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Psychometric evaluation of a questionnaire to measure the quality of life of people with profound multiple disabilities (QOL-PMD)

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ABSTRACT

Because of a shortage of valid instruments to measure the QOL of people with profound multiple disabilities (PMD), the QOL-PMD was developed. In the present study, possibilities for item reduction as well as the psychometric properties of the questionnaire were examined. One hundred and forty-seven informants of people with PMD participated in the study. Fifty items were removed from the questionnaire on the basis of preset criteria. Internal consistency was good for the total questionnaire as well as for the subscales. Evidence of the construct validity of the questionnaire was found. Correspondence between the groups of informants was moderate. The results of this preliminary analysis of the psychometric properties of the QOL-PMD are encouraging, but further validation of the measure is warranted.

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1. Introduction

Over the past few decades, the concept of quality of life (QOL) has increasingly become a focus of research and application in the fields of education and special education, health care, social services and families (Schalock & Verdugo, 2002). In the field of intellectual disabilities (ID) it was initially used as a sensitizing notion, a social construct and a unifying theme. Increasingly, it has been used as a conceptual framework for assessing quality outcomes, a social construct that guides quality enhancement strategies, and a criterion for assessing the effectiveness of those strategies (Verdugo,

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Schalock, Keith, & Stancliffe, 2005). With this increased use of the QOL construct as a basis for policies and practices in the field of ID, the importance of a valid assessment of QOL is heightened (Verdugo et al., 2005).

People with profound multiple disabilities (PMD) are a group of people for which the valid assessment of QOL is a complex and difficult matter, especially when it regards the interrogatories 'what', 'how' and 'who' of QOL measurement. People with PMD have such profound intellectual disabilities that hardly any standardised tests are applicable for a valid estimation of their intellectual capacity, and they possess profound neuromotor dysfunctions, like spastic tetraplegia. In addition to profound intellectual and physical disabilities, sensory impairments are also frequently experienced (Nakken & Vlaskamp, 2002). People with PMD need support in almost every aspect of their daily life. This high level of dependency is reinforced by the fact that they cannot verbally communicate when and how support should be given. The complex interaction and the severity of their disabilities make their lives in large part different from that of other people. As such, the operationalization of QOL, the 'what' of the measurement, needs to be geared to their needs, possibilities and limitations in order to make its assessment valid (Borthwick-Duffy, 1990; Goode & Hogg, 1994; Ouellette-Kuntz & McCreary, 1996). Models of QOL often contain indicators such as income, status, productivity and autonomy. Viewed from the perspective of people with PMD these outcomes may be less relevant. There may, on the other hand, be some important aspects for this target group that are not mentioned in general models of QOL.

'How' to measure the QOL of people with PMD and 'who' should be involved is a second area of concern because people with PMD do not have the required skills to speak for themselves about QOL (Selai & Rosser, 1993). Frequently, a knowledgeable proxy is asked to respond on the person's behalf, but there is serious question about whether information provided by proxies is a valid and accurate substitute for self-reports (Heal & Sigelman, 1996; McVilly, Burton-Smith, & Davidson, 2000; Rapley, Ridgeway, & Beyer, 1998; Stancliffe, 1995; Verdugo et al., 2005). Consequently, as Verdugo et al. (2005) pointed out clearly, QOL researchers are faced a quandary in relation to individuals who cannot communicate their own views about their QOL: either ignore these individuals because they cannot self-report, or obtain data from proxies that may be biased or invalid. At this moment, however, the answer to these problems can hardly be found in the literature. Few models of QOL are described that are geared to people with PMD at the level of the indicators and hardly any valid and reliable assessment instruments are available to measure the QOL of this target group.

Therefore, the main aim of this study was the development of a valid, reliable and useful instrument to measure the QOL of people with PMD, namely the QOL-PMD. The QOL-PMD was developed in several stages. In the first stage we determined clearly the construct we wanted to measure and selected as a starting point the basic domains of QOL as described in the model of Felce and Perry (1995, 1996a, 1996b). Next, an item pool was generated by interviewing 40 parents and 36 direct support staff members of 42 children and 34 adults with PMD. In these interviews we explored whether the selected basic domains are valid and relevant for people with PMD and how these domains can be operationalized for this group of people. The result of this phase was a pool of items that is geared to the characteristics of people with PMD (Petry, Maes, & Vlaskamp, 2005). In a third stage the generated item pool was assessed on its content and structure by a group of 45 international experts (e.g., researchers, support staff, family involved with people with PMD) in a Delphi format with written questionnaires and intermediate feedback (Petry, Maes, & Vlaskamp, 2007). The experts were also requested to give their opinion on the measurement approach that should be used and on the people that should be involved in the assessment. Finally, the pool of items was pre-tested in a multiple case study in a sequential design. In each stage of the development revisions were made in order to enhance the questionnaire.

The result of the preliminary work was a set of 105 items divided in six subscales, namely material well-being ($n = 19$), physical well-being ($n = 19$), social well-being ($n = 21$), communication and influence ($n = 16$), development ($n = 15$), and activities ($n = 15$). This preliminary version of the questionnaire was designed to measure the objective component of QOL of people with PMD. The items are assessed at a 3-point scale with as response categories 'agree', 'partly agree', and 'disagree'. Two additional response categories were added, namely 'don't know' and 'not applicable'. Higher scores on each item are associated with better QOL. As a measurement approach, the experts of the

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