

Predictors of Quality of Life of Persons with Intellectual Disability

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Introduction

The main purpose of this research was to examine factors that influence QOL on people with ID.

Information regarding potential predictor variables is important to meet challenges and overcome barriers that people with ID have been facing,

as well as

to improve public policies or service practices based on QOL framework.





Introduction

The concept of QOL driving this investigation was:

QOL is “a multidimensional phenomenon composed of core domains influenced by personal characteristics and environmental factors.

These core domains are the same for all people,

although they may vary individually in relative value and importance”

(Schalock et al. 2010, p. 21).



REVIEW

Introduction

QOL is a multidimensional concept
and
includes subjective and objective indicators
(Schalock & Verdugo, 2002).

QOL is a hierarchical construct
(Simões et al., 2016; Wang et al., 2010).

QOL comprises universal (etic)
and culture-bound (emic) properties
and
should improve the human functioning'
understanding
(Claes et al. 2010a; Schalock et al. 2007, 2010).





Introduction

Two groups of characteristics were analyzed:

Personal determinants: gender, diagnosis, age;

Environmental determinants: **living arrangement** (own home, family home, and care facility), **daytime activity** (paid job, vocational training, and occupational activity centers), and **geographical location** (North, Centre, Lisbon, Alentejo, and Algarve).





Introduction

It can be said that QOL may have less to do with a presence of an ID and more to do with the opportunities that improve individual's participation in community-based settings.

Thus, the supports have a crucial influence on individual's QOL (Thompson et al., 2009).





Introduction

Identify predictors of QOL are important to focus on how these factors can be used by practitioners to enhance personal outcomes, and focus on personal-environmental interactions that influence QOL of each person.





Research Questions

The research questions driving this investigation were:

- (a) To what extent do personal characteristics (i.e., gender, diagnosis, and age) are predictors of QOL?
- (b) To what extent do environmental characteristics (i.e., living arrangement, daytime activity, and geographical location) are predictors of QOL?
- (c) Are there differences between data collected from self-report and report-of-others measures?



Hypotheses

It was hypothesized that:

- a) There would be personal and environmental factors that predict QOL of people with ID;
- b) There would be agreement between people with ID and their proxies (e.g., caregivers and professionals) regarding the determinants predicting QOL.



Sample

Data were collected from individuals with ID and their proxies.

Why?

Because data based on multi-perception strategy may represent an important step to explore different viewpoints around the factors influencing QOL of people with ID.

Sample

- ✓ The sample comprised 1,264 adults:
 - ✓ People with mild level of ID ($n = 769$);
 - ✓ People with moderate level of ID ($n = 495$, 39.16%).
- ✓ The age of the participants with ID ranged from 18 to 66 years ($M = 31.36$, $SD = 10.55$).



Sample

Characteristics		n (%)
Gender	Male	664 (52.53)
	Female	600 (47.47)
Diagnosis	Mild level of ID	769 (60.84)
	Moderate level of ID	495 (39.16)
Age (intervals)	18–20	233 (18.43)
	21–29	390 (30.85)
	30–39	354 (28.01)
	40–49	209 (16.54)
	50–66	78 (6.17)
Living circumstances	Own home	93 (7.36)
	Family home	924 (73.10)
	Care facility	247 (19.54)
Daytime activity	Paid job	138 (10.92)
	Vocational training	481 (38.05)
	Occupational activity centers	558 (44.15)
	No daytime activity	87 (6.88)
Geographical location	North	307 (24.29)
	Centre	495 (39.16)
	Lisbon	193 (15.27)
	Alentejo	194 (15.35)
	Algarve	75 (5.93)



Sample

- ✓ The support staff ($n = 224$) were psychologists, social workers, special education teachers, psychomotor/occupational therapists, and monitors,
- ✓ The age of the support staff ranged from 22–64 years ($M = 41.46$, $SD = 9.87$).



- ✓ The family members ($n = 109$) were mothers, fathers, siblings, and other relatives,
- ✓ The age of the family members ranged from 21–89 years ($M = 57.37$, $SD = 13.64$).

Measure

The Portuguese version of the Personal Outcomes Scale was used to assess QOL.

Self-Report:
40 items

Answered by the
person with ID

Answered by a
Proxy (family or
support staff)

Report-of-Others:
40 items



Measure

Personal Development
Self-Determination
Interpersonal Relations
Social Inclusion
Rights
Emotional Well-Being
Physical Well-Being
Material Well-Being

(Schalock & Verdugo, 2002)

Indicators
(5 per domain)

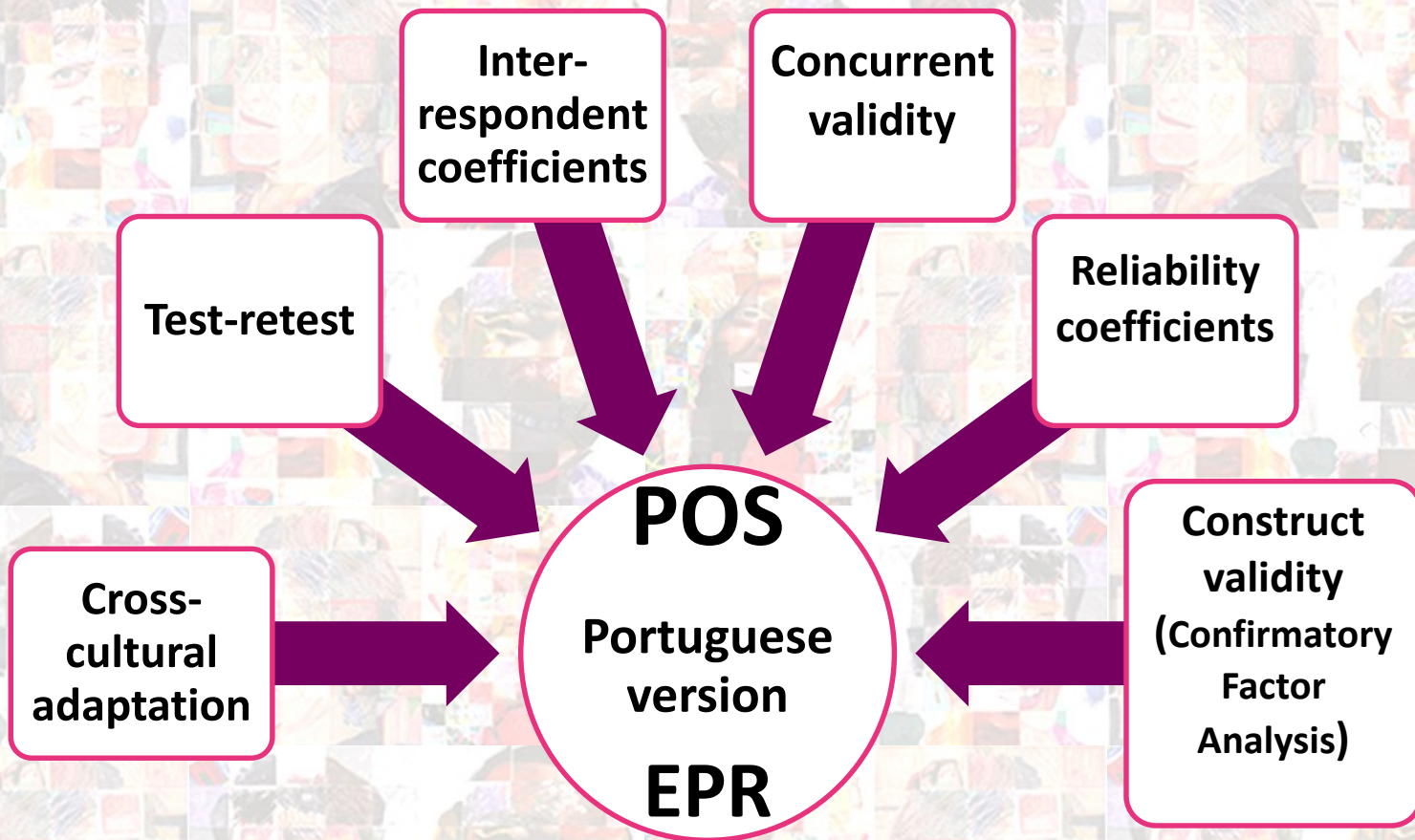
Domains
(8)

Independence, social participation and well-being

Factors
(3)

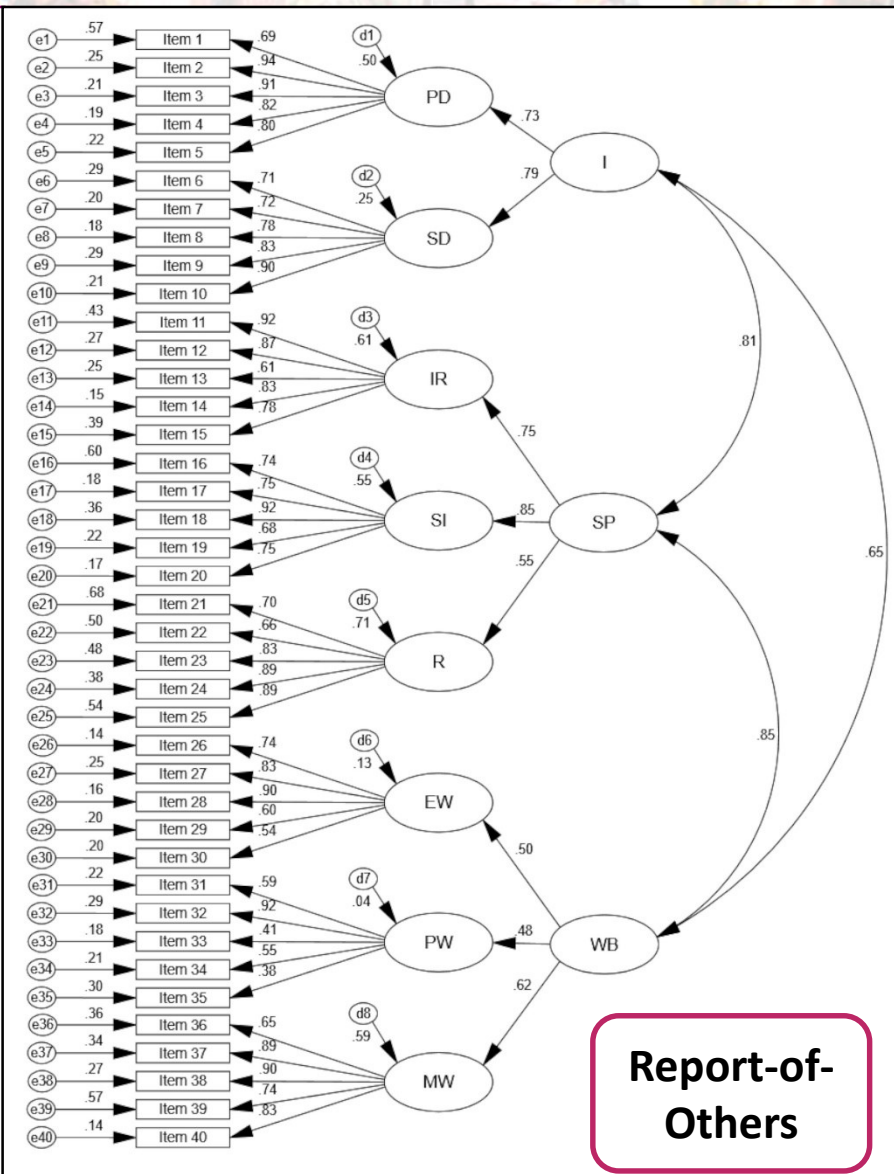
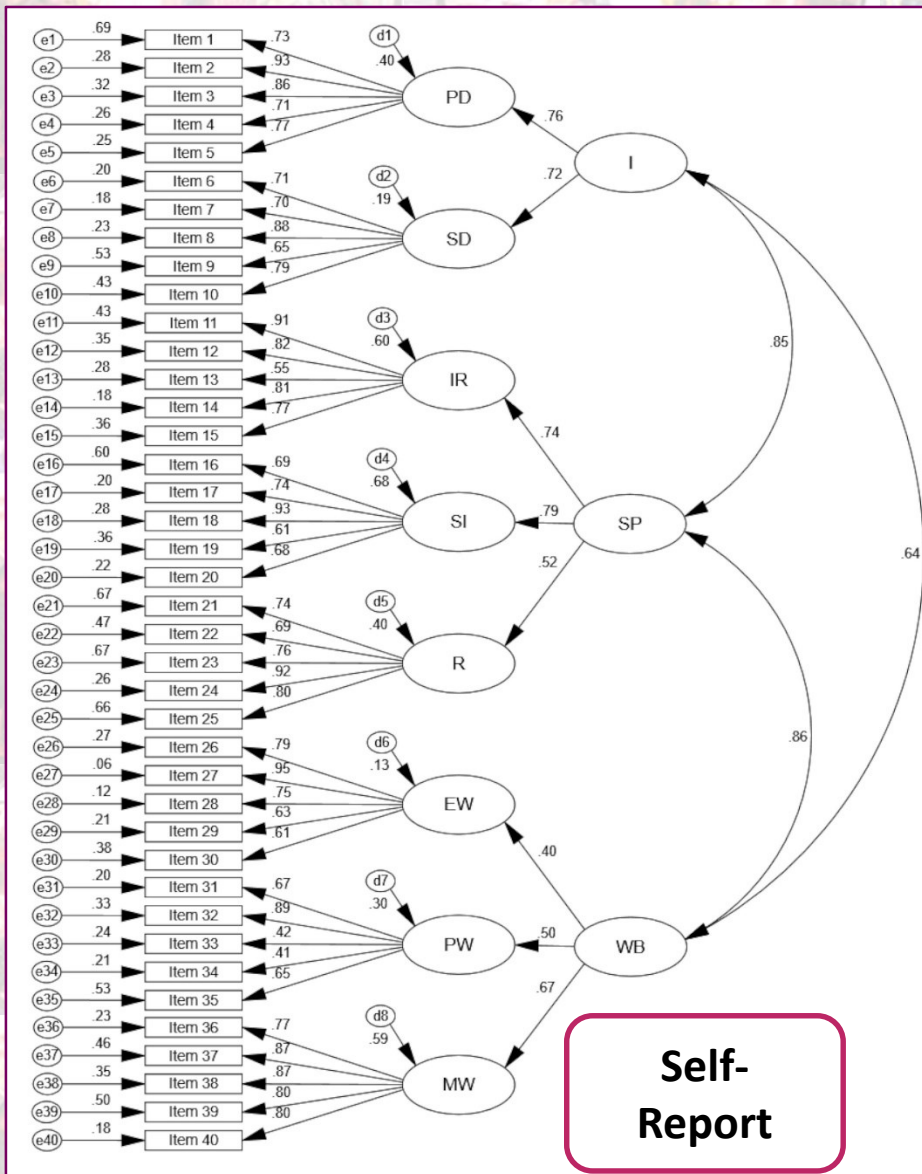
- Self-report QOL index
- Report-of-Others QOL index

Measure



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Self-Report

Report-of-Others



Results



- ✓ The Pearson coefficients between self-report and report-of-others measures ranged from .44 (i.e., emotional well-being domain) to .82 (i.e., personal development domain).
- ✓ According to Andresen (2000) and Cicchetti's (1994) guidelines, the agreement between people with ID and proxies ranged from good ($r \geq .40 < .75$) to excellent ($r \geq .75$).



Results



- ✓ These results are similar to previous Portuguese research (Simões & Santos, in press) and others researches with the POS (e.g., Claes et al. 2012).
- ✓ Suitable agreement between people with ID and their proxies,
- ✓ Although both perceptions can differ.



Results



- ✓ Regression analyses were calculated to examine the potential QOL' predictors of adults with ID.
- ✓ Due p -values indices can be sensitive to sample size (Dunst & Hamby, 2012), Cohen's d scores using Wilson's (2001) computer software were calculated to report and interpret the research findings.



Results



Self-
Report

Two variables had a great explanation of predicting the QOL scores:

- (1) Diagnosis in the **independence** ($\beta = -.39, p < .01, d = -.85$) and **social participation** ($\beta = -.24, p < .01, d = -.50$) factors, as well as in the **QOL total score** ($\beta = -.28, p < .01, d = -.58$)
- (2) Daytime Activity in the **independence** ($\beta = -.32, p < .01, d = -.68$) and **well-being** ($\beta = -.28, p < .01, d = -.59$) factors, and in the **QOL total score** ($\beta = -.31, p < .01, d = -.64$).

Results

Self-Report

Independent variables	Independence		Social participation		Well-being		QOL total score		
	β	d	β	d	β	d	β	d	
Gender	.01	.02	-.14**	-.28	-.12**	-.24	-.11**	-.22	
Diagnosis	-.39**	-.85	-.24**	-.50	-.07*	-.14	-.28**	-.58	
Age	.15**	-.30	-.09**	-.18	-.02	-.04	-.10**	-.21	
Living circumstances	-.01	-.02	-.15**	-.30	-.02	-.04	-.08**	-.16	
Daytime activity	-.32**	-.68	-.17**	-.35	-.28**	-.59	-.31**	-.64	
Geographical location	.05*	.10	.00	.00	.03	.06	.03	.06	
	R^2	.39		.18		.11		.28	
	F	136.06**		47.01**		27.42**		82.06**	
	Df	(6, 1257)		(6, 1257)		(6, 1257)		(6, 1257)	

According to Cohen's (1988) criteria, the coefficients of determination are classified as small ($R^2 \geq .02$), medium ($R^2 \geq .13$), and large ($R^2 \geq .26$).

The independent variables seem to explain 39.10% ($F(6, 1257) = 136.06, p < .01, R^2 = .39$) of the **independence**, 17.90% ($F(6, 1257) = 47.01, p < .01, R^2 = .18$) of the **social participation**, and 27.80% ($F(6, 1257) = 82.06, p < .01, R^2 = .28$) of the **QOL total score**.



Results



Self-
Report

- ✓ Additionally, living circumstances were major predictors of the **rights** domain ($\beta = -.40, p < .01, d = -.87$).
- ✓ Data further revealed that the **gender, age, and geographical location** had insignificant (i.e., Cohen's d from .00 to .19) or small predictive power (i.e., Cohen's d from .20 to .49) of the QOL scores.

Results

Report-of-
Others

	Independence		Social participation		Well-being		QOL total score	
Gender	-.03	-.06	-.12**	-.24	-.10**	-.20	-.10**	-.21
Diagnosis	-.46**	-1.04	-.25**	-.52	-.11**	-.22	-.32**	-.68
Age	-.14**	-.28	-.01	-.02	.08**	.17	-.02	-.04
Living circumstances	-.03	-.06	-.20**	-.41	.09**	.18	-.07**	-.15
Daytime activity	-.19**	-.39	-.09*	-.18	-.21**	-.43	-.19**	-.39
Geographical location	.03	.06	-.04	-.08	-.06*	-.12	-.03	-.06
R ²	.36		.15		.09		.21	
F	116.77**		37.71**		21.08**		55.19**	
Df	(6, 1257)		(6, 1257)		(6, 1257)		(6, 1257)	

Similar to the results obtained by the people with ID, the **diagnosis**, **living circumstances** (e.g., in the rights domain), and **daytime activity** were also predictors of the QOL scores reported by the proxies.

The analyzed variables had medium or large predictive power of the **independence**, **social participation**, and **QOL total score**.

These factors had small predictive power of the well-being factor of people with ID.



Discussion



- ✓ The factors that strongly predicted the QOL scores were diagnosis, living circumstances, and daytime activity.
- ✓ There was a high degree of agreement between the predictors reported by the people with ID and their proxies.
- ✓ In line with earlier researchers, the results of our investigation revealed that QOL is also predicted by individual and environmental factors (e.g., Claes et al., 2012; Gardner & Carran, 2005; Keith & Bonham, 2005).



Discussion

- ✓ First, the diagnosis was the major predictor of the QOL scores among people with ID.
- ✓ Diagnosis seems to be a barrier reported by the people with ID, support staff, and family members.
- ✓ However, the emphasis should move from the person's disability to a social-ecological human functioning.
- ✓ According to this approach, people with ID need additional supports to successfully participate in community-based settings, as do other citizens of society (Thompson et al. 2009).
- ✓ Thus, the service system should modify environments and providing personalized supports, where the focus should be the empowerment of people with ID and the enhancement of their QOL.





Discussion



- ✓ Second, living circumstances were predictors of the rights domain.
- ✓ People with ID living in care facilities showed lower scores in the rights domain.
- ✓ Many individuals with ID did not make fundamental choices about where and how to live their daily lives (Gardner & Carran, 2005).
- ✓ Findings reflect that institutions should respect the human and legal rights of each person with ID.



Discussion



- ✓ Finally, daytime activity was the second robust predictor of the QOL scores of people with ID.
- ✓ These results emphasize that employment directly predicting higher QOL.
- ✓ This is mainly important for Portuguese people with ID because there is a high level of unemployment and very few of them have a paid job.
- ✓ Practitioners should focus on support needed by individuals with ID to obtain and maintain employment in community-based settings.



Discussion



- ✓ Findings from our investigation are encouraging because showed that proxies were sensitive to the perspectives of people with ID and those with ID provide accurate assessment as the primary respondents.
- ✓ The most critical disagreement was observed in adults living in a care facility.
- ✓ It was observed that proxies rated higher life satisfaction than people themselves: a desire for positive outcomes of their work!?!?
- ✓ The perceptions are the best basis for supports, including counselling of key stakeholders for resolving conflicting choices and perceptions.



Discussion



The findings also revealed that inclusive living circumstances (i.e., own home or family home) and daytime activity (i.e., paid job) were associated with experiencing more social participation (i.e., interpersonal relations, social inclusion, and rights) and overall QOL.



Discussion



- ✓ There are no arguments for keeping people with ID away from their families, friends, neighbors, and culturally typical environments.
- ✓ “The community must do much better” (Fujiura 2006, p. 374) and is rich in opportunities or relationship possibilities.
- ✓ People with ID should feel part of an inclusive community to experience improved QOL.
- ✓ It is unquestionable that the central goal of service systems should be ensuring their rights, achieving equal opportunities, promoting the inclusion and the empowerment, and encouraging community-based supports.



Practical Implications

- ✓ Knowledge of the factors that influence the QOL allows incorporating the needs of people with ID to reorganize personalized supports consistent with the social-ecological model of human functioning.
- ✓ Once predictors of QOL are identified, “resources can be allocated to maximize their positive impact on desired personal outcomes” (Schalock et al., 2008, p. 186).



Practical Implications

- ✓ The results of our investigation allow practitioners to focus on the predictors of desired outcomes, rather than focusing exclusively on the outcomes (Schalock, 2004).
- ✓ The results have implications on the logic of the development of programs based on person-centered planning and consistent with the person's choices or goals (Claes et al., 2010).
- ✓ This assumption involves that key practitioners address managing factors that influence QOL, in order to improve personal outcomes.



Practical Implications

Practitioners should:

- (a) Maximize personal outcomes within the context of community-based settings;
- (b) Understand better the local community (e.g., attitudes, work opportunities, natural support networks; Schalock et al., 2008);
- (c) The professional practices of education and rehabilitation should be based on dignity, respect, equity, inclusion, natural support systems, and improving living and daytime activity conditions.



Practical Implications

Organizations should:

- (a) Realign activities in order to increase opportunities for people with ID;
- (b) Realign practitioner functions in order to value the support staff on planning, delivery, and evaluation of services and supports;
- (c) Change the focus of quality of care (e.g., control, power, safety, and categorization) to the operationalization of QOL framework (De Waele et al., 2005), which focuses on eight QOL domains .
- (d) Change the organizations as primary service providers to the organizations as bridges with the community (Schalock et al., 2008).



Conclusion



- ✓ Although promoting each individual's definition of community living, work, and social interaction remain a major challenge the findings of our research highlighted that practitioners should seek opportunities based on community-based inclusion and participation.
- ✓ Such practical attitudes would guarantee that service systems encourage an inclusive society, where individuals with ID participate as respected members of their communities.



Thank you
for your
attention!



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