



Quality of life and special needs: exploring the previous concepts of professionals

Qualidade de vida e necessidades educativas especiais: explorando conceitos prévios de profissionais

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Abstract

This study explores: (a) previous conceptions of parents/professionals about the quality of life of youth with special needs, and their fit with the Schalock and Verdugo's core dimensions; (b) possible differences in its pattern throughout development. The participants responded to a collective, semi-structured questionnaire that provided a sort of characteristics or aspects related to the quality of life (from the participant standpoint) of young persons with special education needs. The obtained characteristics were content analyzed, and developmental phases were compared. The results were discussed according to the existing literature, as well as some implications to research, training and practice.

Keywords: quality of life, inclusive education, special needs students, teachers

Resumo

Este estudo explora: (a) conceitos prévios de pais/profissionais sobre a qualidade de vida de jovens com necessidades especiais, e sua adequação às dimensões de Schalock e Verdugo; (b) possíveis diferenças nos seus padrões ao longo do desenvolvimento. Os participantes responderam a um questionário coletivo, semi-estruturado que forneceu um conjunto de características ou aspetos relacionados com a qualidade de vida (na perspetiva dos participantes) de jovens com necessidades educativas especiais. O conteúdo das características obtidas foi analisado, e as fases desenvolvimentais comparadas. Os resultados foram discutidos considerando a literatura existente, tal como implicações para a investigação, formação e prática.

Palavras-Chave: qualidade de vida, educação inclusiva, estudantes com necessidades especiais, professores

The concept of quality of life (QoL) has been deserving a growing interest in Portugal, as it is most visible in the several studies of instruments for its assessment (e.g., Albuquerque, 2012; Gaspar, Matos, Ribeiro, Leal, Erhart, & Ravens-Sieberer, 2010; Vaz Serra et al., 2006). Yet, it is becoming an important topic for schools and other institutions that intervene at the psychosocial level. This is the case, for instance, of recent Portuguese legislation about individual specific curriculum for special needs students at secondary schools (Ministério da Educação e Ciência, 2015).

The World Health Organization (WHO) defined QoL as the "individuals perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (1997, p.1). In addition, other recent approaches, propose a more comprehensive conceptualization, beyond the scope of health, committed with the Convention on the Rights of Persons with Disabilities (United Nations, 2006). This is the case of the Schalock and Verdugo (2003)'s QoL model, one of the most studied in the special education field. Considering QoL as "a desired state of personal well-being" (Gómez, Verdugo & Areas, 2010, p. 459), it is based on an international consensus about the core aspects of the QoL conceptualization, measurement and application (Schalock et al., 2002). Regarding conceptualization, four principles were settled:

"(1) QoL is composed of the same factors and relationships for all people; (2) QoL is experienced when a person's needs are met and when the individual has the opportunity to pursue life enrichment in major life activity settings; (3) QoL has both subjective and objective components; and (4) QoL is a multidimensional construct, influenced by individual and environmental factors" (Verdugo et al., 2012, p. 1037).

In this model, QoL is operationalized in three different levels (e.g., Gómez et al., 2010): dimensions, indicators and personal outcomes. Eight core dimensions were proposed: personal development (PD), self-determination (SD), interpersonal relations (IR), participation or social inclusion (P), rights (R), emotional well-being (EWB), physical well-being (PWB), and material well-being (MWB) (Figure 1). Each dimension is defined by its main indicators (perceptions, behaviors or specific conditions reflecting the well-being of a person), and, at the bottom, the personal aspirations and valued outcomes by the person. Yet, the importance of the dimensions is considered to vary from one person to another, and across the lifespan (e.g., Gómez et al., 2010).

Several authors defend the application of these models in educational contexts, especially when it comes to build inclusive education and societies (Verdugo & Rodríguez, 2008; Verdugo, Gómez, & Rodríguez, 2011). However, in spite of the generalized use of the idiom “quality of life”, the QoL models themselves are little known and have received few references at the different levels of the Portuguese educational system. In addition, we don’t know much about the social representations (Moscovici, 1981) or personal theories (Kelly, 1955) about QoL, which guide personal actions and choices in real life.

A recent training program, the “mediators to inclusion course”, promoted in the context of the Enablin+ Project (n.d.; see also Candeias et al., 2017), was designed to

address the issues of social and school inclusion with caregivers and professionals working with children with special education needs (SEN). QoL models were included as a core topic, which was first approached considering the trainees’ previous conceptions. This study emerged in this context, with the objectives of exploring: (a) the previous conceptions of the trainees about the QoL of young people with SEN they work (or at least they were acquainted) with, and their fit with the Schalock and Verdugo’s core dimensions; (b) possible differences in the pattern of dimensions throughout three developmental phases (pre-school and school aged children, and adolescents).

QoL dimensions	Indicators	Examples
Emotional well-being	Contentment	"Joy when you are with other children and listen to music"
	Self-concept	"Acceptance (happiness)"
	Lack of stress	"Emotional tranquility"
Interpersonal relations	Interactions	"Playing with other children of different ages"
	Relationships	"Conviviality with all family members (included in family activities)"
	Supports	"Reference person"
Material well-being	Financial status	"Economic conditions"
	Employment	"Insertion in the labor market (economic quality)"
	Housing	"Institutionalization"
Personal development	Education	"Attends 1 PIT"
	Personal competence	"Acquisition of competences (logic, reasoning, intuition)"
	Performance	"Activity performance"
Physical well-being	Health	"Therapies (...) improve muscle tonus"
	Activities of daily living	"Adapted equipment (standing frame, wheelchair)"
	Leisure	"Practices football"
Self-determination	Autonomy/personal control	"Able to control his " stereotypes "
	Goals and personal values	"Do not achieve goals (frustration)"
	Choices	"Opportunity to express his opinions"
Participation / social inclusion	Community integration and participation	"He is at the kindergarten full-time (actively participate in all activities)"
	Community roles	"Volunteer with animals"
	Social supports	"Individual monitoring in class"
Rights	Human	"Access to health care and / or therapies"
	Legal	"Access to special education (material resources needs)"

Figure 1. Dimensions and indicators of Quality of Life in Schalock and Verdugo’s model (e.g., Schalock & Verdugo, 2003). Last column shows examples from this study

Method

Participants

Fourteen female trainees in the “mediators to inclusion course” provided the data for this study. They were teachers (including special education teachers) (n = 10), sociologists (n = 2), psychologist (n=1) and sociocultural animator (n=1), with a mean age of 44.85 years (min = 25, max = 54) and, except for 1 undergraduate student, all referred to have a graduate degree.

Instrument

A collective questionnaire was administered out loud, step by step, so that the participants were taught to focus on a particular child with SEN they were acquainted with, to register his/her age and gender, and three or four revealing characteristics or aspects of the child’s QoL: “think about a specific pre-school aged child/school aged

child/adolescent with SEN. Which characteristics or aspects he/she shows that tell you something about the quality of his/her life? Please, write down the age and gender of the child/adolescent and list three or four of those characteristics or aspects, each one in a different card. Then, mark each one with a plus sign (+) if you see that characteristic or aspect as a positive contribution to his/her quality of life, or mark it with a minus sign (-) if you see it as a negative contribution.”

Table 1.
Frequencies of descriptors by gender and developmental phase

	F	M	F+M
Pre-school aged children	27 (48.2%)	29 (51.8%)	56 (100%)
School aged children	16 (34.8%)	30 (65.2%)	46 (100%)
Adolescents	24 (45.3%)	29 (54.7%)	53 (100%)
Total	67 (43.2%)	88 (56.8%)	155 (100%)

Note. F: Females, M: Males

The procedure was repeated twice to obtain data about pre-school children (3-5 years old), school aged children (6-12 years old) and adolescents (13-18 years old). At the end, a sort of QoL descriptors and their valence was available, by developmental phase.

Procedure

The questionnaire and its administration were designed to elicit from the participants, before any training work on QoL, a repertory of previous conceptions about the QoL of youth with SEN. So, it was administered by the trainer at the beginning of a specific session on QoL.

Afterwards, the sort was content analyzed (Bardin, 2009). The core dimensions of QoL of the Schalock and

Verdugo’s model were considered as eight categories of content analysis which were defined through the indicators and descriptors in literature (e.g., Schalock & Verdugo, 2003). A preliminary reading of the obtained descriptors offered some support to the adequacy of the categories to analyze the contents, and allowed the identification of units of meaning. Most of the descriptors provided could be coded as single units, but a few were broken into two or more descriptors, each one becoming a unit of meaning by itself. According to the present theme, every unity was classified in one, and only one, of the eight QoL categories by two trained coders, who could reach full consensus (see examples in Figure 1). Descriptors were registered as present (1) in one particular category and absent (0) in the other categories. An SPSS v. 22 data base was created such that the descriptors were treated as cases and the variables were youths’ gender and developmental phase, and 8 dichotomous variables (presence, absence), one for each QoL category. A QoL categorical variable with 8 categories was created to count the descriptors in each QoL dimension. The valence of each descriptor was treated a dichotomous variable (positive, negative). A statistical analysis was performed for categorical variables (frequencies and qui-square tests of independence).

Table 2.
Frequencies of quality of life descriptors by developmental phase

Developmental phase		Quality of life dimensions								
		PD	SD	IR	P	R	EWB	PWB	MWB	Tot
PS	Count	9	1	12	11	4	11	11	3	62
	Within Phase	14.5%	1.6%	19.4%	17.7%	6.5%	17.7%	17.7%	4.8%	100.0%
	Within QoLD	34.6%	16.7%	29.3%	32.4%	57.1%	47.8%	47.8%	23.1%	35.8%
S	Count	9	1	13	13	2	8	6	3	55
	Within Phase	16.4%	1.8%	23.6%	23.6%	3.6%	14.5%	10.9%	5.5%	100.0%
	Within QoLD	34.6%	16.7%	31.7%	38.2%	28.6%	34.8%	26.1%	23.1%	31.8%
Ad	Count	8	4	16	10	1	4	6	7	56
	Within Phase	14.3%	7.1%	28.6%	17.9%	1.8%	7.1%	10.7%	12.5%	100.0%
	Within QoLD	30.8%	66.7%	39.0%	29.4%	14.3%	17.4%	26.1%	53.8%	32.4%
Tot	Count	26	6	41	34	7	23	23	13	173
	Within Phase	15.0%	3.5%	23.7%	19.7%	4.0%	13.3%	13.3%	7.5%	100.0%
	Within QoLD	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Notes. PS: Pre-school aged children (2 – 5 year olds). S: School aged children (6 – 12 year olds). Ad: Adolescents (13 years old or more). PD: Personal development. SD: Self-determination. IR: Interpersonal relations. P: Participation / Social inclusion. R: Rights. EWB: Emotional well-being. PWB: Physical well-being. MWB: Material well-being. Tot: Total

Table 3.
Frequencies of quality of life descriptors by valence

Valence		Quality of Life Dimensions								
		PD	SD	IR	P	R	EWB	PWB	MWE	Tot
Neg	Count	13	4	11	7	2	8	10	6	61
	Within Val	21.3%	6.6%	18.0%	11.5%	3.3%	13.1%	16.4%	9.8%	100.0%
	Within QoLD	54.2%	66.7%	29.7%	23.3%	33.3%	34.8%	43.5%	50.0%	37.9%
Pos	Count	11	2	26	23	4	15	13	6	100
	Within Val	11.0%	2.0%	26.0%	23.0%	4.0%	15.0%	13.0%	6.0%	100.0%
	Within QoLD	45.8%	33.3%	70.3%	76.7%	66.7%	65.2%	56.5%	50.0%	62.1%
Tot	Count	24	6	37	30	6	23	23	12	161
	Within Val	14.9%	3.7%	23.0%	18.6%	3.7%	14.3%	14.3%	7.5%	100.0%
	Within QoLD	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Notes. Neg: Negative. Pos: Positive. PD: Personal development. SD: Self-determination. IR: Interpersonal relations. P: Participation / Social inclusion. R: Rights. EWB: Emotional well-being. PWB: Physical well-being. MWB: Material well-being. Tot: Total

Results

Table 1 suggests that QoL descriptors were more frequently of boys (57%) than girls (43%), especially for school aged children, but this association was not statistically significant. A total of 173 descriptors was collected, $M = 12.36$ descriptors by participant, and $M = 4.12$ per child.

QoL dimensions and developmental phase

As Table 2 displays, all the QoL dimensions were mentioned by the participants, including when developmental phases are considered separately. Overall, the most referred dimensions to describe QoL of young people with SEN were IR (24%) and P (20%), followed by PD (15%), EWB and PWB (13%, each). Less referred were SD (3%), R (4%) and MWB (8%).

Considering each developmental phase separately ("within phase" rows in Table 2), the IR followed by P still were the most frequent QoL categories. However, for pre-school aged children, P was as much frequent as EWB and PWB (18%). The IR references seemed to increase across developmental phases (PS, 19%; S, 24%; and Ad, 29%) and the P suggested to be more likely among school aged children (24%, against 18% in the two other stages). For school aged children and adolescents, PD follows (16% and 14%, respectively). EWB (and R) was more used for school aged children (18%) and less for adolescents (7%). On the contrary, SD was referred more frequently to describe adolescents (7% of adolescent descriptors), as well as MWB (13%).

However, a series of qui-square tests showed the association between single QoL categories and developmental phase to be no significant for PD, IR, P, BWB, and PWB. For SD, R and MWB, the small expected count in a number of cells didn't recommend conclusions (the same for the 8 QoL Dimensions \times 3 Developmental Phase test).

QoL dimensions and valence of descriptors

The valence was indicated for 161 descriptors, and 62% were considered positive (Table 3). Two non-significant qui-square tests showed that valence wasn't related to gender, nor developmental phase.

Qui-square tests performed for each QoL dimension suggested a tendency to refer more negative than positive PD descriptors, $\chi^2(1, N = 161) = 3.176, p = .075, \phi = -.140$, and more positive P than negative, $\chi^2(1, N = 161) = 3.319, p = .068, \phi = 0.113$. For the other six QoL categories no significant association was found with valence.

A visual analysis of Table 3 shows that PD is the QoL category that, within valence, received the highest proportion of negative descriptors (21%) followed by IR (18%) and PWB (16%). On the other hand, IR (26%) and P (23%) received the highest proportion within positive descriptors. A qui-square test for 8 QoL Dimensions \times 2 Valence didn't allow conclusions because of the small expected count in a number of cells (involving SD, R and MWB).

Discussion

The main objectives of this study were exploring the fit between the QoL dimensions proposed in Schalock and Verdugo's model and the previous conceptions of the trainees about the QoL of youth with SEN, as well as the possibility that different patterns of dimensions could emerge in different developmental phases.

Results suggested that Schalock and Verdugo's QoL model is able to capture the previous conceptions of participants about the QoL of youth with SEN. All the descriptors were classifiable within the eight dimensions and all the categories registered cases. Besides, coders didn't mention the need of more categories.

This supports the assertion that the model is based on a broad consensual ground. Also, our results go in the same direction as Petry, Maes and Vlaskamp (2005)'s. These authors found that the parents and caregivers were able to refer, spontaneously or when directly asked, all the five dimensions in the Felce and Perry (1995) model (physical well-being, material well-being, social well-being, development and activity, and emotional well-being), as important to the good QoL of children / adults with profound multiple disabilities. Even so, they found a more homogenous picture among QoL dimensions than ours, as follows.

The obtained descriptors suggest that some categories of QoL were more easily accessible to participants and others less. The most frequent to be mentioned were IR and P (overall, and within each developmental phase), which refer to social, immediate involvement of the youth with SEN. This goes in the same direction as the Petry and colleagues' study referred above, but only partially, as in that study social well-being appears together with physical well-being as the most frequently associated with good QoL. In our study, PWB was among the most considered but only for pre-school children. This can be related to the characteristics of both samples, the Petry and colleagues' referring to children and adults with profound multiple disabilities, while our possibly focus more heterogeneous, and not so many severe, cases.

Among the least referred were SD and R dimensions, both related to the affirmation of individuality in social contexts. The MWB is among the less considered categories, as in the Petry and colleagues' study (in which its importance increased when participants were directly asked about). Overall, PC, EWB and PWB, more individualistic features, were moderately considered. Thus, our results suggest a more attuned focus on the immediate, relational aspects of SEN children when considering the quality of their lives.

Statistical non-parametrical tests point in the same direction as Petry and colleagues results and fail to show a clear developmental pattern, contrary to the suggested by some in the QoL models (see Gómez et al., 2010) or developmental (e.g., Masten, Burt, & Coatsworth, 2006) fields. This seems to be an issue to explore more deeply in further studies, as some QoL dimensions received only a few references and a couple of hypotheses emerged. The emotional and physical signs, as well as rights

(mainly related with the access to services and therapies) seemed to be more salient for QoL appreciation in younger children. On the other hand, self-determination and the material life conditions seemed to become more salient (but not much salient, especially the first) when the focus was on adolescents QoL.

Also, some tentative ideas emerged concerning the valence of the descriptors. First, participants focused more on positive than negative aspects of QoL of children and adolescents with SEN. Second, there is no evidence that valence differed across developmental phases, or gender. Finally, a tendency emerged for more negative than positive PD descriptors, and more positive P descriptors than negative. The tendency for the positive in P descriptors could be related to the school system efforts in Portugal for inclusion (Ministério da Educação, 2008), such that the social participation became more salient and invested by the participants, many of them school teachers. On the other hand, the more frequently negative references about personal characteristics, can possibly reflect the particular challenges that SEN children and adolescents present to teachers and caregivers in the way of schools to be inclusive.

The issues explored in this study deserve further research with larger samples of parents, professionals and caregivers of youth and adults with SEN, improved instruments, and longitudinal data to offer a look on developmental trajectories. Professionals, parents and caregivers are considered to be key persons (or proxys) in the QoL assessment of SEN persons, and in implementing interventions to improve their lives. In this context, is important to know how they think and approach this issue, so better training programs could be designed and implemented – an important task in the special education field for the years to come, in a human and inclusive, developed world.

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