



## What makes them feel like they do? Investigating the subjective well-being in people with severe and profound disabilities

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### ABSTRACT

**Background:** Because of the problems measuring subjective well-being in people with severe and profound intellectual disabilities, there are no studies to date which explore the factors contributing to the subjective well-being in these groups. We wanted to explore the client and service characteristics contributing to the subjective well-being of persons with severe and profound intellectual disabilities, as measured by the MIPQ (Ross & Oliver, 2003).

**Materials and methods:** The MIPQ was completed for 360 persons with severe or profound intellectual disabilities by a member of the direct support staff. They also provided us with information on client, service and informant characteristics.

**Results:** We found that the subjective well-being of persons with profound intellectual disabilities was lower than the subjective well-being of people with mild, moderate or severe intellectual disabilities or people without disabilities. Client and informant characteristics but no service characteristics were found to have an influence on the subjective well-being of people with severe and profound intellectual disabilities.

**Conclusion:** As it is important for policy making to identify residence service and staff factors related to subjective well-being of persons with severe and profound intellectual disabilities, further research should try to identify these factors, taking in account the client characteristics that are found to be related to subjective well-being in this study.

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## 1. Introduction

In the last decade, the concept of ‘quality of life’ (QOL) has increasingly been used as a conceptual framework for assessing quality outcomes, as a social construct that guides quality enhancement strategies and as a criterion for assessing these strategies (Verdugo, Schalock, Keith, & Stancliffe, 2005). The frequent use of the quality of life construct as a basis for policy and practices in the field makes the development of a valid measurement of quality of life a compulsory matter. To get a valid measurement of quality of life it is important to include both the subjective and the objective components of quality of life (Cummins, 2005b; Schalock et al., 2002). The objective component of quality of life consists of objective features, which can be observed and measured in the public domain. The subjective component (also called subjective well-being) holds the personal experiences of the client. This subjective component of quality of life can be decomposed into two parts. On the one hand there is the general satisfaction of the individual with several aspects of his/her life (‘life satisfaction’) and on the other

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hand there is his/her expression of negative and positive emotions ('hedonic level') (Cummins, 1998; Diener, 1994; Schallock, 2004).

Measuring the quality of life of people with profound intellectual and multiple disabilities (PIMD) is not self-evident (Petry, Maes, & Vlaskamp, 2005). As people with profound and multiple disabilities have a profound cognitive disability ( $IQ < 20$ ), profound neuromotor dysfunctions and often sensory impairments and medical problems (Nakken & Vlaskamp, 2007), they need support in almost every aspect of their daily life. As this group only communicates at pre- or protosymbolic level via facial expressions, sounds, movements, body posture or muscle tension, there is no way to directly measure the subjective component of their quality of life. A common practice used to get round this problem is involving proxies to give information about the quality of life of the person (Verdugo et al., 2005). Recently, researchers have developed valid measurements of quality of life for people with PIMD. With regard to the evaluation of the objective component, Petry, Maes, and Vlaskamp (2009a) developed the QOL-PMD. This is a questionnaire consisting of 55 items on the domains of physical well-being, material well-being, social well-being, activities, communication and influence and development. This questionnaire uses a proxy-approach with three informants for each person with PIMD. The first evaluation of the psychometric properties of the questionnaire was encouraging (Petry et al., 2009a). Another questionnaire developed to assess the objective quality of life of people with PIMD is the questionnaire by Seifert, Fornefeld, and Koenig (2001). However, according to the authors, this questionnaire is meant to serve as a checklist in the process of making a support plan for a person with PIMD and not as a 'stand-alone' questionnaire. Consequently, the authors did not check the psychometric qualities of the questionnaire.

Progress has also been made with respect to the measurement of the subjective component of quality of life. Lyons (2005) for instance, developed the Life Satisfaction Matrix (LSM), to measure subjective well-being in people with PIMD using two proxies and observations. Petry and Maes (2006) created a procedure to evaluate subjective well-being using behavioural observations. They asked proxies to identify the behaviours used by the person with profound intellectual and multiple disabilities to express positive and negative well-being. This affective profile was then used to code the behaviours of the person as expressing positive or negative well-being. Using a psychophysiological approach, Vos, De Cock, Petry, Van den Noortgate, and Maes, (2010) made a first attempt in using physiological parameters to investigate subjective well-being in people with PIMD. It is however too early to evaluate the effectiveness of this approach, as their group was restricted to three participants. A final instrument used to measure subjective well-being is the mood, interest and pleasure questionnaire (MIPQ) developed by Ross and Oliver (2003). This 25-item questionnaire draws on proxies to evaluate the subjective well-being of people with PIMD over a period of 2 weeks. In an evaluation of the Dutch version of the MIPQ (Petry, Kuppens, Vos and Maes, 2010), a confirmatory factor analysis failed to confirm the two-factor solution proposed by Ross and Oliver (2003). Instead, Petry et al. (2010) found in an exploratory factor analysis a three-factor solution with positive mood, interest and negative mood being the factors. In the same article the authors demonstrated the good psychometric proportions of this three-factor solution (Petry et al., 2010). They found an internal consistency of 0.93 for the positive mood subscale, 0.89 for the interest subscale, 0.84 for the negative mood subscale and 0.94 for the total scale. The test-retest reliability was 0.89 for the positive mood subscale, 0.86 for the interest subscale, 0.90 for the negative mood subscale and 0.90 for the total scale. The inter-rater reliability was 0.76 for the positive mood subscale, 0.69 for the interest subscale, 0.69 for the negative mood subscale and 0.74 for the total scale. High negative correlations between the MIPQ total score and the Aberrant Behavior Checklist's (Aman, Watson, Singh, Turbott, & Wilsher, 1986) 'lethargy, social withdrawal' subscale provided evidence of construct validity.

Until now, there has been only one study investigating the factors that contribute to quality of life in people with profound intellectual and multiple disabilities, and this study focussed on the objective component of quality of life. Investigating the effect of several client and service characteristics in a sample of 49 persons with profound intellectual and multiple disabilities, Petry, Maes, and Vlaskamp (2009b) found the medical condition of the person, the amount of feeding problems and the staffing level of the group to be significantly ( $p < .05$ ) related to the objective quality of life of people with profound intellectual and multiple disabilities. In addition to these significant results, they found several non-significant trends in their data ( $p \leq 1.5$ ). With regard to participant characteristics, they found higher scores of objective quality of life in men than women ( $p = 1.5$ ). They found trends towards negative correlations between the objective quality of life score and age ( $p = 0.09$ ) and amount of medication ( $p = A.11$ ). With regard to the setting characteristics, they found that people in Belgian settings scored higher than people in Dutch settings ( $p = 0.06$ ).

There has been one study investigating the factors contributing to the total quality of life score in people with severe and profound intellectual disabilities. Campo, Sharpton, Thompson, and Sexton (1997) investigated the influence of participant and residence characteristics on a total quality of life score. They found having a larger support network, having a higher degree of individualised support and having high levels of participation to be positively related to the quality of life score. The only study investigating the subjective well-being in people with severe intellectual disabilities is the study of Beadle-Brown, Murphy, and DiTerlizzi (2009). The authors investigated subjective well-being in a cohort of people with severe intellectual disabilities and/or autism and found that people with an IQ higher than 50 had a higher subjective well-being than people with an IQ under 50 and that challenging behaviour was negatively associated with subjective well-being.

Subjective well-being has been investigated more thoroughly for people with mild intellectual disabilities. Cummins (2001, 2005a, 2005b) and Cummins and Lau (2004) showed that the subjective well-being score is a very robust measure. The mean subjective well-being of a group is situated between 70% and 80% of the scale maximum while for individuals the score lies between 50% and 100% of the scale maximum. This robustness of the subjective well-being is supported by Perry and Felce (2005) who did not find any factor related to satisfaction in people with intellectual disabilities. Albeit its

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