



The assessment of the quality of life of adults with intellectual disability: The use of self-report and report of others assessment strategies



Giulia Balboni ^{a,*}, Alessandra Coscarelli ^{b,1}, Giulia Giunti ^a, Robert L. Schalock ^c

^a University of Pisa, Via Roma, 67, 56126 Pisa, Italy

^b University of Valle d'Aosta, Strada Cappuccini, 2A, 11100 Aosta, Italy

^c Hastings College, P.O. Box 285, Chewelah, WA 99190-0285, United States

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ABSTRACT

Assessment strategies that reliably and validly assess the indicators of quality of life (QOL) of individuals with intellectual disability (ID) are necessary for planning interventions and evaluating outcomes. In the present study, inter-rater reliability and concordance of the two assessment strategies report of others and self-report were evaluated in a group of 176 Italian adults with ID using the Personal Outcomes Scale, which employs the same QOL indicators in the self-report and report of others versions. Report of others resulted a reliable assessment strategy. Clients' point of view was compared with both the estimation of their point of view and third-party-point-of-view obtained by two independent caregivers for each client. Results indicated that both self-report and report of others assessment strategies are necessary and that estimation of the client's point of view may be a valid and reliable substitute of self-report when clients are not able to answer.

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1. Introduction

The construct of quality of life (QOL; e.g., Cummins, 1997; Felce, 1997; Felce & Perry, 1995, 1996; Schalock, 1990, 2000) is increasingly being used as framework for planning interventions and evaluating outcomes for individuals with intellectual disability (ID), and for improving the services and supports provided to persons with ID (Gómez, Verdugo, Arias, Navas, & Schalock, 2013; Luckasson & Schalock, 2013; Schalock, Bonham, & Verdugo, 2008; van Loon, Bonham, Peterson, Schalock, Claes, & Decramer, 2013). These used require both the development of empirically validated models of QOL and of valid scales that allow its measurement in individuals with ID (e.g., Cummins, 2005) and the use of assessment strategies that reliably and validly assess the individual's life conditions and circumstances.

One of the most validated quality of life models (Schalock & Verdugo, 2002) includes eight core domains structured in three main factors: (1) Independence that is composed of personal development and self-determination; (2) Social participation composed of interpersonal relations, social inclusion, and rights; and (3) Well-being composed of emotional, physical, and material well-being. This model has been empirically validated across different cultures and countries (Jenaro et al., 2005; Schalock et al., 2005; Wang, Schalock, Verdugo, & Jenaro, 2010).

* Corresponding author at: Department of Surgery, Medical, Molecular & Critical Area Pathology, University of Pisa, Via Roma, 67, 56126 Pisa, Italy. Tel.: +39 050 992370; fax: +39 050 992658.

E-mail address: giulia.balboni@med.unipi.it (G. Balboni).

¹ Present Address: Psychologist Officer, Italian Tax Police.

For a valid measurement of one's quality of life, culturally sensitive indicators for each domain are used (Schalock & Verdugo, 2002; Schalock et al., 2005). This approach to the conceptualization and measurement of quality of life moves the field beyond the previous emphasis on subjective indicators and objective indicators to a standard set of domain-referenced indicators that are used as the basis for the assessment. In addition, however, there is also a need to develop assessment strategies that move beyond the use of proxies and one that focuses on the use of the same indicators that are assessed on the basis of either self-report or the report of others (e.g., Cummins, Lau, Davey, & McGillivray, 2010; Lucas-Carrasco & Salvador-Carulla, 2012; Petry, Maes, & Vlaskamp, 2009a; Petry, Kuppens, Vos, & Maes, 2010). Using the same indicators for both the self-report and report of others versions of a QOL scale, one can evaluate more validly the potential differences between one's self-report and that provided by others such as family members or direct support staff.

To date, there has been conflicting information regarding the concordance between a self-report and the information provided by others (e.g., Schalock & Keith, 1993; Schmidt et al., 2010; Zimmermann & Endermann, 2008). Some have found a very low or even the absence of any agreement (Rapley, Ridgway, & Beyer, 1997; Zimmermann & Endermann, 2008). Conversely, other studies (e.g., McVilly, Burton-Smith, & Davidson, 2000; Schalock & Keith, 1993; Schmidt et al., 2010; Stancliffe, 1999) provide evidence for moderate to strong associations between a self-report and the information provided by others. Many of these differences might well be related to the assessment strategy used as opposed to actual differences (e.g., Petry, Maes, & Vlaskamp, 2009b).

The primary purpose of the present study was to investigate the inter-rater reliability of report of others and the concordance between self-report and report of others related to the assessment of QOL of adults with ID. Quality of life was measured with the *Personal Outcomes Scale* (POS; van Loon, Van Hove, Schalock, & Claes, 2008). Psychometric properties of the POS are described in the Methods Section and additional information can be found in Claes, Van Hove, van Loon, Vandeveld, and Schalock (2009) and van Loon et al. (2008). POS allows for the evaluation of the eight core domains and the three main factors of the Schalock and Verdugo's model of QOL. These domains and main factors are assessed via two different POS versions: self-report and report of others. Self-report is administered to the person with ID and results in the assessment of client's point of view on his/her QOL. Report of others may be compiled with two different assessment strategies: (1) administration to a caregiver of the individual with ID to obtain a third-party-point-of-view regarding the client's QOL; and (2) administration to a second caregiver who are asked to respond on the individual's with ID behalf to obtain an estimation of the client's point of view. This information is useful if client is not be able to answer to the self-report.

2. Study purpose

In the present study the two versions of the POS were used to extend previous research to investigate: (A) the inter-rater reliability of the report of other, and (B) the concordance between self-report and report of other in the same group of adults with ID, as a third party evaluation and as an estimation of the client's with ID point of view. To investigate the inter-rater reliability of the report of others, two independent caregivers were interviewed for each client evaluated to obtain a third party assessment of the client's QOL, in a first group, and an estimation of the client's point of view on his/her QOL, in a second group. To investigate self-report/report of others concordance, the POS was compiled for a third group of adults with ID that were able to respond for themselves under the following conditions: (a) self-Report completed by client; (b) report of others completed by a caregiver of the same individual under the instructions to "respond as if you were the person with ID"; and (c) report of others completed by another caregiver of the same individual used by a third party respondent. We hypothesize that the agreement between self-report/estimation of individual point of view is higher than the corresponding agreement between self-report/third party point of view.

3. Methods

3.1. Participants

One hundred and seventy six adults with a diagnosis of ID (61% male), aged between 18 and 70 years old, were selected among the clients of several facilities for individuals with disability located in the North of Italy. Of them, 85 (48%) had mild or moderate ID and were able to answer to the POS self-report scale (verbal individuals). The remaining 91 (52%) had a more severe ID disorder and were not able to answer to the Self-report scale (non-verbal individuals). Participants lived in the community with their family (37, 21%) or in group residence (24, 14%), or in care facility (115, 65%). Of them, 69 (39%) worked in an occupational center, 11 (6%) had a regular or supported employment, while 96 (55%) did not do any kind of structured activity.

Three different groups were identified in order to investigate the report of others scale inter-rater reliability (third-party-point-of-you evaluation reliability and estimation of the individual's point of view evaluation reliability groups) and self-report/report of others correspondence (self-report/estimation of the individual's point of view evaluation/third-party-point-of-you evaluation agreement group). Characteristics of the groups are reported in Table 1.

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