

# Educational, Psycho Mental and Socio economical needs of an Iranian Cohort with Multiple Sclerosis

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## Abstract

**Objectives:** Multi-dimensional problems of MS patients require emergent and scientific approach to be followed. This present study was carried out in 2009 to ascertain educational needs of MS patients in relation to their psycho mental and socio economic status.

**Methods:** 174 patients referred to Iran's MS Society were included in this study. Samples were chosen using a simple randomized method from patients that fulfill the inclusion criteria. A questionnaire was used for data collection. The questionnaire covered 4 main areas: 1) demographic data, 2) patient tendency for education, 3) patient's need for training about the nature of the disease and 4) educational need in 2 aspects of psycho mental and socio economical.

**Results:** The age of the study group ranged between 32-39 years. 71.3% of the patients were female and 59.8% were married. 27.7% of the patients had an MS history of less than 3 years. The results showed that 39.1% of the patients needed a high level of education. 0.6% of the patients expressed their need to get more information about the nature of MS. While 54.62% required education to decrease their depression and 61.5% needed education for anxiety control. 61.5% of patients required education about drugs procuring and 58% needed education for

their professional difficulties. Further analysis indicated that there was a significant relationship between the need for training in the psycho mental category and education level ( $p=0.0035$ ), as well as the acceptance of the disease by the patients ( $p>0.001$ ). Educational needs of patients within socio economic groups showed no significant correlation with other factors which were investigated in this study.

**Conclusion:** The findings revealed some specific characteristics which necessitate the need for more training for patients experiencing psycho mental problems than patients experiencing socioeconomic problems. This indicates that additional attention is to be followed for delivering education for patients having psycho mental complications.

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## Introduction

Multiple Sclerosis (MS) is a chronic and progressive disease of the central nervous system which causes motor and sensory disorder, muscular cramps, amnesia, cognitive (even sexual dysfunctions), visual loss, hearing loss, mumbling and amblyopia.<sup>1,2</sup> MS is the third major cause of disability in the USA. Unfortunately, the exact statistics of Iranian MS patients are not available, but based on the estimation of the Iranian MS Association, there are approximately 50000 MS patients in Iran, most of whom are living in the Isfahan province (roughly 15-20 sufferers in every 100000 people).<sup>3</sup> The difficulties induced from the disease limit the patients' self care abilities, and escort individuals in somatic problems.

In a study to determine the basic needs of MS patients by Mc Large, the results showed that 23% of the samples had mild, 41% moderate and 36% had severe disability and all of the patients needed a certain level of education.<sup>4</sup> In another study, Sutherland examined the ways of relaxation and methods of promoting the quality of life of MS patients, and found that 49% of the

patients were depressed and concluded that the augmentation of relationship with others may give MS patients more energy and less limitation in mental activities.<sup>5</sup> Diseases such as MS reduce individual independence to take part in social activities and results in a lack of confidence.

Since chronic diseases such as MS have some effects on financial, social and mental aspects on individuals, and often the whole community, controlling procedures and drug treatment should be accompanied with the nurses help to improve the daily activities of MS patients and decrease their socioeconomic and psychiatric problems.<sup>6,7</sup> Since MS patients are less efficient, they may lose their jobs as a result of frequent absences. Also, their treatment is very expensive, which causes many economical problems for families. Given that the disease complications were modified, the patients would be able to perform high quality self care.<sup>8</sup>

When the learning skills of the patients are maximized, their decision making and functioning abilities are enhanced. Therefore, the main objective of patient education is to help them accept more responsibilities of caring for themselves and to adopt the changes which manifest on their physical and practical conditions, in order

to improve their quality of life, whilst functional ability would also be promoted.<sup>9</sup> The nurses spend most time with patients, they have superior opportunities to detect hidden signs that MS patients experience and thus they can distinguish the patients' educational needs.<sup>6,7</sup>

Many studies have been conducted to determine the association of MS disease signs, complications and incidences, but no studies have been carried out to investigate the educational needs of MS patients. This study aims to assess and determine the psycho mental and socioeconomical needs of MS patients during 2009 to promote the quality of life of patients.

## Methods

This is descriptive study conducted to facilitate the application of educational, psycho mental and socioeconomical needs of MS patients who are members of the Iranian MS Association. A simple random sampling was used to select the required samples.<sup>10</sup> 174 patients referred to the Iranian MS Association constitute the study population based on the application of the following criteria; patients have to be literate, aged between 20-45 years, the subjects have to have confirmed diagnosis of the disease by a neurologist, and all patients have to be members of the MS Association.

The subjects were formed by both genders. The data gathering tool was a questionnaire designed by the researchers which focuses on the patients' existing and background information. The scientific validity of the questionnaire was approved by a specialized panel of ten from faculty members including Tehran, Shahid Beheshti and Azad (free) Universities. For appointing the scientific reliability of the scale used, a credit method was used and for acquiring scientific validity, the test-retest model was used. The correlation level among the results from the two stages determined in a period of seven days produced an acceptable reliability ( $r=86\%$ ).

The questionnaire included 4 key areas; 1) demographic data, 2) patient tendency for education, 3) patient's need for training about the nature of the disease and 4) educational need in two aspects of psycho mental and socio economical. The questionnaire was composed of 16 questions, highlighting patient aspiration for education which had two options, namely; "I need education" and "I do not need education." The answers were given values of zero to one. The third part of the questionnaire included 8 questions with regards to the patients' needs for training about the nature of the disease which had the option of "Yes" or "No." A value of zero to one was allocated depending on the given answer. The fourth part included 18 questions regarding the educational needs in two aspects; psycho mental and socioeconomical. A value between zero to three was allocated for each of the four options. After selecting the desired samples, obtaining consent and providing

the necessary information, the questionnaires were distributed amongst the patients.

For data analysis, the descriptive statistics (absolute and relative abundance distribution, mean and standard deviation) and inferential statistics such as kruskal wallis, Mann Whitney and the Spearman correlation coefficient were used.

## Results

The results obtained from data analysis revealed that the age range for 26.4% of the study group was between 32-39 years, while 71.3% of the patients were female and 59.8% were married. 27.7% of the patients had a history of MS for less than 3 years duration. Hence, 46.6% were academically educated and 30% were not householders. 82.8% of the study group were Tehran residents. The results also showed that 42% of the patients were employed and were working 6-8 hours daily. 94.3% of cases were living with their families. 92.5% of the patients accepted their disease and 39.1% had a history of at least one hospitalization. 62% of the patients were using Betaferon.

The results in Table 1 show the distribution for educational needs. 39.1% of the patients exhibited high educational needs, while 41.4% had moderate needs and 19.5% had only mild educational needs. With regards to the nature of the disease, 0.6% had high, 40.2% had moderate and 59.2% had mild level need for education. (Table 2)

**Table 1:** Distribution of absolute and relative abundance of the study samples according to their educational needs.

Level of need for education	Percent	Number
High need	39.1	68
Moderate need	41.4	72
Low need	16.5	34
<b>Total</b>	<b>100</b>	<b>174</b>

**Table 2:** Distribution of absolute and relative abundance of the study samples according to their need for education about the natureof the disease.

Need for education about the disease nature	Percent	Number
High need	0.6	1
Moderate need	40.2	70
Low need	59.2	103
<b>Total</b>	<b>100</b>	<b>174</b>

Table 3 shows that 61.5% of the patients need education regarding “methods of controlling anxiety” while 54.62% need education regarding “ways to reduce the level of depression.” Also, the results revealed that 61.5% of the study population need education on drug procurement, while 40% of the patients wished to learn more information about other aspects of the disease, (Table 4). The Kruskal Wallis test showed that there was a significant correlation between the need for education in the psycho mental category and the degree of educational ( $p=0.003$ ).

**Table 3:** Distribution of absolute and relative abundance of the study samples according to difficulties in psycho mental issues.

Level of education need Determination of education need in psycho mental issue	High need		Moderate need		Low need		Mean%	Total	
	Number	Percent	Number	Percent	Number	Percent		Number	Percent
Methods of controlling anxiety	65	37.4	81	46.6	28	16.1	61.5	174	100
Ways to reduce the level of depression	41	23.6	101	58	32	18.4	54.62	174	100

**Table 4:** Distribution of absolute and relative abundance of the study group according to difficulties in socioeconomical issues.

Level of education need Determination of education need in psycho mental issue	High need		Moderate need		Low need		Mean%	Total	
	Number	Percent	Number	Percent	Number	Percent		Number	Percent
Recovery relation ship with others	20	11.5	37	21.3	117	67.2	40	174	100
Occupational difficulties	65	37.4	31	17.8	78	44.8	58	174	100
Emotional relationship with wife or family	60	34.5	35	20.1	79	45.4	56	174	100
Drug procuring difficulties	41	23.6	51	29.3	82	47.1	61.5	174	100
Insurance service difficulties	43	24.7	84	48.3	47	27	44	174	100

Also, the Mann Whitney test showed that there was a significant correlation between the need for education in psycho mental issues and the disease acceptance ( $p=0.035$ ). In addition, the Kruskal Wallis test showed a significant relationship between the need for education in psycho mental issues and the frequency of being hospitalized ( $p\leq 0.001$ ). However, there was no significant relation between psycho mental issues and the point of effect of the disease between the patients. Also, no significant relation was observed between psycho mental issues and the need for training in socio economical issues and age, education level, sex, occupation, martial status, disease acceptance, monthly income, hospitalization times, insurance and the duration of the disease.

## Discussion

The findings showed that 39.1% of the patients exhibited high educational needs, while 41.4% exhibited moderate needs, and only 19.5% exhibited a mild need for education. Also 0.6% of the study group demonstrated a high level of educational needs regarding the nature of the edisease, while 40.2% showed a moderate level, and 59.2% needed a mild level education regarding the nature of the disease. 54.62% of the patients expressed the need to learn more information about ways of reducing the depression and 61.5% needed training about methods of controlling anxiety. Based on the

study by Korostil et al. investigating anxiety disorders among MS patients, they concluded that 35.7% of the patients had anxiety.<sup>11</sup>

The lowest percentage (40%) was observed in relation to patients need to promote mutual relationship with others and the highest percentage (61.5%) corresponded to the patients need for training about drug procuring which implies the need to obtain more education in this area. Also, the findings revealed that there was no significant relationship between the need for education of somatic issues and age, gender, occupation, marriage, disease acceptance, monthly income, insurance and the affection period.

In addition, there was no significant relationship between the need for education in psycho mental issues and age, sex, occupation, marriage, monthly income, insurance and the affection period. However, the kruskal wallis test showed a significant relationship between the need for education in psycho mental issues and the level of official education ( $p=0.003$ ,  $X^2=12.58$ ). In other words, the higher the academic qualification, the less need for training in psycho mental matters.

In a survey on the experiences of MS patients, Mohammadi et al. reported that there was a significant relation between educational need and the degree of education ( $p=\leq 0.001$ ).<sup>12</sup> Also, the Mann Whitney test showed that there was no significant relation between the need for training in psycho mental issues

and disease acceptance ( $Z=-2.11$ ,  $p=0.035$ ). This means that the acceptance of disease affects patients' needs for education in psycho mental issues. In contrast, a study trying to explore the 10 basic needs of MS patients, Koopman noticed that there was a significant relation between the need for training and disease acceptance ( $p=0.010$ ).<sup>13</sup>

In addition, based on the Kruskal Wallis test, it was reported that there is a significant relationship between the need for training in psycho mental issues and the frequency of hospitalization ( $p\leq 0.001$ ,  $X^2=28.20$ ). On the other hand, the need for education in psycho mental issues would decline if the patient was hospitalized. Furthermore, there was no significant relation between the need for education in socio economic issues and age, level of official education, sex, occupation, marital status, disease acceptance, and monthly income, frequency of hospitalization, insurance and duration of the disease.

Overall, the lowest percentage (51.9%) observed reflected the training needs of MS patients in socio economic issues. This result was in contrast with the findings of Koopman, who reported similar patients had a higher demand to acquire basic education. The results showed 81% of the cases had training needs in socio economic areas. This result is fairly similar to the results from a study by MacLurg, where 84% of the patients expressed the need for training about socio economic areas. MS being a chronic and prevalent disease exhibits undesirable effects on the patients' quality of life, in some patients it causes disability. Continuous pain and suffering makes MS patients impractical and in consequence, impose direct and indirect expenses to the community.<sup>1</sup>

## Conclusion

The findings from this study showed that the majority of the MS patients were married and most of them were housewives. As a result, it is recommended that for promoting knowledge and self care skills of female patients, the MS Association and related hospitals should conduct some classes regarding ways of eliminating MS induced problems and complications. Also, this study revealed that most of the patients had a variety of difficulties regarding drug procurement and MS Association support, therefore, it is suggested that some educational programs in this field by the MS Association authorities should be designed to promote patient knowledge in order to improve function. Also, the Association must describe the limitations of its activities and outline in helping patients.

Being aware that patients need some education in psycho mental issues, it is fundamental to consider these issues which must be taken into account. One of the suggestion is to give the

results of this research to nurses, particularly the MS Association instructors in order to use them in their self care education programs, which not only help to promote patients quality of life, but also to prevent hospitalization.

Furthermore, help man powers from wasting resources which result in the promotion of community healthcare. The limitations observed were solved through coordination by authorities. Some limitations were out of the researchers control, these included; the presence of some mental factors and MS complications which in some cases, disturbed the responsiveness from patients. Other observed limitations were the presence of hygiene or medical personnel who had some kind of relationships with the patients. This perhaps may have affected the expression of educational needs by the patients.

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