

# Measuring subjective well-being of persons with profound intellectual and multiple disabilities

S. Dero, K. Petry, and B. Maes

*Faculty of Psychology and Educational Sciences, Centre for Parenting, Child Welfare and Disabilities, Catholic University of Leuven, Leuven, Belgium, Sarah.Dero@ped.kuleuven.be*

One of the most difficult challenges in the quality of life-research is the measurement of the subjective well-being of people with profound intellectual and multiple disabilities (PIMD). This group is characterized by profound cognitive disabilities (IQ<20) and severe motor and/ or sensory limitations and medical problems, often caused by severe brain damage. Since persons with PIMD lack the necessary cognitive and communicative abilities to make a global judgment of their life, self-reports on their subjective well-being are not applicable. A frequently used alternative is the 'proxy-approach', in which someone who knows the person well forms an opinion about several life aspects instead of the person him/ herself. The literature however yields conflicting results concerning the psychometric value of this proxy-approach [1].

Research on the subjective well-being of persons with PIMD focuses increasingly on the 'hedonic level' of the subjective well-being – this is defined as 'the individual's expressions of positive or negative emotions or moods'. Direct emotional reactions are complex and multifaceted. Measuring the hedonic level of persons with PIMD, therefore, needs to focus on the behavioral, nonverbal and/ or physiological aspects. Recently some procedures have been developed that imply an observation of behavioral and nonverbal expressions of positive and negative affect [2, 3, 4]. Although these procedures look promising, they still need further validation. To date, the physiological component of emotional reactions has not been included in measures of the subjective well-being of persons with PIMD. In research on emotions some physiological variables have been successfully used to measure emotional responses [5]; they also seem to distinguish between positive and negative emotions and give information about the frequency, the intensity and, to a minor extent, the variability of emotions. Next to this, this approach might offer a possibility to evaluate emotions in a more objective way and without relying on the intermediary position of a proxy or a researcher.

Since physiological parameters are not yet considered as indicators of positive or negative emotions on the subjective well-being of persons with PIMD, a preliminary investigation is required. The aim is to validate the measurement of physiological parameters of emotional reactions. To gain a sharpened understanding of this approach, we will set up a case-study research. Four adult persons with PIMD (over 18 years of age) will be selected to participate in the study. In several daily situations – corresponding to the direct behavioral procedure – 'extreme' expressions of positive and negative emotions/ mood will be manipulated. Because of ethical reasons and the enormous heterogeneity of people with PIMD, members of direct support staff will be involved in defining the stimuli for each participant. During these situations several physiological parameters will be registered continuously. We selected parameters which have been used previously in research on subjective well-being and are usable in the target group, namely heart rate, heart rate variability, bodily temperature, respiratory function and skin conductance. The physiological parameters will be measured by means of easy-to-use non-invasive ambulatory technology. At the same time the situations will be recorded on videotape. In this way,

it might provide hypotheses which may be tested systematically with a larger number of cases in the main study of this research project. Next to investigate the validity of this methodology, the application of the ambulatory technology to measure the physiological parameters will be examined. Finally, the selection of physiological measuring will be refined or enlarged.

In the main study the aim is to examine a set of measures to assess the 'hedonic level' of subjective well-being of persons with PIMD. To achieve this aim, 25 people with PIMD will be selected. Three measures will be administered for each person with PIMD in the sample within a four week period.

(1) In week one, the direct behavioral procedure will be set up. On the basis of an interview with a member of direct support staff and a parent/ family member, an affective communicative profile of the person with PIMD will be drafted. At the start of week two, several daily situations will be recorded on digital videotape during a two-week period. Finally, these video recordings will be analyzed. The researcher codes the frequency and the intensity of expressions of positive and negative affect, using the earlier drafted affective profile. In order to extract observational data from the video recordings, professional software will be used. Based on these data, the frequency, intensity and valence of affect will be calculated.

(2) During the video recordings of the selected daily situations, several physiological parameters will be registered continuously. The selection of the physiological parameters and the non-invasive ambulatory technology is based on the preliminary investigation.

(3) In week four, two members of the direct support staff will complete an informant questionnaire, namely the MIPQ (Mood, Interest & Pleasure Questionnaire). The MIPQ is an indirect observational measure that addresses the nonverbal as well as the behavioral component. The informants will be asked to rate operationally defined observable behaviors, which relate to the construct of mood, interest and pleasure, on a five-point Likert-type rating scale. The MIPQ gives information on the valence and the frequency of affect.

To answer our research questions, several relations will be explored, for instance using correlation coefficients: between the frequency data of all three measures, between the intensity data of the physiological measures and the direct observational procedure, between the frequency, intensity or variability data for the positive and negative emotions, between the indirect observational and direct observational measures, etcetera. For the MIPQ, reliability will be determined on the basis of internal consistency and inter-rater reliability. For the direct observational procedure, 25% of the material will be double coded by a second researcher.

---

## References

1. Perry, J., Felce, D. (2002). Subjective and objective quality of life assessment: Responsiveness, response bias, and resident: proxy concordance. *Mental Retardation*, **40**, 445-456.
2. Lyons, G. (2005). The Life Satisfaction Matrix: an instrument and procedure for assessing the subjective quality of life of

- individuals with profound multiple disabilities. *Journal of Intellectual Disability Research*, **49**(10), 766-769.
3. Petry, K., Maes, B. (2006). Identifying expressions of pleasure and displeasure by persons with profound multiple disabilities. *Journal of Intellectual and Developmental Disability*, **31**(1), 28-38.
  4. Ross, E., Oliver, C. (2003). The assessment of mood in adults who have severe or profound mental retardation. *Clinical Psychology Review*, **23**, 225-245.
  5. Cacioppo, J.T., Berntson, G.G., Larsen, J.T., Poehlmann, K.M., Ito, T.A. (2000). The psychophysiology of emotion. In M. Lewis & J.M. Haviland-Jones (Eds.), *Handbook of Emotions*, 2<sup>nd</sup> Ed. (pp. 173-191). New York: Guilford.