



## Validity and Reliability of the Persian Version of the PERception de la Sclérose En Plaques et de ses Pousse'es Questionnaire Evaluating Multiple Sclerosis-related Quality of Life

Mahsa Ghajarzadeh, Sepehr Azizi<sup>1</sup>, Abdorreza Naser Moghadasi<sup>2</sup>, Mohammad Ali Sahraian<sup>3</sup>, Amirreza Azimi<sup>4</sup>, Mehdi Mohammadifar<sup>5</sup>, Amirhossein Mohammadian Bajgiran<sup>6</sup>

Brain and Spinal cord Injury Research Center, Tehran University of Medical Sciences, Tehran, Iran, <sup>1</sup>Tehran University of Medical Sciences, Tehran, Iran, <sup>2</sup>MS research Center, Neuroscience Institute, Tehran University of Medical Sciences, Tehran, Iran, <sup>3</sup>MS research Center, Neuroscience Institute, Tehran University of Medical Sciences, Tehran, Iran, <sup>4</sup>MS research Center, Neuroscience Institute, Tehran University of Medical Sciences, Tehran, Iran, <sup>5</sup>Zanjan University of Medical Sciences, Zanjan, Iran, <sup>6</sup>Department of Medicine, Mashhad University of Medical Sciences, Mashhad, Iran

### Correspondence to:

Dr. Mahsa Ghajarzadeh, Brain and Spinal cord Injury Research Center, Tehran University of Medical Sciences, Tehran, Iran. E-mail: [m.ghajarzadeh@gmail.com](mailto:m.ghajarzadeh@gmail.com)

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### ABSTRACT

**Background:** Multiple sclerosis (MS) affects all aspects of patients. Recently, the "PERception de la Sclérose En Plaques et de ses Pousse'es" (PERSEPP) scale was designed to assess MS-related relapse on quality of life (QoL). The aim of this study was to evaluate validity and reliability of Persian version of PERSEPP scale in Iranian patients with MS.

**Methods:** Two-hundred eleven patients with relapsing-remitting form of the disease asked to fill the PERSEPP scale, MSQOL-54, and SF-36 questionnaires. Fifty cases filled the questionnaire 2 weeks later to assess reliability. The intraclass correlation coefficient (ICC) and Cronbach's alpha analysis were used.

**Results:** Mean age and mean duration of disease were  $32.2 \pm 8.4$  years and  $6.5 \pm 2.5$  years, respectively. One hundred sixty-seven (79.1%) were female and 44 (20.9%) were male. Forty-one (19.4%) were in relapse phase of the disease. ICC score of all items was above 0.8. Cronbach's alpha of all items was above 0.8. The results show that the mean scores of four items (relationship difficulties, time perspective, and symptoms) were significantly different between cases in relapse and none relapse. Coping and relationship difficulties scores were significantly different between different expanded disability status scale groups. Pearson correlation score for QoL 54 and PERSEPP calculated as  $r = 0.44$ ,  $P < 0.001$  and  $r = 0.66$ ,  $P < 0.001$  between SF36 and PERSEPP.

**Conclusions:** Persian version of PERSEPP questionnaire provides valid and reliable instrument to assess MS-related QoL.

**Keywords:** Multiple sclerosis, Persian, quality of life

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### INTRODUCTION

Multiple sclerosis (MS) is a chronic auto immune disease that affects all aspects of patient's lives.<sup>[1-3]</sup> Physical, emotional, cognitive, intellectual, sexual, and social feature of their lives are impaired.<sup>[4-6]</sup> Health-related quality of life (QoL) is defined as individual's perception of function and health further than the contemporary

condition. Previous studies demonstrated that QoL is impaired in cases with MS.<sup>[7,8]</sup> Nearly, 85% of the patients present with relapsing-remitting (RR) form of the disease.<sup>[9]</sup> In relapse phase, new clinical signs, the reappearance of old symptoms, or the worsening of preexisting symptoms occurs.<sup>[10]</sup> Relapses are not predictable and have negative impact on QoL.<sup>[11]</sup> In a previous study, there was significant difference between QoL scores in relapse and nonrelapse phases.<sup>[12]</sup> Different scales have been developed for QoL assessment in MS cases, but none of these scales focus on relapse phase.

Recently, the “PERception de la Sclérose En Plaques et de ses Pousse’es” (PERSEPP) scale was designed specifically for RR MS patients to assess MS-related relapse on QoL.<sup>[13]</sup> Different aspects such as social support, difficulties with social relationships, fatigue, state of mind and sleep, time perspective, coping, symptoms, and perception of treatment are included in the PERSEPP scale. The aim of this study was to evaluate validity and reliability of Persian version of PERSEPP scale in Iranian patients with MS.

## METHODS

In this cross-sectional study, 250 patients with RR type of MS who referred to MS Clinic of Sina Hospital (affiliated to Tehran University of Medical Sciences) were enrolled. The inclusion criteria were definite MS due to McDonald criteria<sup>[14]</sup> and RR type of the disease. Two groups of patients enrolled: Patients in relapse and those who were not in relapse at the time of study.

All cases were asked to fill the informed consent forms. The study had been approved by the local Ethics Committee.

Demographic data (sex and age), duration of the disease, marital status, and types of medications were recorded. The Kurtzke expanded disability status scale (EDSS) was recorded after examination by an expert neurologist.

Using the forward-backward translation method, PERSEPP questionnaire was translated into the Persian by two medical physicians in the field of research, and then Persian version was translated again into English. Two independent neurologists compared the translated English version with the original English version (content validity).

The PERSEPP questionnaire includes 66 questions; each question contains six response types where “0” was “strongly disagree” and “5” was “strongly agree” according to a Likert scale. It includes scales such as social support, relationship difficulties, satisfaction with care, fatigue, state of mind and sleep

disorders, time perspective, and coping (module) as symptoms (module) and treatment (module).

The scores should be transformed to a range of 0–100, where 100 was the best QoL possible. The higher the score is the better the QoL of the patients.

Participants were asked to answer the valid and reliable Persian version of the MSQOL-54 and SF-36 questionnaires (convergent validity).

MSQOL-54 is a structured, self-report questionnaire containing 14 subscales (physical function, role limitations-physical, role limitations-emotional, pain, emotional well-being, energy, health perceptions, social function, cognitive function, health distress, overall QoL, sexual function, satisfaction with sexual function, and change in health).<sup>[15]</sup>

Sum of subtotals such as physical function, health perceptions, energy/fatigue, role limitation-physical, pain, sexual function, social function, and health distress makes the physical health composite and sum of subtotals such as health distress, overall QoL, emotional well-being, role limitation-emotional, and cognitive function makes the mental health composite. The higher the score is the better the QoL.

The SF-36 questionnaire consists of 36 questions in eight aspects and is an instrument for the evaluation of the QoL. All questions are scored on a scale of 0–100, with 100 representing the highest level of functioning possible. Higher scores indicate less impairment in the QoL. The questionnaire consists of eight subscales such as physical functioning, role limitations due to physical health, role limitations due to emotional problems, energy/fatigue, emotional well-being, social functioning, pain, and general health.<sup>[16]</sup>

In order to perform test-retest assessment, 50 patients filled the questionnaire 2 weeks after the first completion.

All data were analyzed using SPSS software version 20 (SPSS Inc., Chicago, IL, USA). Data were presented as mean  $\pm$  standard deviation for continuous or frequencies for categorical variables. The intraclass correlation coefficient (ICC) was measured for repeatability evaluation, and ICC coefficient over 0.70 was considered acceptable. Cronbach’s alpha was calculated in each three-factor of the questionnaire to assess the internal consistency reliability. Cronbach’s alpha coefficient  $\geq 0.70$  was considered excellent reliability. Correlation coefficient along with the partial correlation coefficient was calculated for assessing the relationship between PERSEPP questionnaire scores and other variables.

## RESULTS

Finally, 211 completed questionnaires collected (response rate: 84%).

Mean age and mean duration of disease were  $32.2 \pm 8.4$  years and  $6.5 \pm 2.5$  years, respectively. One hundred sixty-seven (79.1%) were female and 44 (20.9%) were male. Eighty-five (40.3%) were single, 121 (57.3%) were married, and 5 (2.4%) were divorced. One hundred twenty-three (58.3%) were unemployed and 88 (41.7%) were employed. Forty-one (19.4%) were in relapse phase of the disease. ICC score of all items was above 0.8 [Table 1].

Cronbach's alpha of all items was above 0.8 [Table 2].

Pearson correlation score for QoL54 and PERSEP calculated as  $r = 0.44$ ,  $P < 0.001$  and  $r = 0.66$ ,  $P < 0.001$  between SF36 and PERSEP.

Except four items, mean scores of different items were significantly different between cases with and without relapse [Table 3].

Coping and relationship difficulties scores were significantly different between different EDSS groups [Table 4].

## DISCUSSION

The aim of this study was to determine validity and reliability of the Persian version of PERCEPP questionnaire in a sample of Iranian MS patients.

The high ICC values are indicative of the high reliability of the Persian version of PERCEPP questionnaire. We also found that Cronbach's alpha of each factor is high and indicative of acceptable internal consistency. In a previous study conducted by Baroin *et al.*, Cronbach's  $\alpha$  of all items except coping were more than or equal to 0.7. Their results also showed that ICC score of all items was above 0.7, which are consistent with our results.<sup>[17]</sup>

The results show that the mean scores of four items (relationship difficulties, time perspective, and symptoms) were significantly different between cases in relapse and none relapse ones that could show discriminant validity of these items. In Baroin *et al.* study, time perspective, treatment, and symptoms were significantly different between relapse and none relapse ones.<sup>[17]</sup> The different between symptom scale could show clinical differences between relapse and none relapse cases. On the other hand, disturbances and concerns met in the relapse PERIOD could explain the difference of time perspective scale.

Total score of PERCEPP questionnaire was significantly correlated with SF36 and QoL54 questionnaires that could show convergent validity that is consistent with Baroin *et al.*, study.<sup>[17]</sup> In their study, symptoms and treatment subscales were significantly different

**Table 1: ICC score of different factors**

	ICC score
Social support	0.82
Satisfaction with care	0.55
Relationship difficulties	0.89
State of mind	0.88
Fatigue	0.88
Time perspective	0.92
Coping	0.83
Symptoms	0.92
Treatment	0.79

ICC=Intraclass correlation coefficient

**Table 2: Cronbach's alpha of all items**

	Cronbach's alpha
Social support	0.84
Satisfaction with care	0.86
Relationship difficulties	0.95
State of mind	0.94
Fatigue	0.81
Time perspective	0.8
Coping	0.86
Symptoms	0.84
Treatment	0.9

**Table 3: Mean scores of different items in cases with and without relapse**

	Patients in relapse phase	Patients without relapse	P
Social support	$6.8 \pm 5.7$	$6.5 \pm 3$	0.8
Satisfaction with care	$8.8 \pm 3.3$	$8.6 \pm 3.6$	0.4
Relationship difficulties	$19.6 \pm 10.2$	$15 \pm 9.2$	0.006
State of mind	$20.1 \pm 6.2$	$17.7 \pm 7.5$	0.02
Fatigue	$12.2 \pm 5.1$	$11.1 \pm 5.2$	0.2
Time perspective	$20.4 \pm 6.8$	$17.1 \pm 7.1$	0.008
Coping	$25.6 \pm 6.8$	$25.6 \pm 6.7$	0.9
Symptoms	$45.9 \pm 16.9$	$33.9 \pm 18$	<0.001
Treatment	$14.4 \pm 4.3$	$14.1 \pm 3.7$	0.6

**Table 4: Scores of different items in different EDSS groups**

	EDSS			P
	0-3.5	4-5.5	≥6	
Social support	$6.6 \pm 6.7$	$6.9 \pm 2.4$	$7.2 \pm 2.1$	0.9
Satisfaction with care	$8.4 \pm 3.8$	$10.6 \pm 2$	$6.2 \pm 2.7$	0.1
Relationship difficulties	$15.4 \pm 9.2$	$23.5 \pm 8.1$	$27.4 \pm 11.7$	0.001
State of mind	$17.7 \pm 7.5$	$19.8 \pm 5.4$	$19.4 \pm 7$	0.5
Fatigue	$11.1 \pm 5.2$	$12.5 \pm 4.1$	$16.4 \pm 2.7$	0.06
Time perspective	$17.4 \pm 6.9$	$21.7 \pm 7.2$	$22 \pm 12.6$	0.06
Coping	$25.7 \pm 6.5$	$20.6 \pm 8.4$	$28.2 \pm 5.3$	0.03
Symptoms	$36 \pm 18.3$	$45.1 \pm 12.6$	$46.8 \pm 21.8$	0.1
Treatment	$14.1 \pm 3.9$	$15.5 \pm 2.2$	$13.8 \pm 2.1$	0.5

EDSS=Expanded disability status scale

between cases with different EDSS scores while in this study, mean relationship difficulties and coping were significantly different. This could be indicative of impact of advanced disease on managing the personal and inter personal relations.

Nowadays, considering QoL in patients with MS is an important issue in the field of neurology.<sup>[18]</sup> Different questionnaires such as SF36 and MS-QoL54 have been applied for this purpose, but they do not focus on relapse phase of the disease. The relapse phase has negative effect on patient's QoL and it has especial effect on psychological and social dimensions.<sup>[11]</sup> So, the PERSEPP scale that is designed for RR MS patients is valuable to assess QoL in MS patients and impact of relapse phase on their QoL. This scale helps physicians to consider aspects of QoL of patients in relapse and nonrelapse phases.

## CONCLUSIONS

Persian version of PERCEPP questionnaire provides a valid and reliable instrument to assess MS-related QoL.

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