



Psychometric validation of the Persian version of the CarerQol-7D instrument on caregivers of patients with multiple sclerosis

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Keywords

CarerQol-7D; Multiple Sclerosis; Reliability and Validity; Caregivers

Abstract

Background: Providing informal care can deeply influence, both physically and emotionally, the quality of life (QoL) of caregivers, especially when the disease becomes chronic. CarerQol-7D is one of the most common instruments for measuring informal care. We aimed to develop a Persian version of the CarerQol-7D in the context of Iranian caregivers of patients with multiple sclerosis (MS). To this end, we investigated the validity and reliability of the mentioned instrument.

Methods: In this cross-sectional study using consecutive sampling method, the backward-forward translation method was used to achieve the Persian version of CarerQol-7D. Structural equation modeling (SEM) was used to perform confirmatory factor analysis (CFA). Cronbach's alpha was also reported for this

instrument for the evaluation of internal consistency.

Results: This tool was evaluated based on a sample of 452 caregivers of patients with MS from Sina Hospital, Tehran, Iran. Most of the participants were men (62.6%) and spouses of patients (56.6%). Based on the correlation of caregivers' characteristics, the clinical validity of this tool was observed to be relatively moderate. The Cronbach's alpha for this tool was estimated to be 65%. The normed fit index (NFI) (0.906), relative fit index (RFI) (0.812), incremental fit index (IFI) (0.948), Tucker-Lewis index (TLI) (0.892), comparative fit index (CFI) (0.946), and root mean square error of approximation (RMSEA) (0.049) were the model fit indices for the CarerQol-7D instrument.

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Conclusion: The findings showed good internal consistency and strong validity of the CarerQol-7D. Thus, we suggest researchers use this instrument to measure the QoL of caregivers for use in economic evaluations.

Introduction

Informal care is a prominent part of healthcare, as it reduces the pressure of formal care and decreases the total costs of healthcare.¹ In a report published by the European Commission in January 2021, the prevalence of informal care in Europe averages 14.4%. The report also indicated that 90% of informal care lasted more than 3 months.² Providing informal care can deeply influence the quality of life (QoL) of caregivers physically and even emotionally, especially when the disease becomes chronic.¹

An economic evaluation with two major components, namely cost and outcome, gives us the cost-effectiveness data of a therapeutic intervention. In economic evaluations, the impact of an intervention on not only patients, but also their family members, relatives, and friends should be considered.³⁻⁵ Thus, measuring and evaluating informal care is pivotal and provides a methodological homogeneity and transferable

results between different caregivers’ contexts.⁶ The Second US Panel on Cost-Effectiveness Analysis in Health and Medicine and the National Institute for Health and Care Excellence (NICE) recommend the necessity of considering the spillover effect in the denominator of economic evaluations to obtain a better estimation of the cost-effectiveness ratio for both patients and caregivers.^{4,5,7} Although the inclusion of informal care in economic evaluations is favorable, it is usually ignored. Recently, some instruments like the CarerQol-7D have been used to measure the QoL of caregivers.

Furthermore, the QoL of caregivers should be measured in economic evaluation studies, as caregivers’ QoL is greatly affected by the act of caregiving. For this purpose, the quantitative scale known as the quality-adjusted life year (QALY) is used to measure the effectiveness of therapeutic interventions⁸ and is considered a benchmark.⁹ There are several valid instruments to measure QALY of patients, but when it comes to the QALY of their caregivers, the most commonly applied instrument is the CarerQol-7D.¹⁰

The CarerQol-7D (Figure 1) is an instrument for measuring and valuing the health-related QoL of caregivers.

CarerQol-7D

Please draw an “X” to indicate which description best fits your current care giving situation

	no	some	a lot of		
a.	I have	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	fulfillment with carrying out my care tasks.
b.	I have	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	relational problems with the care receiver (e.g., he/she is very demanding, he/she behaves differently, we have communication problems).
c.	I have	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	problems with my own mental health (e.g., stress, fear, gloominess, depression, concern about the future).
d.	I have	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	problems combining my care tasks with my daily activities (e.g., household activities, work, study, family and leisure activities).
e.	I have	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	financial problems because of my care tasks.
f.	I have	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	support with carrying out my care tasks, when I need it (e.g., from family, friends, neighbors, acquaintances).
g.	I have	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	problems with my own physical health (e.g., more often sick, tiredness, physical stress).

CarerQol-VAS

Please draw an “X” on the scale below to indicate how happy you feel currently

Completely unhappy	Completely happy

Figure 1. CarerQol-7D questionnaire

This instrument was developed by Brouwer et al.¹⁰ in 2006 and was based on EuroQol (EQ). It combines seven burden dimensions, in two positive and five negative perspectives. CarerQol-7D has been validated in several studies.¹¹⁻¹⁵

To date, the CarerQol-7D has been translated into 12 languages and is currently available in Dutch, English, German, Hungarian, Italian, Japanese, Norwegian, Slovenian, Spanish, Swedish, Polish, and Portuguese.¹⁶ However, the Persian version was non-existent. The current study aimed specifically to develop a Persian version of the CarerQol-7D and assess its validity alongside the EQ-5D questionnaire in the context of Persian language.

Multiple sclerosis (MS) is a chronic functional and progressive disease that may make a patient dependent on their families or caregivers. This level of dependency makes caregivers experience a significantly lower QoL than the general population. To reach the desired sample, we chose MS as a functional disease which depends on family and friends to be patient caregivers.

Materials and Methods

Participants: Four hundred and sixty patients and their corresponding primary caregivers by using consecutive sampling method were recruited from Sina Referral Hospital in Tehran, Iran, and from private offices. Among those recruited, 452 people consented to participate in this cross-sectional study, which was conducted from October 2019 to May 2020. Eight cases declined to continue and dropped out of the study. Caregivers and the patients' physicians provided informed consent. The diagnosis of MS and disability status were confirmed through the 2017 McDonald criteria¹⁷ and the Kurtzke Expanded Disability Status Scale (EDSS),¹⁸ respectively, which was also confirmed by qualified neurologists.

Inclusion criteria: Caregivers aged 15 to 65 years old and those who were serving as primary caregivers were included in our study. A primary caregiver was defined as the most responsible person who cares for the patient with MS based on self-declaration. Parents, children, siblings, spouses, friends, and members of extended families were all considered eligible as primary caregivers in our study.

We recruited all patients with MS during the study period, regardless of the stage of their diseases based on 2017 McDonald criteria, and Kurtzke EDSS confirmed by the patients' neurologists.

Efforts were made to gather all patients with relapsing-remitting MS (RRMS). Participants took part voluntarily and received no incentives.

Exclusion criteria: Since our caregivers were responsible for filling out all questionnaires on their own, illiterate caregivers were excluded. Caregivers were asked to fill in both their and their patient's demographic data and four questionnaires.

Data collection and tools: Caregivers consented to complete the questionnaire. Tehran University of Medical Sciences approved the study protocol under the ethical code IR.TUMS.VCR.REC.1399.458. Through self-report questioning, demographic information and the CarerQol-7D instrument data were collected.

This study aimed to translate and analyze the CarerQol-7D instrument to make it available for Persian speakers. This questionnaire, which was designed to assess caregiver outcomes, was constructed based on the EQ instrument.¹⁹ This instrument presents a score ranging from 0 (worst informal care QoL) to 100 (best informal care QoL).¹⁰

Translation: To use the backward-forward translation method, two Iranian expert translators were invited to translate the English version of this tool into Persian separately. Then two different people who resided outside Iran – in English-speaking countries – but were fluent in English were asked to translate the English version into Persian separately. To accommodate the variations between them, every step of the process was monitored and supervised by two different translators independently.

The basic information of participants was analyzed and reported in count (%) and mean \pm standard deviation (SD). Structural equation modeling (SEM) was used to perform confirmatory factor analysis (CFA) to show the structural validity of the instrument. Cronbach's alpha was also reported for this instrument to evaluate internal consistency. Additionally, convergent validity of this instrument was tested using Pearson correlation test (compared against EQ-5D). SPSS AMOS software (version 24, IBM Corporation, Armonk, NY, USA) was used for basic analysis and CFA.

Results

In table 1, the basic characteristics of the study participants are presented, providing an overview of the sample under investigation. The majority of participants were men (62.6%), 26-54 years old (74.1%), married (83.6%), the spouse of a patient

(56.6%), and employed (60.8%); the patients were mostly women (85.2%), 26-54 years old (85.6%), and had been living with MS for 6-10 years (40.7%).

Table 1. Baseline characteristics of under study sample (n = 452)

Variables	Level	n (%)
Patient's gender	Man	67 (14.8)
	Woman	385 (85.2)
Patient's age group (year)	≤ 25	47 (10.4)
	26-54	386 (85.6)
	≥ 55	18 (4.0)
Caregiver's gender	Man	283 (62.6)
	Woman	169 (37.4)
Caregiver's age group (year)	≤ 25	33 (7.3)
	26-54	335 (74.1)
	≥ 55	84 (18.6)
Marital status	Single	74 (16.4)
	Married	378 (83.6)
Education years	≤ 12	189 (41.8)
	13-16	200 (44.2)
	≥ 17	63 (13.9)
Income level	≤ 74 \$	47 (10.4)
	74-185 \$	275 (61.0)
	≥ 185 \$	129 (28.6)
Relativity to patient	Parent	119 (26.4)
	Spouse	256 (56.8)
	Sibling	35 (7.8)
	Friend	5 (1.1)
	Child	36 (8.0)
Occupation	Unemployed	116 (25.7)
	Student	12 (2.7)
	Employed	274 (60.8)
	Retired	49 (10.9)
Disease duration (year)	≤ 5	132 (29.9)
	6-10	180 (40.7)
	11-15	63 (14.3)
	≥ 16	67 (15.2)

The mean ± SD of score for the CarerQol-7D in the first to seventh domains were 11.5 ± 3.2, 10.3 ± 3.3, 14.4 ± 9.3, 5.9 ± 2.6, 13.6 ± 5.9, 4.1 ± 3.8, and 15.7 ± 5.5, respectively, and the total score was 75.8 ± 18.7.

As demonstrated in table 2, the scores of the CarerQol-7D were found to be significantly associated with the patient's age group, type of disease, caregiver's gender, education level, income, relationship with the patient, and occupation (P < 0.05), indicating a good level of clinical validity for this instrument.

Regarding convergent validity, the CarerQol-7D instrument displayed a strong correlation with the EQ-5D (r: 0.901, P < 0.001), suggesting sufficient convergent validity. Furthermore, the

internal consistency of the CarerQol-7D was evaluated using Cronbach's alpha, resulting in a coefficient of 0.65, indicating moderate internal consistency.

Additionally, CFA was conducted to assess the structural validity of the CarerQol-7D instrument. The minimum value of the discrepancy (CMIN value) observed with a chi-square (χ^2) distribution and the CMIN/degree of freedom (DF) ratio were found to be 2.103 for the default model. The model fit indices described in table 3, including normed fit index (NFI) (0.906), relative fit index (RFI) (0.812), incremental fit index (IFI) (0.948), Tucker-Lewis index (TLI) (0.892), comparative fit index (CFI) (0.946), and root mean square error of approximation (RMSEA) (0.049), indicated a good fit for the CarerQol-7D instrument, suggesting satisfactory internal consistency of the latent factor. Excellent adjustment is defined as having an RMSEA value of 0.06 or lower,²⁰ which was the case in the current study.

Discussion

The current study aimed to develop a well-translated version of the CarerQol-7D for Persian-speaking caregivers in Iran and other nations with Persian-speaking residents. We translated the main instrument and tried to evaluate some of the psychometric properties of the translated version, focusing on some validity and internal reliability features in a sample of informal caregivers of patients with MS.

Although this tool is relatively a recently introduced questionnaire in this field, it has already been translated into many languages, including Italian and Hungarian.⁶ The clinical validity of this tool has been shown in other studies.^{6,10,11,19} However, some main points in this regard include the negative association of CarerQol-7D scores with the care recipients' health status,⁶ the negative association with the duration of caregiving,^{6,10} and the lower CarerQol-7D scores with the caregiver and the care recipient living in the same household¹⁰ and with the care receiver mainly suffering from mental health problems.^{11,19} From results of different studies and their version of the CarerQol-7D tool, it can be concluded that this tool has highly acceptable clinical validity.

The results of this study show that our Persian version of this tool has a moderate to high Cronbach's alpha coefficient, indicating that the internal consistency of this version is marginally acceptable.

Table 2. Clinical validity of CarerQol-7D in under study sample (n = 452)

Parameter	Level	CarerQol-7D	
		Mean \pm SD	P*
Patient's gender	Man	72.9 \pm 20.9	0.272
	Woman	76.3 \pm 18.3	
Patient's age group (year)	< 25	69.1 \pm 18.1	0.006
	26-54	76.8 \pm 18.4	
	> 55	72.2 \pm 23.7	
Type of disease	RRMS-EDSS 1-3.5	77.9 \pm 18.0	0.017
	RRMS-EDSS 4-6	75.2 \pm 17.1	
	RRMS-EDSS 6.5-9.5	81.6 \pm 17.6	
	SPMS-EDSS 4-6	73.2 \pm 19.2	
	SPMS-EDSS 6.5-9.5	66.0 \pm 22.8	
Caregiver's gender	Man	79.3 \pm 17.0	< 0.001
	Woman	69.9 \pm 20.0	
Caregiver's age group (year)	< 25	80.8 \pm 17.4	0.063
	26-54	76.3 \pm 18.2	
	> 55	72.1 \pm 20.5	
Marital status	Single	71.3 \pm 21.4	0.062
	Married	76.6 \pm 18.1	
Education year	< 12	68.6 \pm 19.2	< 0.001
	13-16	80.6 \pm 16.9	
	> 17	81.7 \pm 15.8	
Income level	\leq 74 \$	60.9 \pm 22.3	< 0.001
	74-185 \$	74.3 \pm 18.6	
	\geq 185 \$	84.0 \pm 13.2	
Relativity to patient	Parent	67.8 \pm 19.2	< 0.001
	Spouse	79.3 \pm 17.9	
	Sibling	71.9 \pm 17.5	
	Friend	85.6 \pm 16.7	
	Child	79.8 \pm 16.1	
Occupation	Unemployed	67.8 \pm 20.5	< 0.001
	Student	82.0 \pm 11.8	
	Employed	78.5 \pm 17.1	
	Retired	78.1 \pm 19.2	
Disease duration (year)	\leq 5	77.2 \pm 18.6	0.552
	6-10	75.0 \pm 18.0	
	11-15	77.8 \pm 17.2	
	\geq 16	73.8 \pm 22.5	
Type of medicine	Injection	76.5 \pm 18.6	0.302
	Oral	75.1 \pm 17.0	

RRMS: Relapsing-remitting multiple sclerosis; SPMS: Secondary-progressive multiple sclerosis; EDSS: Expanded Disability Status Scale; SD: Standard deviation

*P < 0.01

It should be noted that as the alpha coefficient is affected by the number of items on a questionnaire or tool, the low value of alpha could be the result of the number of questions on the CarerQol tool (n = 7).

Our finding is in concordance with other

studies in which the alpha coefficient is reported to be 0.61.²¹

The current study used other methods to evaluate the internal consistency. The CFI, TLI, and RMSEA showed good and acceptable levels of internal consistency for this latent factor.

Table 3. Effective factors on confirmatory factor analysis (CFA)

Model	NFI	RFI	IFI	TLI	CFI
Default model	0.906	0.812	0.948	0.892	0.946
Saturated model	1.000		1.000		1.000
Independence model	0.000	0.000	0.000	0.000	0.000

NFI: Normed fit index; RFI: Relative fit index; IFI: Incremental fit index; TLI: Tucker-Lewis index; CFI: Comparative fit index

The recommendations of Bentler²² and Byrne²³ were followed, which state that to determine the degree of adjustment between the covariance matrix of the observed data and the covariance matrix predicted, the CFI, TLL, and the RMSEA should be observed. After our CFA, the model was confirmed by obtaining acceptable indices (CFI and TLI),²⁴ showing that this model has an excellent adjustment level. This result is similar to what Fitzgerald et al.²¹ showed in their study, but they did not use the same analytic methods as the current study.

Limitations: The current study is subject to several limitations that could have influenced the results and interpretation of the findings. Firstly, the impact of the coronavirus disease 2019 (COVID-19) pandemic on respondents' mood may have influenced their reported QoL scores, potentially affecting the validity of the results. Additionally, the relatively small sample size of 452 patients and their caregivers may limit the generalizability of the findings. Moreover, the use of the United Kingdom (UK) population tariff for the CarerQol-7D, due to the absence of an Iranian tariff, may have introduced potential bias given the cultural variations between countries. Furthermore, the recruitment of participants from a single hospital and private offices in Tehran may have introduced selection bias and limited the generalizability of the findings to the broader population of patients with MS and their caregivers in Iran. It is essential to consider these limitations in interpreting the findings of the study, as they could have influenced the results in ways that may not fully represent the broader population.

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Conclusion

The current study aimed to develop a Persian version of the CarerQol-7D to facilitate its use among Persian caregivers. The results demonstrated high internal consistency and strong validity of the instrument among caregivers of individuals with MS. These findings suggest that the CarerQol-7D could serve as a valuable tool for assessing the QoL of caregivers, complementing the measurement of patients' QoL in economic evaluation equations.

Furthermore, the robust psychometric properties of the Persian version of CarerQol-7D indicate its potential for broader application in research and clinical settings, providing a standardized and culturally relevant measure for assessing caregiver well-being. Researchers and practitioners may consider integrating the Persian version of CarerQol-7D into their studies and interventions to gain a comprehensive understanding of the QoL of both patients and their caregivers.

Conflict of Interests

The authors declare no conflict of interest in this study.

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