

# Italian validation of the DEMQOL-PROXY: Exploratory Factor Analysis, Convergent and Divergent Validity

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**Abstract.** *Background and aim of the work.* we present in this paper a complete Italian validation version. We show some psychometric properties of the Italian version of the DEMQOL-PROXY: Structural validity (by use Exploratory Factor Analysis), convergent validity and divergent validity in Italian language. *Method.* We enrolled a sample of 182 caregivers of people with mild to moderate Dementia. In particular, we collected 90 questionnaires of professional caregivers and 92 questionnaires of family caregivers. We used Exploratory Factor Analysis (Varimax rotation), to identify the saturation of items on the relevant factors. The internal consistency of the instrument was evaluated by using the Cronbach Alpha coefficient. Finally, referring to the Validity of convergent and Divergent validity, we used Spearman's correlation coefficient by comparing the various instruments of the study. *Results.* Our result shows that the variance explained by 4 factors corresponds to almost 51% of the total variance. Factors extracted in our Italian version are: Cognition, Negative and Positive emotion; Daily activity and Membership. *Conclusion.* The Italian version of the DEMQOL-PROXY point out very good psychometric properties: factors extracted are similar to the original version and convergent and divergent validity show good proprieties. We consider this paper as a complete Italian Validation. ([www.actabiomedica.it](http://www.actabiomedica.it))

**Key words:** quality of life; dementia, exploratory factor analysis, convergent validity, divergent validity

## Introduction

Dementia is a chronic and progressive condition defined as a public health priority. Dementia causes decline in cognitive, physical and social functions, disability and increasing dependence on help from others in those affected (1,2); the World Health Organization (WHO) estimates 47 million people worldwide affected by dementia and forecasts that by 2050 there will be 132 million (1). The consequences on the economic and organizational level are imaginable, dementia represents substantial human costs for the society, family and individuals (3,4).

Dementia is therefore a particularly relevant problem and represents the first cause of the lowering of the Quality of Life (QoL) among neurodegenerative diseases (5).

The univocal definition of QoL has never been fully realized, the construct of QoL has constantly evolved over time and it is represented by a lot of definitions (6,7). WHO defines the QoL as "individuals' perceptions 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"(8). QoL is therefore generally recognized as subjective and multidimensional and its definition

overlaps with that of a broader state of health that includes perception of health, physical, mental, social and role functioning (7,9).

Maintaining a good QoL is a primary and realistic goal of dementia treatment, therefore tools that assess quality of life are needed to evaluate the effectiveness of the interventions implemented (7,9,10). In the international context many tools have been developed to assess the QoL in dementia, but to our knowledge there are only two instruments validate in Italian language (7,11). The QOL-AD scale is indicated for patients with Alzheimer's disease (12) and the QUALID scale is indicated for people with severe or terminal dementia (13), at the moment there seems to be a lack of an instrument in Italian that evaluates the QoL in patients with mild and moderate dementia. In Italy, about 400,000 people are affected by dementia in varying degrees of severity (3) and a tool is needed that can assess the QoL even in patients with a mild or moderate degree of dementia.

The dementia Quality of Life scale (DEMQoL) (14) was developed to assess the QoL in patients with moderate and mild degree of dementia, there is also a PROXY version that assigns the assessment to caregivers, applicable in different contexts (hospital wards, hospices, home and long care settings) (7). DEMQoL has shown good psychometric properties of validity and reliability, also confirmed in the German, Spanish, Chinese and Japanese versions and a recent review recommends its use for future studies (14–19).

A first evaluation of the Italian version of the DEMQoL-PROXY scale was made, demonstrating good psychometric properties for the face and content validity (7;20). In this paper we present the final complete results obtained from the validation of the Italian version of the DEMQoL-PROXY scale (7;20).

## Aim

No Italian version of DEMQOL-PROXY has been validated in Italian language thus far. In line with this gap, we present in this paper a complete Italian validation version. We show some psychometric properties of the Italian version of the DEMQOL-PROXY: Structural validity (by use Exploratory Fac-

tor Analysis), convergent validity and divergent validity in Italian language.

## Materials and methods

This is an observational study of the cross-sectional, using the Italian version of the DEMQOL-Proxy obtained from the pilot pre-validation study (7). It was approved by Ethics Committee of the Santa Maria Nuova Hospital of Reggio Emilia (protocol no. 2018/0141634; approved on 19/12/2018) and took 10 months to complete, from April 2020 to February 2021.

### Measurement

We explored psychometric properties such as reliability of the original model, reliability of the questionnaire, convergent and divergent validity.

Specifically, for validities, we used the following validated scales:

1. The Italian version of QOL-AD - Quality of Life Alzheimer's Disease (12) to explore convergent validity.
2. The Italian version of the CBI - Caregiver Burden Inventory (21; 22) to explore divergent validity.

The Quality of Life in Alzheimer's Disease [QoL-AD] (12) is a short and easy to submit questionnaire, it is in fact one of the most used scales in research. It consists of 28 items (interrogative form): 13 for patients with Dementia and 15 for their caregivers; it can be submitted to subjects who have obtained a score at MMSE higher than 11. The cut-off for impairment in cognitive skills is 26 (scores between 0 and 30). Authors identified five domains: cognitive, physical, psychological, social-family and related to the activities of daily life. Submission takes 10-15 minutes and items are rated on a 4-point Likert scale ranging from 1 (poor) to 4 (excellent).

The second scale is the Italian version of the CBI - Caregiver Burden Inventory (22), focused on the caregiver's "burden of the cure". The CBI actually measures the burden that changes in the cognition and behaviour of patients with psychiatric, geriatric and

oncological diseases have on their families, and the patient's consequent need for care and assistance. The point of view of the caregiver's experience is multidimensional, in fact it investigates 5 different types of burden: burden-time dependence, developmental, physical, social, and emotional burden. It includes 24 items rated on a 5-point Likert scale ranging from 0 (at all) to 4 (very).

#### *Sample eligibility criteria*

The study included caregivers (professional and family caregivers) of patients with mild or moderate Dementia (with 10 to 20 Mini Mental State Examination); a convenience sample was recruited excluding caregivers of people with severe dementia and we did not collect sensitive data, as the focus is on the analysis of evaluating scale submitted to caregivers. Written informed consent was obtained from subjects after a detailed explanation of the purpose of the study.

So, we submitted the DEMQOL-Proxy scale, together with the CBI and QoL-AD scales to a total sample of 182 caregivers of people with mild to moderate Dementia. This included the samples recruited in the previous two years of study (2019 and 2020). In particular, we collected 90 questionnaires of professional caregivers and 92 questionnaires of family caregivers.

#### *Statistical Analysis*

The statistical analysis was performed by using IBM SPSS Statistics Version 25. We used Exploratory Factor Analysis (Varimax rotation), to identify the saturation of items on the relevant factors.

The internal consistency of the instrument was evaluated by using the Cronbach Alpha coefficient. To assess Convergent Validity and Divergent Validity, we used Spearman's correlation coefficient to match the various instruments of the study.

#### *Ethical considerations*

The study has been conducted in agreement with the Ethical Principles for Medical Research Involving Human Subjects-the Declaration of Helsinki and

it has been approved by the International Research Board of the University of Parma.

All the Hospitals where the study took place were contacted and were asked for their availability to participate in the research. An explanatory document of the study was sent to the coordinators of the operating units in order to inform them, and to agree on the access times in the structures.

All eligible participants were informed of the purpose and characteristics of the study and received a clear informative written document, explaining the design, aims, procedure and ethical considerations of the research. Informed consent was obtained before the professionals' participation. Those who signed the consent have been informed that participation in the study was voluntary and that they could withdraw their consent to participate at any time.

## **Results**

#### *EFA and Construct Validity*

Factorial analysis is performed to identify and describe relationships in a set of variables, allowing one or more factors or dimensions to be identified. The basic hypothesis is that the correlation between the variables is determined by unobservable dimensions (factors) that somehow determine the scores observed in the variables.

Table 1 shows that the variance explained by 4 factors corresponds to almost 51% of the total variance, an adequate percentage to the purpose of the analysis. It also emerges that the first factor accounts for 17% of variance, the second for 16%, the third for 12% and the fourth for the remaining part.

Then, Table 2 shows the rotated component matrix (Varimax), in which it is highlighted the major saturations for each item of the questionnaire, respectively to each of the 4 identified factors. We can note that for each factor there are at least 4 high saturations (adequacy criterion for the number of factors identified by the EFA). Table 2 presents the result of factor analysis: the Italian translation of the DEMQol-Proxy showed a similar structure of the original version. Questions #1, #2, #3, #4, #5, #6, #7, #8, #9, #10 load on a factor

**Table 1.** Total Variance

Component	Initial Eigenvalues			Extraction Sums of Squares Loading			Rotation Sums of Squares Loading		
	Total	% of Variance	% Cumulative	Total	% of Variance	% Cumulative	Total	% of Variance	% Cumulative
1	5.495	17.172	17.172	5.495	17.172	17.172	4.929	15.404	15.404
2	5.174	16.168	33.340	5.174	16.168	33.340	4.452	13.912	29.316
3	3.984	12.449	45.789	3.984	12.449	45.789	3.464	10.826	40.142
4	1.522	4.757	50.546	1.522	4.757	50.546	3.329	10.404	50.546
5	1.457	4.552	55.099						
6	1.207	3.771	58.870						
7	1.132	3.538	62.408						
8	0.976	3.050	65.458						
9	0.888	2.774	68.232						
10	0.846	2.642	70.874						
11	0.765	2.390	73.264						
12	0.733	2.291	75.555						
13	0.701	2.190	77.745						
14	0.656	2.049	79.793						
15	0.629	1.965	81.758						
16	0.581	1.815	83.573						
17	0.533	1.664	85.238						
18	0.493	1.542	86.779						
19	0.479	1.498	88.277						
20	0.449	1.403	89.681						
21	0.440	1.376	91.057						
22	0.409	1.277	92.334						
23	0.362	1.133	93.467						
24	0.349	1.090	94.556						
25	0.332	1.038	95.594						
26	0.279	0.871	96.465						
27	0.244	0.762	97.227						
28	0.213	0.665	97.893						
29	0.194	0.607	98.500						
30	0.180	0.564	99.063						
31	0.163	0.509	99.572						

namely *Negative And Positive Emotion*; questions #12, #13, #14, #15, #16, #17, #18, #19 and #20 load on the same factor of the original version *Cognition*; questions #21, #22, #27, #28, #29, #30 and #31 load on a factor that can be called *Membership*; questions #11, #23, #24, #25 and #26, load on the same factor namely

*Daily Activity*.

#### *Cronbach's Alpha Coefficient*

To verify the reliability of items included in the Italian version of the DEMQoL-Proxy scale, we used the analysis for the Cronbach Alpha coefficient.

In order to be acceptable, Cronbach's Alpha is ex-

**Table 2.** Rotated component matrix

	Component			
	1	2	3	4
Cheerful	0.721	-0.038	-0.182	-0.054
Worried or Anxious	0.518	-0.018	0.195	0.303
Frustrated	0.698	0.150	0.046	0.164
Full of Energy	0.568	-0.012	0.063	-0.361
Sad	0.809	-0.038	0.062	0.021
Content	0.681	0.018	-0.074	0.016
Distressed	0.647	0.131	0.031	-0.064
Lively	0.634	-0.033	-0.041	-0.197
Irritable	0.595	0.161	-0.165	0.199
Fed-up	0.697	-0.048	0.177	0.140
That he/she has things to look forward to	0.378	0.061	-0.125	-0.460
His/her memory in general	-0.085	0.398	0.308	0.240
Forgetting things that happened a long time ago	0.001	0.617	-0.169	0.273
Forgetting things that happened recently	-0.007	0.723	0.003	0.207
Forgetting people's names	-0.028	0.785	0.051	0.036
Forgetting where he/she is	0.073	0.691	-0.085	-0.165
Forgetting what day is it	0.036	0.842	-0.088	0.067
His/her thoughts being muddled	0.142	0.755	0.173	-0.022
Difficulty making decisions	0.065	0.722	0.044	-0.064
Making him/herself understood	0.112	0.564	0.054	-0.194
Keeping him/herself clean	-0.107	0.040	0.490	0.417
Keeping him/herself looking nice	-0.203	0.007	0.584	0.412
Getting what he/she wants from the shops	-0.003	0.018	0.390	0.714
Using money to pay for things	0.145	0.031	0.219	0.809
Looking after his/her finances	0.127	-0.043	0.223	0.778
Things taking longer than they used to	0.094	0.219	0.405	0.515
Getting in touch with people	-0.103	-0.152	0.508	0.003
Not having enough company	0.132	0.067	0.675	0.047
Not being able to help other people	-0.024	0.066	0.666	0.131
Not playing a useful part in things	0.045	0.043	0.679	0.208
His/her physical health	-0.025	-0.003	0.698	0.263

Extraction Method: Principla Component Analysis. Rotation Method: Varimax con Kaiser Normalization.

a. Rotation converged in 5 iterations.

**Table 3.** Reliability Statistics

Cronbach's Alpha	N. of items
.82	31

pected to be higher than .70. In addition, the score should not exceed the value of .90, otherwise there would be no adequate difference between items on the scale.

As shown in Table 3, Cronbach's Alpha is .82 it is acceptable.

**Table 4.** Spearman' Rho

		QOLADTOT	CBITOT
Spearman's Rho	DEMqoLTOT	Correlation Coefficient	0,190*
		Sig. (2-tailed)	0,011
		N	180
			-0,096
			0,200
			180

*Spearman's Rho*

Finally, in order to evaluate convergent and divergent validity, we used Spearman's correlation coefficient by comparing the total scores obtained from the various instruments of the study. Table 4 shows the scores obtained from the various correlations.

The correlation between Demqol-Proxy and Qol-AD was positive and significant ( $C=,190$ ;  $p.<.05$ ) while the correlation between Demqol-Proxy and CBI is negative and not significant ( $C=-,096$ ;  $p.>.05$ ).

**Discussion**

We have select a theoretical model of 4 factors. We have found 4 factors differently from the original version (14). In the original version, the 5 factors were:

- Cognition
- Negative emotion
- Positive emotion
- Daily activity
- Membership

In our Italian model, we have point out a model of 4 factors in which Positive emotions and Negative emotions factors become a unique element.

So, for the Italian version factors extracted of the scale are

- Cognition [Factor number 2]
- Negative and Positive emotion [Factor number 1]
- Daily activity [Factor number 4]
- Membership [Factor number 3]

The total explained Variance was almost 51% and results was considerable.

A good reliability was found, Cronbach's Alpha is 0,825, this data was congruent with also the Spanish version of DEMQoL-Proxy (16).

Our Italian version of the DEMQOL-PROXY

show valid psychometric characteristics: reconfirming the original version (14) and adaptations produced so far (15-18). In this paper, we have completed our Italian pre-validation (7,20) and we have added: Structural validity, convergent and divergent validity have been explored and satisfied criteria.

We have also compared 3 tools to explore validity of DEMQoL-Proxy. On one hand, we have produced correlation between total score of each one tools. In this way, we have explored Convergent Validity thanks to the correlation between DEMQoL-Proxy and QoL-AD (both instruments assess construct of QoL for people affected by Dementia). On the other hand, we have tested Divergent Validity with the correlation between DEMQoL-Proxy e CBI (both instruments assess different construct of QoL for people affected by Dementia).

Finally, about the comparison between professional caregivers and non-professional caregivers, results obtained allow to consider that DEMQoL-Proxy is able to detect differences between perspective of professional caregiver and not-professional about QoL of patients. So, can be relevant respect and take of different point of view. This result must be re-tested and re-confirmed by future research.

**Conclusions**

The DEMQOL-PROXY could be in Italy an important tool dedicated from mild to moderate dementia (with 10 to 20 MMSE), in order to assess the QoL from the caregiver perspective. Our proposed pilot Italian version of the DEMQOL-PROXY reconfirm good psychometric properties: its structure and the results it leads to are similar to the original version (14) and to the other translations produced so far (15-18). In this paper, we have completed our Italian pre-validation (7,20) and we have added:

Structural validity, convergent and divergent validity have been explored and satisfied criteria.

DEMQOL-PROXY in fact, is an instrument able to explore QoL for patients from mild to moderate dementia. This construct is a fundamental element to understand how to improve patient's experience (14). DEMQOL-PROXY application could be helpful to better manage patients with a level of dementia from mild to moderate (with 10 to 20 MMSE). This questionnaire can be utilized by non-professional caregiver and professional caregiver.

Some limitations can be considered: size of sample, origin of sample (Caregivers were recruited from almost all from one Italian Region).

Implications for future research; could be interesting to go into detail different perspective of caregivers. So, detect differences between professional caregiver and not-professional point of view about QoL of patients will be a productive data to improve clinical setting.

**Conflict of Interest:** Each author declares that he or she has no commercial associations (e.g. consultancies, stock ownership, equity interest, patent/licensing arrangement, etc.) that might pose a conflict of interest in connection with the submitted article

## References

- World Health Organization (WHO). Global action plan on the public health response to dementia 2017 - 2025. Geneva World Heal Organ 2017;27.
- Scheltens P, Blennow K, Breteler MMB, et al. Alzheimer's disease. *Lancet* 2016 Jul 30;388(10043):505-17.
- Ministero della Salute. Linee di indirizzo Nazionali sui Percorsi Diagnostico Terapeutici Assistenziali per le demenze [National guidelines on Diagnostic Therapeutic Assistance Pathways for dementias] 2017
- Rose KM, Williams IC, Anderson JG, Geldmacher DS. Development and validation of the family quality of life in dementia scale. *Gerontologist* 2021;61(6):E260-8.
- Martyr A, Nelis SM, Quinn C, et al. Living well with dementia: A systematic review and correlational meta-analysis of factors associated with quality of life, well-being and life satisfaction in people with dementia. *Psychol Med* 2018;48(13):2130-2139
- McPherson S, Oute J, Speed E. Quality-of-life measurement in depression trials: A consumerist relic. *Health (London)* 2022;136345932210748.
- Miraglia Raineri A, Bonfiglioli C, Camaiani F, Sarli L, Artioli G. Italian pilot version of demoql-proxy: Content and face validity: A methodological bridge for a future Italian validation. *Acta Biomed* 2020;91(6-S):100-5.
- World Health Organization (WHO). Draft Programme on Mental WHOQOL User Manual. 1998.
- Bowling A, Rowe G, Adams S, et al. Quality of life in dementia: A systematically conducted narrative review of dementia-specific measurement scales. *Aging Ment Health* 2015;19(1):13-31.
- Harrison JK, Noel-Storr AH, Demeyere N, Reynish EL, Quinn TJ. Outcomes measures in a decade of dementia and mild cognitive impairment trials. *Alzheimer's Res Ther* 2016;8(1):1-10.
- Cartabellotta A, Eleopra R, Quintana S, et al. Linee guida per la diagnosi, il trattamento e il supporto dei pazienti affetti da demenza [Guidelines for the diagnosis, treatment and support of patients with dementia]. *Evidence* 2018;10(10):e1000190
- Bianchetti A, Cornali C, Ranieri P, Trabucchi M. Quality of life in patients with mild dementia. Validation of the Italian version of the quality of life Alzheimer's disease (QoL-AD) Scale. *Journal of Gerontology and Geriatrics* 2017;65:137-143.
- Gomiero T, Weger E, Marangoni A, et al. Misurare la qualità della vita nella Disabilità Intellettiva con demenza: una valutazione psicometrica della versione italiana della scala Quality of Life in Latestage Dementia (QUALID) [Measuring the quality of life in Intellectual Disability with dementia: a psychometric assessment of the Italian version of the Quality of Life scale in Latestage Dementia (QUALID)]. *J Alzheimers Dis* 2011;1(2):2-5
- Smith SC, Lamping DL, Banerjee S, et al. Measurement of health-related quality of life for people with dementia: Development of a new instrument (DEMQOL) and an evaluation of current methodology. *Health Technology Assessment. Health Technol Asses* 2005;9(10):1-93
- Kuo MCC, Au KT, Li YS, et al. Validation of the Chinese version of dementia quality of life measure-proxy in care home residents with dementia. *East Asian Arch Psychiatry* 2021;31(1):9-12.
- Lucas-Carrasco R, Lamping DL, Banerjee S, Rejas J, Smith SC, Gómez-Benito J. Validation of the Spanish version of the DEMQOL system. *Int Psychogeriatrics [Validation of the Spanish version of the DEMQOL system]* 2010;22(4):589-97.
- Niikawa H, Kawano Y, Yamanaka K, et al. Reliability and validity of the Japanese version of a self-report (DEMQOL) and carer proxy (DEMQOL-PROXY) measure of health-related quality of life in people with dementia. *Geriatr Gerontol Int* 2019;19(6):487-91.
- Schwab CGG, Dichter MN, Berwig M. Item distribution, internal consistency, and structural validity of the German version of the DEMQOL and DEMQOL-proxy. *BMC Geriatr* 2018;18(1).

- 19 . Yang F, Dawes P, Leroi I, Gannon B. Measurement tools of resource use and quality of life in clinical trials for dementia or cognitive impairment interventions: A systematically conducted narrative review. *Int J Geriatr Psychiatry* 2018;33(2):e166-e176.
- 20 . Bonfigliuoli C, Miraglia Raineri A, Foa' C, , et al. A protocol for Italian validation of DEMQoL-Proxy Scale: assessing the Quality of Life of people with moderate or mild dementia. *Acta Biomed* 2021;92(S2):e2021040.
- 21 . Novak M, Guest C. Application of a multidimensional caregiver burden inventory. *Gerontologist* 1989, 29, 798-803.
- 22 . Marvardi M, Mattioli P, Spazzafumo L, et al. The Caregiver Burden Inventory in evaluating the burden of

caregivers of elderly demented patients: results from a multicenter study. *Aging Clin Exp Res* 2005;17: 46–53.

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Received: 19 February 2022

Accepted: 1 April 2022

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