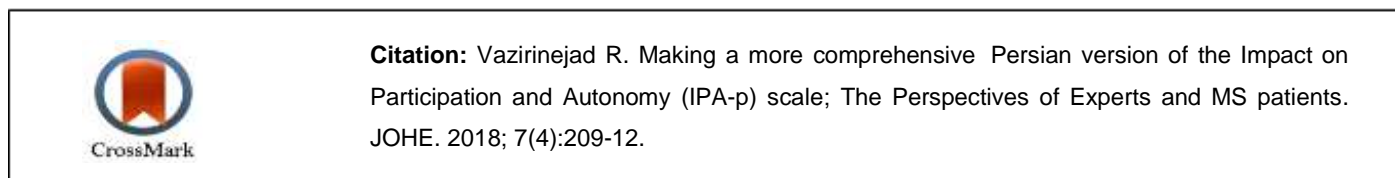




## Making a more comprehensive Persian version of the Impact on Participation and Autonomy (IPA-p) scale; The Perspectives of Experts and MS patients

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### Abstract

**Background:** After all efforts made to introduce a valid and reliable tool for measuring the health of patients, such as MS sufferers, the concept of “participation and autonomy”, which might be affected by the disease, has been introduced. An efficient health measurement should consider all different aspects of a patient’s life. This research was conducted aimed at introducing a new aspect of the individual’s life that seems necessary to be added to the health measurement scale of Persian-speaking MS patients.

**Materials and methods:** In a comprehensive study, 10 specialists and 360 MS patients were recruited to help measure the validity and reliability of the Persian version of the impact on participation and autonomy (IPA) scale. More details are provided in the published paper. An important section of the findings derived from the data collected from experts and patients has been presented in this paper.

**Results:** Further to the previous reports, the results showed that about 70% of the experts and 80% of the patients who responded to the relevant items stated that some questions should be added to the scale about the patients’ ability to do their religious affairs.

**Conclusion:** Based on what the experts (specialists) and respondents (MS patients) stated, it seems that at least a religious domain must be added to the Persian version of the IPA (IPA-p) scale if a more comprehensive IPA scale is required to be developed for the use among Persian-speaking patients.

**Keywords:** Quality of Life, MS (Multiple Sclerosis), Patients.

### Introduction

After all efforts made to develop a valid and reliable tool for measuring the level of health of MS people living in the communities, the concept of “participation and autonomy” was introduced (1). The need for a positive practical approach to measure the level of health of both apparently healthy and diseased people, has been always stressed (2, 3).

As the most common utilization of such a tool is assessing the effect of provided health services on the health level of those who received them, besides increasing their survival rate? In addition, interventions to promote health level among human

being communities are all based on the level of health of individuals. Spending limited sources for promoting health level more efficiently needs details about all different domains of human life to be considered in such scale (4).

For many years, the concept of quality of life (QOL) has been at the core of all efforts made in designing valid and reliable instruments to assess the level of human health (5). Many questionnaires have been designed for measuring the QOL of both healthy individuals and the ones suffering from diseases (SF-36, SF-12, MSQOL-54 ...) (6-8).

Remarkable differences between the concept of QOL and other concepts, such as ‘handicap’ (9) ‘disability’ (10), and ‘Satisfaction’ (11) in measuring

the level of health convinced many scientists to use QOL scales for over four decades. However, the QOL concept was accused of being perceived too much subjectively in planning, implementing, and assessing health policies as well as treatment decisions (12). A concept more objectively assessable would be more effective in the practical field of measuring the level of health and planning health policies.

Finally, in the last few years of 20th century, some attempts were made to develop scales for assessing the impact of diseases on the participation and autonomy of patients which caused departure from health (1), as a new concept. IPA was one of the major scales designed to measure "the impact on participation and autonomy". This scale was originally designed in the Netherlands (1). The English version of IPA (IPA-e) was provided using forward and backward translation procedures from the Dutch language to the English language (13, 14). The authors and colleagues assessed the acceptability of IPA-e in an out-patient setting of MS patients, with the results being satisfactory (15).

In 2015, when the Persian version of IPA (IPA-p) was produced from IPA-e using forward and backward translation procedures, this new version was used in most studies conducted on Persian-speaking people (16). The validity and reliability of the Persian version was approved among Iranian MS patients (17).

Like other scales designed to assess the health level of the people in communities (such as Quality of Life Scale 'QOLs'), the IPA scale is designed to cover all aspects of human life, when assessing the individuals' health level. Therefore, every single aspect of human life is important in this respect. Human health is dependent on many factors in human communities, including economy, culture, customs, social situations, etc. A comprehensive assessment of human health requires paying attention to all aspects of human life, which could be partly different from one society to another. In particular, in ideological communities, such as Muslims, religion is a high-priority aspect of individuals' life that should never be ignored when assessing individuals' health. However, this aspect is important among all other communities, such as Christians, with different levels of priority. The present study was conducted aimed at determining how important religion is, based on the results of research in Persian language patients, being added to the scale which is designed to measure participation and autonomy of individuals (patients or healthy people) living in Persian-speaking communities.

## Materials and Methods

A descriptive study was designed among Persian MS patients and face and content validity and reliability of the Persian version of the IPA (IPA-p) (complementary 1) were measured. Ten experts in various relevant disciplines, including epidemiology, psychology, and neurology were recruited to assess the face validity of the scale (IPA-p). Experts were asked to report their opinion about all domains of the scale including further domains which might be needed to increase the comprehensiveness of the scale on the study checklist. Furthermore, 380 Persian-speaking MS patients were also invited to answer IPA-p items, including all translated items of the English version, as well as some demographic items. The IPA-p scale items were answered once again in 45 days. More details of the study methods have been published somewhere (17). Written informed consent was obtained from the respondents. To assess the content validity and reliability of the questionnaire, the collected data were analyzed. As already mentioned, an item of the study checklist asked experts' opinions about other aspects that could be added to the scale (IPA-p) to provide more complete coverage of Persian-speaking MS patients' life. An open question was also originally added to the IPA scale asking respondents (MS patients) opinion about their experience as the three main problems caused by their health condition as "In your own words, what do you experience as the three main problems caused by your health condition or disability?"

## Results

The specialists expressed their opinion about the IPA-p items, as well as the whole structure of the scale. They were 10 experts in three different disciplines, including three epidemiologists (one professor, one associate professor, and one assistant professor), three psychologists (two associate professors and one assistant professor), and four neurologists (one professor, two associate professors, and one assistant professor). Table 1 demonstrates the frequency distribution of the experts based on some demographic features.

In response to the question "which other aspects could be added to the scale (IPA-p) to provide more complete coverage of Persian-speaking MS patients' life?", more than half of the experts (n=7, 70%) stated that the item asking about the patients' ability to do their religious affairs could be added to make a more comprehensive assessment of the impact on participation and autonomy in Persian-speaking MS patients.

**Table1:** Frequency distribution of the experts based on some demographic features

Expert features		N	%
Age	< 35	2	2
	35-50	3	30
	50+	5	50
Gender	Male	8	80
	Female	2	20
Disciplines	Epidemiology	3	30
	Psychology	3	30
	Neurology	4	40
Job experience (years)	< 10	7	40
	10- 20	3	30
	20+	3	30

In the other part of the study, the respondents (MS patients) were asked to report their experience of the three major problems created by their health condition. In response, only about 41% of the respondents, i.e. MS patients (n=149, out of 364), answered this item. Out of those who answered the item, 80% (n= 119, out of 149) stated that their experience of not being able to do their religious affairs due to their disease was their major problem. The respondents' features are reported somewhere else (17).

## Discussion

Seventy percent of the specialists and 80% of the respondents who answered the relevant item on the IPA scale stated that more items asking about religious affairs were needed to be asked from the respondents. According to the perspectives of both experts and respondents, if a more comprehensive assessment of the impact on participation and autonomy of people (often patients) was to be made, at least those aspects of the patients' life that could be potentially affected by the patients' conditions had to be considered. In other words, when designing a new scale, comprehensiveness is one of the major features of the scale, yet the content of the English version of IPA was not complete enough to cover all important aspects of Persian-speaking patients.

Various factors in human life determine the aspects effective in their life. However, the factors are not the same in different human communities. Thus, the major aspects of human life depend on these factors, which vary based on the personal and social conditions of human life, as well as the interaction between them. Economy, policy, culture, and many other relevant factors, including religion play crucial roles in people's life in many parts of the world, such as Arab or Persian communities. Although these factors, including religion, are very important in some human communities, they might

have less significant effects on the quality of individuals' life in some other communities.

There are three Persian-speaking nations in the world, including Iran, Afghanistan, and Tajikistan. Although these countries are not quite similar in valuing the factors mentioned above, religion is an important aspect in their peoples' life, regardless of some differences among their cultures.

The results obtained from the current research on Iranian people showed that apart from the nine original aspects of the IPA scale, which are all important enough to be included in the Persian version of the scale, the aspect of religion must also be added to IPA-p.

## Conclusion

Based on the results of the current study, as well as the opinions of the experts and respondents (MS patients) expressed in response to the relevant items of the checklist and the IPA-p scale, it seems that another aspect titled 'religion' is required to be included in the Persian version of IPA (IPA-p) to create a more comprehensive IPA scale for use by Persian-speaking patients. A copy of the final version of the IPA-p scale is attached titled 'supplementary 1'.

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**Conflict of interest:** None declared.

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