The relationship between quality of life and self-determination: an international study

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Abstract

Background The aim of this study was to evaluate the relationship between self-determination and quality of life (QOL) of persons with intellectual disabilities (ID) living in four countries (Canada, United States, Belgium and France).

Method Participants were 182 adults with mild ID living in community settings (with families, living independently or in supported living environments). QOL was measured with the Quality of Life Questionnaire. Self-determination was measured using the Adult version of The Arc’s Self-Determination Scale. Discriminant function and correlational analyses were conducted.

Results Discriminant function analysis indicated that essential characteristics of self-determination predicted membership in the high QOL group and that overall self-determination and QOL were significantly correlated, as were sub-scale scores.

Conclusions The study replicates findings from a previous study with an international sample and confirms the importance of self-determination to enhance QOL. Subsequent research should examine the direction of the relationship between self-determination and QOL and examine the relationship of essential characteristics of self-determined behaviour and core domains of QOL in greater detail.

Keywords intellectual disabilities, international, measurement, quality of life, self-determination

Introduction

A recent analysis of the international quality of life (QOL) literature (Schalock & Verdugo 2002) and an examination of cross-cultural understandings of QOL by people with intellectual disabilities (ID), their families, and direct support personnel (Schalock et al. 2005), have confirmed the multidimensional structure of QOL suggested by Schalock (1996) who suggested that QOL is composed of eight core domains: (1) emotional well-being; (2) interpersonal relations; (3) material well-being; (4)
personal development; (5) physical well-being; (6) self-determination; (7) social inclusion; and (8) rights.

There is both an empirical and theoretical link between self-determination (SD) and QOL (Wehmeyer & Schalock 2001). With regard to the latter, in addition to Schalock’s (1996) identification of SD as a core domain of QOL, the QOL construct has been used to define SD. Wehmeyer (1996, p. 18) defined SD as ‘acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life free from undue external influence or interference’, thus suggesting that SD is best understood within the context of a person’s overall QOL. Wehmeyer & Schwartz (1998) conducted an examination of the relationship between SD and QOL for 50 adults with ID and found that SD predicted membership in a high QOL group. In line with recent efforts to examine cross-cultural aspects of the QOL construct, we were interested in extending findings from Wehmeyer and Schwartz to an international sample.

Method

Participants

Participants were 182 adults (92 men and 90 women) with mild ID living in community settings (with family, living independently or in a supported living environment). Participants in the sample were from Canada (n = 52), United States (n = 26), France (n = 81) and Belgium (n = 23).

Procedures

The study was initiated by researchers who are members of the International Research Group on Quality of Life and Self-Determination (http://www.uqtr.ca/GIRAQ). The measures used (described subsequently) were already available in English and French from previous collaborations. All researchers were familiar with the instruments and all pertinent documents (procedural guidelines and scales) were accessible through our Website. Investigators recruited participants (through collaboration with services providers’ agencies) and trained research assistants to complete data collection (Lachapelle et al. 2002).

Analyses

We conducted a discriminant function analysis with QOL as the grouping variable and SD (individual domain scores) as predictor variables. One purpose of discriminant function analysis is to predict group membership on the basis of a set of predictor variables. To create dichotomous groups for the grouping variable (QOL), we conducted a median split of the sample based on total QOL scores. Thus, participants whose total QOL score fell below the 50th percentile (< 89) were assigned to the low QOL group, while persons whose scores were 89 and above were assigned to the high QOL group. The low QOL group consisted of 92 persons with mean QOL scores of 78.77 (SD = 8.15) and mean SD scores of 80.58 (SD = 16.13). The high QOL group consisted of 90 participants with mean QOL scores of 98.10 (SD = 5.66) and mean SD scores of 97.27 (SD = 19.14).

To further explore the relationship between SD and QOL, we conducted a correlational analysis of these two measures using a one-tailed Pearson product-moment procedure. All analyses were conducted using SPSS for Windows, version 12.0.

Instrumentation

Participant QOL was measured using the Quality of Life Questionnaire (QOL-Q; Schalock & Keith, 1993). The QOL-Q is a 40-item rating scale designed to measure overall QOL for persons with ID. The scale is administered in interview formats and yields data regarding overall QOL, consisting of scores from four sub-scales: satisfaction, competence/productivity, empowerment/independence, and social belonging. The original English version of the QOL-Q showed very good internal reliability (alpha = 0.90) as well as inter-observer reliability and concomitant validity (Schalock & Keith 1993).

Self-determination was measured using French and English versions of the adult version of The Arc’s Self-Determination Scale (Wehmeyer & Bolding 1999), a 72-item scale. Section 1 measures autonomy, including the individual’s independence and the degree to which he or she acts on the basis of personal beliefs, values, interests and abilities. The second section measures self-regulation in two sub-domains: interpersonal cognitive problem-solving, and goal-
setting and task performance. Higher scores reflect effective social problem-solving and goal-oriented behaviours. The third section is an indicator of psychological empowerment. High scores reflect positive perceptions of control. The final section measures self-realization, including self-awareness and self-knowledge. The Arc’s scale, normed with 400 adults with cognitive disabilities, has adequate construct validity, discriminative validity, internal consistency (Chronbach alpha = 0.83), and factorial validity (Wehmeyer & Bolding 1999). The French version (Wehmeyer et al. 2002) has also been shown to have adequate reliability and validity (Lachapelle et al. 2002).

Results

Table 1 provides the means and SD for QOL-Q and The Arc’s Self-Determination Scale scores for the overall sample. Table 2 provides the means and SD for predictor variables (i.e. component elements of SD behaviour) from the discriminant function analysis by QOL group status. Univariate statistics generated by the discriminant function analysis procedure indicated significant differences between SD sub-scale scores based on QOL group membership. Table 3 provides univariate F-ratios and P-values for each independent variable, as well as Wilks Lambda for these variables. Wilks Lambda provides an indicator of differences between the means of identified groups of subjects on a combination of dependent variables, in this case SD variables.

In discriminant analysis the emphasis is on analyzing the variables together instead of individually.
On the basis of all predictor variables, a single discriminant function was calculated with Chi-square = 48.241 (P = 0.0001) and Omnibus Wilks’ Lambda = 0.76. Examination of the canonical discriminant functions evaluated at group means (or group centroids, which refer to the mean discriminant scores for each of the dependent variable categories for each of the discriminant functions) showed that this discriminant function distinguished the high QOL group (function = 0.561) from the low QOL group (function = -0.549).

Correlational analyses determined significant positive correlations between overall QOL-Q and SD scores (r = 0.49, P < 0.01) as well as on all but one sub-scale scores.

**Discussion**

The results from this international dataset mirrored findings from Wehmeyer & Schwartz (1998), and suggested that subsequent data collection on an international level is warranted and can contribute to understanding the relationship between SD and QOL. The discriminant function analysis indicated that each of the essential characteristics of self-determined behaviour (autonomous functioning, self-regulation, psychological empowerment, and self-realization) predicted membership in the high QOL group and suggested that overall, SD contributes to enhanced QOL, as theorized by Schalock (1996) and Wehmeyer (1996). It was inappropriate to enter total SD scores into the function because there were no other predictor variables, but in subsequent research we will collect data on other potential contributors to QOL and will be able to say more about the contribution of SD.

It is interesting to note that QOL-Q mean scores obtained by participants in the present study were higher than those observed by Wehmeyer & Schwartz (1998), whereas SD mean scores were much lower. Although it is important to exercise caution in generalizing this result to a wider audience, it does bring up an interesting question as to whether support services across these countries have become effective at doing things for persons with ID (thus enhancing QOL), but not at giving them opportunities to do things for themselves, such as make decisions and choices, solve problems, and exercise SD. The correlational results confirm the relationship between SD and QOL.

The sample was too small to conduct between country analyses, and our principal concern is not so much in comparing between countries but in using an international dataset to better understand the SD construct and its relationship to QOL. One frequent criticism of SD is that it has been understood principally within the context of western, developed countries, such as the USA, Canada or the UK (Lachapelle & Wehmeyer 2003). However, there is an emerging literature base that suggests the construct is applicable to other countries and within diverse cultures, including within Native American cultures (Frankland et al. 2004), and Korean (Lee & Wehmeyer 2004), Taiwanese (Zhang et al. 2005), Japanese (Ohtake & Wehmeyer 2004), and Spanish (Peralta & Zulueta 2003) societies. The intent of the ongoing research of this international research group is to expand the data collection to additional English and French language countries, as well as to Spanish language countries so as to better examine the relationship between SD and QOL, to determine the nature and direction of that relationship and, ultimately to influence practice to promote both outcomes.

**References**


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