

Evaluation of the Needs of Patients with Multiple Sclerosis

Ali Dehghani,¹ Sima Mohammadkhan-Kermanshahi,^{*1} Robabeh Memarian¹

1. Department of Nursing, Faculty of Medical Sciences, Tarbiat Modares University, Tehran, Iran

Article information	Abstract
<p>Article history: Received: 12 Mar 2011 Accepted: 23 Apr 2011 Available online: 16 Oct 2012</p>	<p>Background: Multiple sclerosis (MS) is a demyelinating disease of the central nervous system that causes many problems in patients. Since training should be done in according to the educational needs, this study is performed to assess the educational needs of MS patients.</p> <p>Materials and Methods: This is a descriptive cross-sectional study, and its tool was a questionnaire on the educational needs of MS patients. Fifty patients referred to the MS society were selected through simple sampling.</p> <p>Results: Based on the obtained results, 60% of patients were female, 52% were single, and 16% were high school undergraduates. Seventy-eight percent of the patients needed training about disease nature, 82% about treatment and care, 46% about nutrition, and 32% about physical activity.</p> <p>Conclusion: The findings showed that patients need more education about treatment and self-care.</p>
<p>Keywords: Training needs (physical, mental, social), Multiple sclerosis MS Society of Tehran</p>	
<p>*Corresponding author at: Department of Hematology, School of Medical Sciences, Tarbiat Modares University, Tehran, Iran. E-mail: kerman_s@modares.ac.ir</p>	

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Introduction

Multiple sclerosis (MS) is a chronic progressive and demyelinating disease of the central nervous system that affects sensory/motor function. It is most prevalent in ages 20-40, years of the highest familial and social responsibility. Multiple sclerosis affects 1 person in every 1000, and its prevalence rate is 1.1 million people, worldwide [1]. The Multiple Sclerosis Association of America announced that there are 2.5 million MS patients in the world in 2001; 80% of them have some degrees of disability [2, 3]. Its prevalence in Iran is about 15 to 30 persons in 100,000 [4, 5]. Thus, such a rise in MS patients in Iran requires more attention to patients' therapeutic problems.

Patients suffering from disabling diseases like multiple sclerosis confront many difficulties related to their illness, which ultimately affect their daily life and quality of life adversely [6, 7]. In a study on the educational need assessment of the patients with multiple sclerosis performed by Sahebzamani et al. in 2007, the findings showed that 39.1% of patients needed high level training [8]. On the other hand, the patients stated that they had a persistent tendency to achieve more reliable informational resources about symptoms, management, access to health care and rehabilitation professionals.

Patient empowerment is the key of successful management of chronic diseases such as multiple sclerosis. Information about relapse of the disease and management of symptoms is increasingly known as an important factor in patient empowerment, which can improve life quality in MS patients. There is a significant gap between obtained information and required information for MS patients; this means that training

according to patients' needs assessment can provide greater efficacy for them; also, training based on needs assessment saves cost, time, and labor [9]. Training without needs assessment will not be effective and will raise health care costs [10]. On the other hand, nurses spent the most time with patients including MS patients whose needs in all aspects of care process should be considered. Thus, at first, these needs should be determined in order to perform principal nursing care and treatment [11]. In addition; there is limited research on the training needs of multiple sclerotic patients; only physical training needs of these patients have been assessed. Therefore, the present study was performed to discover what the training needs of multiple sclerotic patients in physical, social, and psychology fields are.

Materials and Methods

This is a descriptive cross-sectional study conducted in 2010 aiming to assess the educational needs of MS patients at the multiple sclerosis society of Iran, in Tehran. The research population included multiple sclerotic members of the multiple sclerosis society of Iran. Fifty MS patients were simple randomly selected from those referring to the MS society and were studied. Inclusion criteria were: literacy, 20-50 years of age, confirmation of the illness by the society physician, membership of the society, at least 6-month history of the illness, and an expanded disability status scale (EDSS) of 0-5.5. Exclusion criteria were: history of participating in educational courses during last six months, suffering from acute or chronic physical, mental or psychological

disorders such as severe depression, impaired speech or listening, and illiteracy to read and complete the research questionnaire. To determine the sample size, one item of the completed questionnaire by patients was randomly chosen in order to determine the validity of the tool, then the frequency of the answer was counted according to researcher answer and the obtained number was put in the following sampling formula which resulted to 50; the number of required MS patients to complete the questionnaire.

$$d = \frac{1}{10} p = \frac{1}{10} \times 0/9$$

(The frequency of researcher-desired answer to the selected question was 14 persons out of 15.)

In this study, the needs assessment questionnaire was used as the tool of collecting data from MS patients. The questionnaire had 3 parts; demographic information (7 questions); MS patients training needs in 3 areas of physical problems (4 questions), such as, "What were you unable to realize about therapeutically cares or the cares that you should perform?"; social problems (4 questions), such as, "What effect did your current status have on your family?"; and psychological problems (3 questions), such as, "What do you do in stress and anxiety conditions?" The last part was about the factors effecting patient health (5 questions). The questions were multiple-choice, and each option was given a separate code. Face and content validity of the tool was assessed by 10 professors. The test-retest method was used to determine the reliability of the tool. The questionnaires were completed on two occasions within 7 days by 15 eligible patients, and the total reliability of $r=0.97$ was eventually confirmed. The data were analyzed with SPSS-16 statistical software.

To observe ethics in this research, after obtaining written permission from university authorities and the MS society, the questionnaires were completed by patients after the completion of the informed consent.

Results

Regarding the number of samples (50 persons), the results showed that the disease duration was less than 5 years in 44% of the patients. Also, based on these findings, in 44% of the patients, diplopia was the first cause of referral to a physician. Forty-four percent and 26% of the patients had stated adaptation with the illness and having complete information about it, as their comfort factors, respectively. Seventy-six percent of the patients believed that physicians and nurses can give information about the disease. Other demographic information and educational needs are given in tables 1 and 2. In this study, the Spearman test showed a significant relationship between training needs in physical (self-care behaviors) and educational field and frequency of hospitalization ($p=0.008$). Also, the Spearman test showed a significant correlation between training needs for treatment (medications and control of medications side effects) and educational level ($p=0.001$). Based on the Spearman correlation, there was a positive correlation

between education and numbers of hospitalization, but not a significant relationship ($p=0.08$).

The findings also indicated no significant correlation between self-care training needs and age, gender, occupation, marital status, illness duration, and EDSS.

Discussion

Based on the findings of this study, 82% of the patients needed training in treatment and self-care behaviors. Also, in the study conducted by Maclurg et al. on the primary needs assessment of people with multiple sclerosis, it was concluded that disability range was low in 23%, moderate in 41%, and severe in 36% of the patients in need of training. In addition, in this study, 84% of the patients required physical training in the field of motor and urinary problems. Furthermore, the highest need of the patients in the present study was in the field of self-care, including the control of urinary disorders; these studies specify the necessity of training in this field.⁷ Based on the results of the present study, 46% of the patients needed training in the field of nutrition. In a study conducted by Miltenburger and Kobelt to evaluate life quality of MS patients, 49% of the patients had nutritional problems in the researched items, including the lack of knowledge about the consumption of food [13], which are consistent with the findings of the present study.

The study done by Sahebzamani et al. on the educational needs assessment of patients with multiple sclerosis concluded that samples' training needs on the nature of illness were high in 0.6%, moderate in 40.2%, and low in 59.2%. In this study also there was a significant relationship between training needs in the field of physical and education [8]. In this study, 64% of the patients needed training in the field of stress and anxiety control methods. Moreover, Korostil and Feinstein's study on anxiety disorders in patients with MS concluded that 34% of the samples were anxious and needed training in the field of anxiety control ways [14].

Table 1. Absolute and Relative frequency distribution of demographic data the units under research

Demographic specifications	Number (%)	
Age (yr)	20 - 35	33(66)
	36 - 50	17 (34)
Sex	Female	30 (60)
	Male	20 (40)
Education	Under diploma	8 (16)
	Diploma	27 (54)
	Above diploma	15 (30)
Job position	Housewife	16 (32)
	Jobless	22 (44)
	Employed	12 (24)
Hospitalization frequency	No hospitalization	7 (14)
	Once	10 (20)
	Twice	9 (18)
	thrice	9 (18)
Expanded disability status scale (EDSS)	More of thrice	15 (30)
	0 - 1.5	32 (64)
	2 - 3.5	14 (28)
	4 - 5.5	4 (8)

Table 2. Absolute and relative frequency distribution educational needs of multiple sclerosis patients

Educational need	Educational need fields of assessment	Having educational need		Not having educational need	
		Absolute frequency	Relative frequency	Absolute frequency	Relative frequency
Physical need	Nature of the disease	39	78	11	22
	Sensitivity to occurrence of symptoms and referring to doctor	2	4	48	96
	Treatment (consume drugs and controlling drugs side effects)	41	82	9	18
	Self care (exhaustion, muscle contraction, controlling urine disorder)	41	82	9	18
	Exercise	16	32	32	68
	Diet	23	46	27	54
	Awareness about health and hygiene	39	78	11	22
Social need	Manner of compatibility with disease	36	72	14	28
	Decrease in social skills and communication	28	56	22	44
Psychological need	Controlling stress and anxiety	32	64	18	36

Furthermore, in this study the highest mean of patients' needs (61.5%) were about drug problems and side effects, which are consistent with the present study [14]. Regarding the performed needs assessment, 32% of the patients in this study achieved information about their disease from their counterparts in the MS society; on the other hand, studies have shown that social communications with other patients and similar persons who have experienced the same conditions empower the patients for coping with chronic diseases [15]. Hence, the researcher suggests the training of these patients along with the peer group.

According to the study findings, patients needed more training in the field of treatment and self-care; thus, it is necessary to pay attention to their needs and organize training programs. Since education is not possible without the determination of these needs, and since nurses have

more contact with MS patients, they can evaluate the educational needs of patients in physical, psychological, and social fields and achieve the main goals of care.

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Authors' Contributions

All authors had equal role in design, work, statistical analysis and manuscript writing.

Conflict of Interest

The authors declare no conflict of interest.

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References

- Ghaffari S, Ahmadi F, Memarian R. [The effect of progressive muscle relaxation on depression, anxiety and stress in patients with multiple sclerosis] Persian. *Shahid Beheshti J Res Med Sci* 2008; 32(1): 45-53.
- Schulz KH, Gold MS, Witte J, et al. Impact of aerobic training on immune-endocrine parameters, neurotrophic factors, quality of life and coordinative function in multiple sclerosis. *J Neurol Sci* 2004; 225(1-2): 11-18.
- Werring DJ, Thompson AJ. Improving the quality of life of patients with multiple sclerosis. *Drugs Today* 1998; 34(2): 145-156.
- Beiske G, Svensson E, Sandanger I, et al. Depression and anxiety amongst multiple sclerosis patients. *Eur J Neurol* 2008; 15(3): 239-245.
- Esmaili M, Hosseini F. [Multiple sclerosis and stressful thought habit] Persian. *J Nurs* 2008; 3(10, 11): 25-31.
- Murray J. Multiple sclerosis the history of disease. 12th ed. New York: Demos medical press; 2005: 14-21.
- MacLurg K, Reilly P, Hawkins S, et al. A primary care based needs assessment of people with multiple sclerosis. *Br J Gen Pract* 2005; 5(514): 378-383.
- Sahebzamani M, Rashvand F. [Educational need assessment the patients with Multiple sclerosis] Persian. *Eslamic Azad Univ J Res med Sci* 2008; 18(3): 195-199.
- Matti A, Mccarl H, Klaer P, et al. Multiple sclerosis: Patients' information sources and needs on disease symptoms and management. *Patient Prefer Adherence* 2010; 4(3): 157-161.
- Donaldson C, Mooney G. Needs assessment, priority setting, and contracts for health care: an economic view. *BMJ* 1991; 303(6816): 1529-1530.
- Gillam S, Murray A. Needs assessment in general practice. *Occas Pap R Coll Gen Pract* 1996; 73: 1-55.
- Veismoradi M, Anoosheh M. [Assessment care errors cause in nursing cares] Persian. *Proceeding of the second. Nursing problems congress. Khoramabad; Lorestan University of Medical Sciences: 2007.*
- Miltenburger C, Kobelt G. Quality life and coast of multiple sclerosis. *Clin Neurol Neuro Surg* 2004; 14(4): 272-275.
- Korostil M, Feinstein A. Anxiety disorder and their clinical correlates in multiple sclerosis patient. *Mult Scler* 2007; 13(1): 67-72.
- Sharif F, Abshorshori N, Tahmasebi S, et al. [The effect of peer-led education on the life quality of mastectomy patients referred to breast cancer-clinics in Shiraz, Iran] Persian. *Health Qual Life Outcomes* 2010; 8(74): 3-7.

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