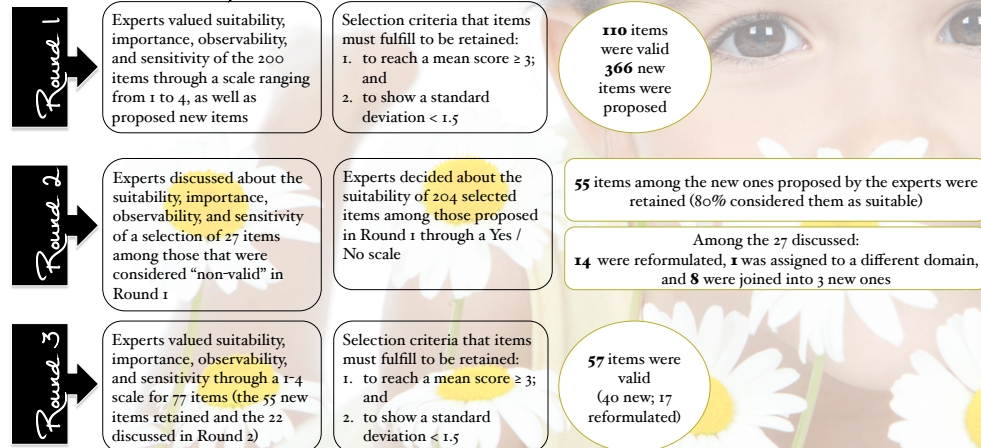
The goal of this poster is to present a Delphi study carried out to get a better understanding of central quality of life indicators for children and adolescents with profound intellectual and multiple disabilities. The main result of this study is an operationalization of quality of life for this population with adequate evidences of validity.

Significant progress has been made in the operationalization of quality of life for people with intellectual disability and subsequent development of quality of life measures. However, most of this progress has been achieved for those with the highest levels of functioning who are able to communicate their preferences, opinions, perceptions, and goals. In contrast, the operationalization for those with profound and multiple disabilities is still a pending task that has been acknowledged in the published research since more than two decades. In the same way, there are a very considerable number of instruments to assess quality of life –not so many with sound psychometric properties–, but most of them are hardly suitable for people with profound intellectual disability who may also have significant motor dysfunctions, chronic health issues, challenging behaviors, sensory impairments, or mental health problems.

To date, the only effort to operationalize the concept of quality of life for this population has been made by Petry, Maes, and Vlaskamp (2005, 2007, 2009) on the basis of the five-domain model proposed by Felce and Perry (1995, 1996). They carried out the first research in 2005 in Belgium, Holland, and Germany through a Delphi study. They achieved a pool composed of 176 items that constituted the first quality of life operationalization for adults.

Taking their studies as a starting point, our goal was to get a **valid operationalization of quality of life for children and adolescents with multiple and profound disabilities in Spain**. On the basis of the indicators found by Petry et al., the San Martin Scale (an instrument recently developed in Spain to assess quality of life of adults with significant disabilities), and other quality of life questionnaires, we carried out a Delphi study with the goal of **identifying core indicators for the eight domains** proposed by Schalock and Verdugo (2002). The starting point was a pool of 200 items (i.e., 25 per domain).

14 experts participated in a Delphi study involving 3 rounds:



A selection of the best valued items conformed the field-version of the KidsLife Scale. Please, find more information about the scale and its development and validation process in the subsequent poster

The operational definition of quality of life resulting from the Delphi study (N = 167 items):

