

## Translation of the Multiple Sclerosis Quality of Life-54: Brazilian Version

Rosane Soares<sup>\*</sup>, Dionísio Ferme, Pedro Schestatsky, Alessandro Finkelzstejn, Julian Vicenzi and Paulo Dornelles

Universidade Federal do Rio Grande do Sul, Hospital de Clínicas de Porto Alegre. Porto Alegre, Rio Grande do Sul, Brazil

<sup>\*</sup>Corresponding author: Soares R, Universidade Federal do Rio Grande do Sul, Hospital de Clínicas de Porto Alegre, Rio Grande do Sul, Brazil, Tel: 5551991632029; E-mail: [sanesoares@gmail.com](mailto:sanesoares@gmail.com)

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### Abstract

**Objective:** This study translated the Portuguese version of the Multiple Sclerosis Quality of Life-54 (MSQoL-54) questionnaire.

**Methods:** The original version of 18 items from the MSQoL-54 was translated into Brazilian Portuguese using international guidelines. Two independent translations were completed by Brazilians fluent in English and the results were evaluated and harmonized, concluding version:

1. This version was back-translated by an American living in Brazil and then another analysis was conducted, resulting in version
2. Concluding the translation and harmonization phase, the final version was pre-tested with ten participants from the Reference Centre for Multiple Sclerosis at the Porto Alegre Clinical Hospital in Rio Grande do Sul (RS)-Brazil.

**Results:** The questionnaire was well accepted by the patient's sample that tested the 18 specific items. They presented no conceptual problems.

**Conclusion:** Patients with multiple sclerosis (MS) felt the questionnaire was easy to understand. We thus attained terms of conceptual equivalence between the original questionnaire and the translation.

**Keywords:** Quality of life; Multiple sclerosis; MSQoL-54; Translation

### Introduction

MS is a neurological disease that primarily affects young adults. Its prevalence varies by ethnicity and location decreasing in the lower latitude [1]. According to recent data from the World Health Organization (WHO), the estimated number of people with MS worldwide increased from 2.1 million in 2008 to 2.3 million in 2013 [2]. Although its etiology remains uncertain, evidence suggests that MS is an immune-mediated attack on myelin with secondary destruction of axons causing progressive disability [3]. The disease's symptoms include weakness, fatigue, sensory loss, dizziness, lack of coordination, sexual dysfunction, urinary incontinence, optic atrophy, dysarthria, and mental problems. The longevity of patients with MS is about eight years less than that of a healthy person. Longevity is bimodally distributed with many patients having normal longevity and some dying at a significantly younger age depending on disease aggressiveness, disability severity, infection, or suicide [4,5]. One third of patients with MS will need to use a wheelchair. About two-thirds will have disabilities that prevent them from working [6]. It is important to incorporate a quality of life (QoL) evaluation from the beginning, during patient monitoring, and when evaluating the effects of the treatment used [1].

In 1995, Vickrey et al. [5] at the University of California in Los Angeles (UCLA) developed a specific instrument for the MS population with 12 sub-scales; all showed good internal consistency

with Cronbach's alphas, 0.75–0.96 and good reliability, with test-retest intraclass correlation coefficients in ranging from 0.66–0.96. This instrument, the MSQoL-54, was translated into multiple languages [4,7-14] and has since been one of the most utilized questionnaires in the scientific community.

The objective of this study was to translate and transculturally adapt the MSQoL-54 to Brazilian Portuguese. Then, its reliability will be evaluated, making it available for use in the Brazilian scientific community.

### Methods

Permission to use the MSQoL-54 instrument was requested from the original author of this questionnaire who approved the translation into Brazilian Portuguese.

In general, there are four main steps involved in a linguistic validation of an instrument: translation (from the original to the intended language), back-translation (quality control), comprehension testing, and international harmonization. The function of each step is to improve the translation's quality for conceptual equivalence between the original and translated instruments enabling easy patient understanding [1]. The Free and Informed Consent Form was signed by the participants in the pre-test phase. They received all research information, including that data would be kept confidential and that they could leave the study at any time.

## Instruments

The MSQoL-54 has 54 items, 36 of which belong to the generic Short Form 36 Health Survey (SF-36). It then added 18 additional specific items related to MS. It is a structured self-report questionnaire that the patient can usually complete with little or no assistance, except for those with disease-related clinical deficiencies. Of the 54 items that

comprise the instrument, 52 measure 12 health-related QoL scales, evaluating two major components: physical health and mental health (Table 1). There are also two additional measurements; one is part of the SF-36, “change in health,” and the other is from the 18 specific items, “satisfaction with sexual function.”

Domain	Item	Component		
		Specifics (n)	FH (n)	MH (n)
	<b>Generics-FH-36 (n)</b>			
<b>Physical Function</b>	3, 4, 5, 6, 7, 8, 9, 10, 11 and 12 (10)		*	
<b>Role limitations due to physical problems</b>	13,14,15 and 16 (4)		*	
<b>Role limitations due to mental problems</b>	17,18 and 19 (3)			*
<b>Pain</b>	21 and 22 (2)	52 (1)	*	
<b>Emotional well-being</b>	24, 25, 26, 28 and 30 (5)			*
<b>Energy</b>	23, 27, 29, 31 (4)	32 (1)	*	
<b>Perception of health</b>	1, 34, 35, 36 and 37 (5)		*	
<b>Social Function</b>	20 and 33 (2)	51 (1)	*	
<b>Cognitive Function</b>		42, 43, 44 and 45 (4)		*
<b>Health distress</b>		38, 39, 40 and 41 (4)	*	*
<b>Overall Quality of life</b>		53 and 54 (2)		*
<b>Sexual Function</b>		46, 47, 48 and 49 (4)	*	
<b>Total</b>	35	17		

**Table 1:** Schema representing the 2 components, 12 domains and 54 items of the MSQoL-54 Translation of 18 specific items.

This article describes the translation into Portuguese (Brazil) of 18 specific items for evaluating QoL in MS patients translated, a process similar to what occurred in other languages where the SF-36 had also already been validated [4,7,8,13]. The SF-36 was previously translated,

adapted, validated, and published in Brazilian Portuguese [15] and is widely used. The translation of the MSQoL-54 instrument to Brazilian Portuguese was completed per international recommendations [16] and other articles that used equivalent methodology [7,13] (Table 2).

<b>Stage 1: Translation</b>	The two qualified independent translators were both Brazilian neurologists fluent in English and residing in the questionnaire’s country of origin. They translated the 18 specific items of the MSQoL-54 into Portuguese. Both were aware of the study’s objective. Then they compared the translations and worked on the discrepancies electronically until they reached a consensus on the linguistic, conceptual, and semantic aspects, resulting in version 1. In cases where they still diverged, the first author and a nurse with experience in translation research and transcultural questionnaire adaptation into Brazilian Portuguese intervened and finalized this process, resulting in version 2.
<b>Stage 2: Back-translation</b>	Version 2 was back-translated by a teacher who is a native speaker of English living in Brazil. He did not participate in the previous step and was not aware of the study’s objective. Then the first author conducted a comparison between the original version and the back-translation. There were minor differences between the two.
<b>Stage 3: Content validity</b>	Version two of the MSQoL-54 - Portuguese was evaluated by a neurologist specialist in MS on the item relevance to the intended measure. The interpretation and meaning of the sentences was evaluated by a nurse with secondary training in literature. The first author participated in both evaluations and no modifications took place at this stage. In this respect, the content validity was approved.
<b>Stage 4: Face validity</b>	To evaluate face validity, a pre-test was conducted with in a patients sample selected during their routine visit to the Centro de Referência em Esclerose Múltipla (CREEM) at the HCPA. They were invited to read, complete, and express their opinions on their understanding and the relevance of the 18 items from version 2. The criteria for receiving the invitation were as follows: MS diagnosis, over 18 years old, and ability to read and answer the questionnaire without help. The 18 items included the option “not applicable” to identify those that were difficult to understand or not culturally appropriate. The patients received prior explanation about the option. The evaluators also instructed them on the importance of signaling or suggesting, either verbally or in writing, the items about which they had doubts or with which they did not agree. All of them had a positive opinion. Since there was no need for changes in version 2, this was the final version of the MSQoL-54 in Portuguese.

**Table 2:** Description of the phases of the study of translation.

## Results

All the patients who participated in the last phase were mostly women (70%) with a mean age of  $42 \pm 9.67$  years (26–59 years), diagnosed with MS for a mean of  $7.67 \pm 4.36$  years. Of them, 70% had completed secondary school. All were in MS treatment, eight with glatiramer acetate (80%) and two with beta interferon. The mean response time for the 18 items was five minutes.

The MSQoL-54 was well accepted and easily administered to the study population. None of the items was identified by the patient sample as being embarrassing.

Four (40%) of the participants marked the option “not applicable,” which had been added to evaluate comprehension of the question. They said that they did not know how to proceed. They understood the items, but since they had not had sexual relations in the last four weeks, they had no way to mark any of the alternatives. Thus, there was no need to revise version 2, as described in the results.

## Discussion

Of the patients who participated in the pre-test, four marked the option “not applicable.” This was not an interpretation, embarrassment, or misunderstanding problem, but rather because they had not had sexual intercourse in the last four weeks. This can also be observed in other studies on translations of the MSQoL-54 [10-14], including the original [4]. Among these, some also observed that the highest percentage of items with no response on sexual function and

satisfaction with sexual function come from female patients [10,12,14]. This differs from our results where the proportion was 1:1, but in a smaller sample than that of the validation. To explain these results, the study conducted in Turkey suggested that this was due to the fact that people with MS may find sex-related items distressing, difficult to understand, or too private [12]. Solari et al. also found this in the Italian validation study and they attributed this result to the social and cultural characteristics of Italian society [14].

The fact that the MSQoL-54 was well accepted and that there was no embarrassment about answering the items was also observed in other studies. However, these results are presented primarily in the validation phase. The Turkish version presented a similar result, but the women said that they only found the sexual satisfaction and sexual function domain-related items to be embarrassing [12].

It was not possible to discuss linguistics, which deals with tool translation into a language different from both the original and the other languages in which articles on the transcultural translation of the MSQoL-54 have been published [7-9]. Therefore, the researchers conducted a conceptual review on the idiomatic, semantic, and conceptual equivalence of item content of the final Portuguese version.

We wanted to understand the specific items and alternatives that presented discrepancies in translation, as well as the committee’s work to improve the semantics prior to the final version. Below we individually describe the items they addressed to improve understanding (Table 3).

N	Original	Translation (Portuguese)	Black-translation	Final Portuguese version
38	Were you discouraged by your health problems?	Você se sentiu desencorajado (ou desanimado) devido a seus problemas de saúde?	Were you discouraged by your health problems?	Você se sentiu desencorajado devido a seus problemas de saúde?
39	Were you frustrated about your health?	Você esteve frustrado com sua saúde?	Were you frustrated about your health problems?	Você se sentiu frustrado com sua saúde?
41	Did you feel weighed down by your health problems?	Você se sentiu “para baixo” por causa dos seus problemas de saúde?	Did you feel overwhelmed by your health problems?	Você se sentiu desanimado por causa dos seus problemas de saúde?
43	Did you have trouble keeping your attention on an activity for long?	Você teve dificuldade em manter sua atenção em uma mesma atividade por um longo tempo?	Did you have difficulty keeping your attention on an activity for a long time?	Você teve dificuldade em manter sua atenção na mesma atividade por um longo tempo?
45	Have others, such as family members or friends, noticed that you have trouble with your memory or problems with your concentration?	Outras pessoas, como familiares e amigos, perceberam que você estava com problemas de memória ou de concentração?	Have others, such as your family or friends, noticed that you have trouble with your memory or concentration?	Outras pessoas, como familiares e amigos, perceberam que você teve problemas de memória ou concentração?
46	Lack of sexual Interest	Perda do interesse sexual	Lack of sexual Interest	Falta de interesse sexual
50	Overall, how satisfied were you with your sexual function during the past 4 weeks?	De maneira geral (no geral), o quanto satisfeito você esteve com relação à sua função sexual durante as últimas 4 semanas?	Overall, how satisfied were you with your sexual function during the past 4 weeks?	De maneira geral, o quanto satisfeito você está com relação a sua função sexual durante as últimas 4 semanas?
51	During the past 4 weeks, to what extent have problems with your bowel or bladder function interfered with your normal social activities with family, friends, neighbors, or groups? Not at all/Slightly/ Moderately/ Quite a bit/Extremely	Durante as últimas 4 semanas, até que ponto problemas com a função da sua bexiga ou intestino interferiram nas suas atividades sociais normais com sua família, amigos, vizinhos ou grupos? Nem um pouco/Levemente/ Moderadamente/Bastante/Extremamente	During the past 4 weeks, to what extent have problems with your bowel or digestive functions interfered with your normal social activities with family, friends, neighbors, or groups? Not at all/Slightly/Moderately/Quite a bit/Extremely	Durante as últimas 4 semanas, até que ponto problemas com sua função urinária ou intestinal interferiram nas suas atividades sociais normais com sua família, amigos, vizinhos ou grupos? Nem um pouco/Um pouco/ Moderadamente/

				Bastante/Extremamente
53	Overall, how would you rate your own quality-of-life? Worst Possible Quality-of-life. As bad as or worse than being dead	De maneira geral (no geral), como você avaliaria sua própria qualidade de vida? Qualidade de vida pior possível. Tão ruim ou pior do que estar morto.	Overall, how would you rate your own quality of life? Worst Possible Quality of life Equal to or worse than being dead	De maneira geral, que nota você daria para sua própria qualidade de vida? Pior qualidade de vida possível. Igual ou pior do que estar morto.
54	Which best describes how you feel about your life as a whole? Terrible/Unhappy/Mostly dissatisfied/Mixed - about equally satisfied and dissatisfied/Mostly satisfied/Pleased/ Delighted	O que melhor descreve como você se sente com relação à sua vida como um todo? Terrível/Infeliz/Insatisfeito na maior parte do tempo/Misto-igualmente satisfeito e insatisfeito/Satisfeito na maior parte do tempo/Satisfeito/Contente	Which alternative best describes how you feel about your life as whole? Terrible/Unhappy/ Dissatisfied most of the time/Mixed (equally satisfied and dissatisfied)/ Mostly satisfied/Satisfied/Very satisfied	Qual alternativa melhor descreve como você se sente com relação à sua vida como um todo? Terrível/Infeliz/Na maioria das vezes insatisfeito(a)/ Misto-praticamente igual entre satisfeito(a) e insatisfeito(a)/Na maioria das vezes satisfeito(a)/Satisfeito(a)/Muito satisfeito

**Table 3:** Result of translation of the MSQoL-54 instrument to Brazilian Portuguese.

To better follow the translation of items from 38 through 45, it is important to present the English instruction to which they refer. “How much of the time during the past four weeks...” is translated into Portuguese as “Quanto tempo, nas últimas 4 semanas.” To understand this phrase in Portuguese, it is not necessary to maintain the word “durante” as in the original (“during”). This title is used in two domains: “Health Distress,” which comprises items 38 through 41, and “Cognitive Function,” formed by items 42–45. In Portuguese, these are “Função Cognitiva” and “Preocupação com a Saúde,” respectively, discussed below.

The patients judged the questionnaire to be quick and easy to understand, but we must consider that this sample responded only to the 18 items evaluated [7] out of the 54 that comprise the tool. Considering that they took an average of five minutes to answer, the 54 items would thus take 15 minutes, which is consistent with what the instrument’s author suggests [4]. The most debated items were also cited by Acquadro in the French Canadian version [7]; the problems occurred mainly due to semantics. For the Portuguese questionnaire to have the same result when it is used, it should follow the patterns of the study’s circumstances. It is well known that it is an instrument that can be completed in an environment with other patients, i.e., in waiting rooms. It is also well known that the result will only be reliable if the patient does not receive any support from their family on the best response. This does not prevent the patient from receiving help to read or complete the items due to any clinical difficulties, despite being a self-assessment questionnaire. If the respondent has trouble understanding it, they should read it as many times as necessary, but may not receive any help with interpreting it.

The results of this study were positive and the Portuguese-language MSQoL-54 instrument is in the process of being validated.

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### Ethical Approval

The research project followed the Declaration of Helsinki approved by the Brazil Platform (CAAE 17172313.5.0000.5327). All patients received clarification regarding the research process and signed the informed consent form. Legal guardians signed the forms for minors and patients with severe illness.

### Conflict of Interest

The authors declare no potential conflict of interest with respect to the research, authorship and/or publication of this article.

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