

INTOLERANCE OF UNCERTAINTY, HOPE AND SELF-EFFICACY IN PATIENTS WITH MULTIPLE SCLEROSIS

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ABSTRACT

Background and Aim: Due to the unpredictable nature of multiple sclerosis and causing confusion and anxiety in patients, it is necessary to measure the effect of the disease on their ability to tolerate uncertainty, hope and self-efficacy to adapt to the disease.

Methods and Materials: In this descriptive-correlational study of 200 patients referred to Alborz Multiple Sclerosis Association from April to June 1398 by available sampling method, uncertainty intolerance questionnaire (IUS) of Freeston et al. (1994), Herth Hope questionnaire (1991) and multiple sclerosis self-efficacy scale by Rigby et al. (2003) was evaluated.

Results: Most of the participants in the study were between 25 and 30 years old and women. The mean and standard deviation scores of uncertainty intolerance, hope and self-efficacy were 98.17 ± 4.62 , 13.48 ± 1.61 and 37.68 ± 6.19 , respectively. The more intolerance of uncertainty in the individual, the lower the hope ($r = -0.32$) and self-efficacy ($r = -0.37$). Also, with increasing hope in the individual, self-efficacy also increases ($r = 0.41$).

Conclusion: Nurses can work to increase hope and self-efficacy as well as increase the tolerance of uncertainty in patients with MS.

Keywords

Hope, Multiple sclerosis, self-efficacy, uncertainty.

Introduction

Multiple sclerosis (MS) refers to a chronic inflammatory disease of the central nervous system (CNS), which is a major cause of disability in young adults in developed countries (1). While 500,000 people in the United States suffer from the disease, its prevalence in Iran has recently been estimated at five out of every 100,000 (2). In patients with progressive multiple sclerosis (PMS), the time of onset of the disease attacks, and the symptoms and severity of disease and

attacks are unknown. The patient is constantly concerned about why, when, and how symptoms appear (3). The intolerance of uncertainty is expressed to be associated with concern. In fact, the intolerance of uncertainty is a person's inappropriate orientation towards perceiving, interpreting and responding to uncertain situations. Dugas et al. state that people who are unable to tolerate uncertainty find uncertainty worrying and unpleasant. It is important for patients to be able to deal with possible adverse consequences in the future to stop worrying (4).

A large proportion of MS patients are willing to use complementary and alternative medicines (CAMs) in addition to basic medical treatments (5). Patients can deal with their disease or eliminate its effects and consequences with the help of external factors such as faith and hope (6). Hope plays an important role in health and is an integral part of achieving MS treatment. Feelings of hopelessness are common in these patients, which increases the risk of infection, recurrence or death. Disappointment is a threat to a person's independence and sense of worth (7). Hope is essential in all aspects of life and increases a person's capacity to cope with their problems and circumstances (8).

On the other hand, self-efficacy can also help a person cope with the symptoms of the disease. Therefore, people who believe that they can overcome their illness may be able to cope more effectively. In addition, self-efficacy is related to different care behaviors as well as the consequences of different diseases such as smoking cessation, weight loss and use of exercise programs (9).

Finally, due to the increasing number of MS patients in Iran, it is important to pay attention to their physical and mental condition. Therefore, efforts are being made to identify and apply the modifiable causes of this disease. Patients can seek help from these factors to control many of the complications of the disease, such as physical disability or recurrence. In line with this goal, the nurse, considering the managerial, supportive role and as an important member in the process of patients' recovery, which has the most interaction between all sections of society and other professions of medical sciences, can play a key role in caring for and providing information to patients and families. In addition, due to the lack of information on the simultaneous study of the role of intolerance of uncertainty, hope and self-efficacy in MS patients, and the lack of sufficient information on the impact of various factors in the cases mentioned in the literature review in Iran, the present study aimed to investigate the correlation between intolerance of uncertainty and hope and self-efficacy in MS patients.

Materials and methods

In this descriptive cross-sectional study conducted from March to June 2019 in the Multiple Sclerosis Society of Alborz Province, Iran, 200 patients were included in the study after being assessed in terms of inclusion criteria and obtaining informed written consent. Considering the test power of 90%, the first type of correlation error of 5%, the second type of error of 10% and $r=0.3$, the sample size was calculated to be 200 by calculating the dropout of 10%, who were selected by the convenience sampling method after obtaining the code of ethics

(IR.SBMU.RETECH.REC.1397.1090) and receiving the necessary permissions from Multiple Sclerosis Society of Alborz Province. To maintain confidentiality, code for questionnaires was used instead of patients' names.

Inclusion criteria were definitive diagnosis of MS according to McDonald criteria by the physicians of association, ability to communicate and literacy. Exclusion criteria included the patients in hope therapy and psychology classes, and inability to complete questionnaires. It should be noted that patients with different levels of disability and at different stages of MS (primary progressive, secondary progressive, relapsing-remitting, and progressive relapsing) enrolled in this study.

Data were collected using a four-part questionnaire including a checklist of demographic information (including age, sex, marital status, educational level, employment status, duration of diagnosis, age of onset, family members with the disease and history of hospitalization), uncertainty intolerance questionnaire (IUS; Freeston et al., 1994), Herth Hope Scale (HHS, 1991) and multiple sclerosis self-efficacy scale (MSSS; Rigby et al., 2003). The 27-item intolerance questionnaire (IUS; Freeston et al., 1994) describes the type of reaction of individuals to life uncertainties, and considers two factors important in distinguishing anxious people from healthy people. The first factor: uncertainty has self-referential implications and negative behavior, and the second factor: uncertainty is unfair and ruins everything. The answers to the questions are scored on 5-point Likert scale and are categorized from strongly

wrong to strongly true. The minimum score of this scale is 27 and the maximum is 135 (10). Test validity has been reported as satisfactory by Freeston et al. in 1994 (11). Buhr and Dugas (2006) obtained the correlation coefficient of this scale with the Concern Questionnaire ($r=0.60$), Beck Depression Inventory ($r=0.59$) and Beck Anxiety Inventory ($r=0.55$) at the significance level of 0.001 (12) and reported Cronbach's alpha coefficient of 0.94 (14).

The Herth Hope Scale (HHS, 1991) has 12 questions, the answers to which were formulated in a 3-point Likert scale. The highest score is 20 and the lowest is 12, indicating a high score as a higher level of life expectancy (15). In a study of Abdi & Lari (2012), the Cronbach's alpha coefficient is 97% and the correlation coefficient is 91% using test-retest reliability method (16). In Iran, Hejazi (2015) reported the reliability of 80% for this questionnaire (17).

The 11-item multiple sclerosis self-efficacy scale (MSSS; Rigby et al., 2003) measures three dimensions of independence and activity ($n=4$), concerns and interests ($n=4$), personal control ($n=3$). This tool is scored on a 5-point Likert scale. Scores range from 11 to 55 and higher scores mean more self-efficacy (18). The reliability of this scale in the main study was obtained by calculating the internal consistency of Cronbach's alpha coefficient of 0.81 and test-retest reliability of 0.81. In a research by Reshvanloo and Soleimani (2014), the validity of the questionnaire was reported to be acceptable using construct validity, and the reliability and Cronbach's alpha coefficients of the whole questionnaire were reported to be 0.90 and 0.87, respectively. Cronbach's alpha coefficients for each of the components of independence and activity, personal control, concerns and interests were 0.80, 0.78 and 0.72, respectively (19). Data were analyzed by SPSS.v.24 software using descriptive (mean and standard deviation) and analytical (independent t-test, analysis of variance (ANOVA), Pearson and Spearman correlation coefficients) statistics after examining the normality of data distribution, at a significance level of $P < 0.05$.

Results

In this study, 200 MS patients participated, 55% of whom were women. Among them, 37.5% of the subjects were between 25 and 30 years old. Among the participants in the study, most of them (37.5%) had progressive relapsing MS. Most participants (45%) were married. Among the subjects, most of them had less than high school level (35.5%) and a history of MS in family members (71%) and mentioned a history of 2 to 10 hospitalizations due to MS (58.5%). It should be noted that 31% of housewives and 29.5% were unemployed; 80% did not have enough income to pay for medical expenses; about half of the people (45%) had a duration of MS between one and five years, and were diagnosed with MS between the ages of 25 and 30; finally, 74.5% had no exercise during the week.

The mean and standard deviation of the intolerance of uncertainty, hope and self-efficacy were 98.17 ± 4.62 , 13.48 ± 1.61 and 37.68 ± 6.19 , respectively. The mean and standard deviation of the first factor of intolerance of uncertainty, i.e. self-referential implications and negative behavior was 54.62 ± 3.40 and the second factor, i.e. unfairness was 43.55 ± 2.91 . According to the results of the present study, 69% of people received a score less than 100 from the IUS. Moreover, the level of hope was low in the patients participating in the study. In addition, 61.5% of patients received a score below 40 from the MSSS. Among the various dimensions of self-efficacy, the personal control dimension received the lowest score. The results of Table 1 show the mean and standard deviation, minimum and maximum scores of IUS, HHS and MSSS and their subdimensions.

Table 1: Mean and Standard Deviation of Intolerance of Uncertainty, Hope and Self-efficacy in Patients with Multiple Sclerosis (N = 200)

Variable	Mean	Std	Min	Max
Intolerance of Uncertainty	98.17	4.62	83	113
Self-referential Implications and Negative	54.62	3.40	46	68

Variable	Mean	Std	Min	Max
Behavior				
Unfair	43.55	2.91	33	51
Hope	13.48	1.61	12	20
Self-efficacy	37.68	6.19	11	51
The Dimension of Independence and Activity	24.18	5.94	7	35
The Dimension of Concerns and Interests	13.57	3.32	4	20
The Dimension of Personal Control	10.19	2.82	3	15

The results of this study revealed that the more intolerance of uncertainty in a person, the lower the hope ($r=-0.32$) and self-efficacy ($r=-0.37$). Furthermore, the self-efficacy enhances with increasing hope in the individual ($r=0.41$). According to Tables 2 and 3, the intolerance of uncertainty, hope and self-efficacy are all related to gender, age, disease stage, marital status, employment status, monthly income, duration of disease, age of onset and hospitalization, as well as the hope and self-efficacy are related to the number of hospitalizations and exercises ($P<0.005$).

Table 2: Correlation between Intolerance of Uncertainty, Hope and Self-efficacy with Demographic Variables in Patients with Multiple Sclerosis (N = 200)

Variable	Intolerance of Uncertainty		Hope		Self-efficacy	
	M (Std)	P-value	M (Std)	P-value	M (Std)	P-value
Gender		< 0.001*		< 0.001*		< 0.001*
Female	99.2 (4.2)		12.3 (0.4)		39.7 (6.2)	
Male	96.9		14.9		35.2	

	(4.8)		(1.3)		(5.1)	
Disease Stage		0.002*		< 0.001*		< 0.001*
Progressive-Receding	99.9 (3.6)		12.0 (0.0)		41.7 (4.6)	
Primary Progressive	97.7 (4.0)		12.9 (0.2)		37.6 (6.5)	
Secondary Progressive	96.3 (4.7)		16.2 (1.5)		33.6 (6.2)	
Relapsing-Remitting	97.7 (5.1)		13.7 (0.9)		36.2 (5.3)	
Marital Status		< 0.001*		< 0.001*		< 0.001*
Single	95.1 (5.2)		14.6 (1.8)		29.0 (4.8)	
Married	98.0 (3.5)		13.5 (1.4)		36.9 (1.9)	
Divorced	99.5 (4.6)		12.9 (1.1)		42.7 (1.3)	
Partner Died	102.3 (3.0)		12.0 (0.2)		48.3 (1.8)	
Employment Status		< 0.001*		< 0.001*		< 0.001*
Student	97.0 (3.34)		12.6 (0.51)		38.5 (3.20)	
House Wife	98.9		13.0		39.6	

		(4.4 4)		(1.2 2)		(2.1 1)	
	Employee	101.3 (3.1 7)		12.4 (0.9 6)		46.3 (2.3 3)	
	disabled	97.5 (4.9 2)		14.2 (1.9 8)		38.1 (2.8 5)	
	Unemployed	98.0 (3.5 6)		13.6 (1.5 5)		36.3 (2.9 5)	
	Self-employment	94.4 (5.3 7)		14.8 (1.8 9)		28.1 (4.9 3)	
Monthly Income			< 0.001*		< 0.001*		< 0.001*
	Enough	94.8 (5.1 7)		14.5 (1.9 2)		29.7 (5.9 9)	
	Inadequate	99.0 (4.0 9)		13.2 (1.4 2)		39.6 (4.3 9)	
Duration of Diagnosis			0.004*		< 0.001*		< 0.001*
	1-5 Years	99.2 (4.7 7)		12.8 (1.1 5)		39.4 (6.3 8)	
	6-10 Years	96.8 (4.1 1)		14.5 (1.7 4)		35.1 (6.0 1)	
	More than 10 Years	98.0 (4.6 0)		13.1 (1.4 5)		37.9 (4.7 5)	
Age of Onset of the Disease			0.028*		< 0.001*		< 0.001*
	Less	97.		12.		35.	

	than 25 Years	1 (4.8 4)		9 (0.2 5)		7 (8.0 5)	
	26-30 Years	99.0 (4.2 9)		12.6 (1.6 8)		39.6 (6.0 5)	
	31-35 Years	97.2 (4.4 8)		14.6 (0.8 6)		35.5 (5.0 7)	
Family History of MS			0.688		0.818		0.073
	Yes	98.2 (5.0 8)		13.4 (1.6 6)		38.2 (7.1 9)	
	No	97.9 (3.5 3)		13.5 (1.5 1)		36.5 (3.0 1)	
History of Hospitalization			0.028*		< 0.001*		0.005*
	Yes	98.6 (4.7 1)		12.8 (0.9 6)		38.4 (6.5 1)	
	No	97.0 (4.2 4)		14.9 (1.9 5)		35.7 (4.8 7)	
Number of Hospitalization			0.147		< 0.001*		0.019*
	0	97.0 (4.2 4)		14.9 (1.9 5)		35.7 (4.8 7)	
	Less than 2	99.1 (6.0 0)		12.7 (0.7 3)		38.3 (5.0 1)	
	2-10 Times	98.5 (4.5 1)		12.9 (1.0)		38.2 (6.7 8)	

More than 10 Times	99.5 (4.72)		12.8 (0.98)		42.0 (4.81)	
Exercise		0.063		< 0.001*		0.024*
Yes	97.1 (4.34)		14.9 (1.99)		36.0 (4.83)	
No	98.5 (4.68)		12.9 (1.07)		38.2 (6.50)	

Table 3: Correlation between Intolerance of Uncertainty, Hope and Self-efficacy with Age and education in patients with M.S (n = 200)

Variable	Intolerance of Uncertainty		Hope		Self-efficacy	
	P-value	r	P-value	r	P-value	r
Age	< 0.001*	-0.2	< 0.001*	0.8	< 0.001*	-0.03
Education	0.21	0.08	0.48	-0.05	0.03	0.14

Discussion

The results of the present study demonstrated that nearly two thirds of the participants in the study did not tolerate uncertainty. Considering that about half of the patients had been suffering from this disease for one to five years, but most of them showed intolerance of uncertainty. The intolerance of uncertainty has also been reported low in people with depressive symptoms, obsessive-compulsive disorder (20, 21). The intolerance of uncertainty is one of the main measures of mental health. The reduction of uncertainty tolerance in the patient falters ability to adapt to the disease (22). Uncertainty interferes with a person's proper functioning, so that uncertainty is considered distressing and stressful. Uncertainty about the future is not believed to be

fair, and unexpected events are negative and should be avoided (21).

The level of hope in patients participating in this study was low. The mean score of hope in the study of Hejazi et al. (2014) in hemolysis patients was also reported to be low, which was due to the long and chronic course of the disease and treatment, going through different psychological stages in the face of chronic disease and inclusion criteria (17). Hope was reported to be low in studies by HUS et al. (2003) among patients with lung cancer, and Moghtadar et al. (2017) and Sadoughi et al. (2017) among women with breast cancer (23-25). Most studies in chronic diseases have low hopes that are consistent with the results of the present study. The duration of disease is long in the MS patients who suffer from a variety of disabilities during this period, eventually resulting in dependence on others, impaired social and family role and physical weakness. While hopefulness is one of the most important roles in nursing, most nurses' care is devoted to meeting physical needs. Therefore, nurses can meet the psychological needs of patients by identifying the effective factors and performing the necessary interventions (26).

We also found that more than half of the participants had a low score on self-efficacy and the lowest score belonged to the personal control dimension. Studies by Hejazizadeh et al. (2020) and Tanhaye Reshvanlo and Soleimanian (2014) among the MS patients had similar results to the present study (19, 27). Asea et al. (2017) reported that the self-efficacy in the MS patients is lower than other diseases associated with disability (28). Chronic diseases are likely to affect a person's level of activity and self-efficacy and reduce the patient's self-efficacy compared to a healthy person due to the nature of the disease, and its complications and problems, especially mobility difficulty in the MS patients.

In the present study, the results of linear regression indicated that the more intolerance of uncertainty in the individual, the lower the hope and self-efficacy. In addition, increasing one's hope enhances self-efficacy. The patients with chronic diseases are less able to cope with the harsh conditions, pressures and stresses caused by their disease, and cannot use appropriate defense

mechanisms to moderate their disease (29). Studies have shown that intolerance of uncertainty has a positive relationship with depression and is a predisposing factor for emotional problems and a risk factor for depression and anxiety (30, 31). Indeed, there is a strong association of uncertainty intolerance with anxiety and depression (22). On the other hand, the more depressed the patient, the less hope there is. Hope is considered as a strong adaptation mechanism in chronic diseases, and people with more hope can easily endure the disease crisis (32). People with more hope, with higher self-efficacy, can reduce their level of stress in stressful situations, and thus affect many aspects of personal functioning (33).

According to the findings of this study, women with MS exhibit more intolerance of uncertainty and less hope, but higher self-efficacy than in men with MS. As in the present study, Dehbashi et al. (2014) found greater hope in male patients undergoing dialysis (34). Daniali et al. (2016) in a study of MS patients concluded that the self-efficacy is not different between men and women (35), but Saeidinejat et al. (2014) reported that the self-efficacy is lower in men with type II diabetes than in women (36).

In this study, the people with deceased spouse had less intolerance of uncertainty, but more self-efficacy, as well as the single people showed more hope. However, in the studies of Moghimian et al. (2012) on cancer patients and Hejazi et al. (2014) on 62 hemodialysis patients and 63 caregivers, the results showed that the marital status had no significant relationship with hope (17, 37), but Tol et al. (2017) found more self-efficacy in married women (38).

The results of this study showed that students have the least intolerance of uncertainty. Self-employed people experienced more hope. Employees also reported the highest self-efficacy. Pour Ghaznain et al. (2005) in kidney transplant recipients and Dehbashi et al. (2014) in dialysis patients found no significant relationship between hope and employment (34, 39). In addition, Tol et al. (2017) found a significant relationship between self-efficacy and employment in patients with type II diabetes (38). Jongen et al. (2014) reported that people who reduced their working hours per

week after being diagnosed with MS had lower self-efficacy (40).

According to the present study, people with insufficient income had less intolerance of uncertainty but more self-efficacy. People with sufficient income showed higher hopes. Pour Ghaznain et al. (2005) found no correlation between economic status and hope in kidney transplant recipients (41), but Tol et al. (2017) observed that perceived adaptation self-efficacy is more prevalent in people with higher incomes (38).

People six to ten years after the onset of the disease showed less intolerance of uncertainty and more hope. Newly diagnosed people, who had been suffering from the disease for between one and five years, were more self-sufficient. Studies by Danilali et al. (2016) among the MS patients and Tol et al. (2017) among the type II diabetes found no association between self-efficacy and duration of disease (35, 38). Geyh et al. (2012) acknowledged that, in patients with spinal cord injuries, self-efficacy and post-traumatic hospital discharge time were associated with adaptation to chronic disease, depressive symptoms, pain, and social support (42).

People with the onset of the disease between the ages of 26 and 30 had less intolerance of uncertainty but greater self-efficacy. In addition, people with MS onset between the ages of 31 and 35 had higher hopes. The older the person, the less intolerance of uncertainty and self-efficacy, but with increasing age, the hope increases. Daniali et al. (2016) did not observe the effect of age on self-efficacy in the MS patients (35), but Tol et al. (2017) revealed a significant relationship between age and self-efficacy in the patients with type II diabetes (38). Pour Ghaznain et al. (2005) did not find a significant relationship between age and hope in kidney transplant recipients (41).

The results of this study demonstrated that people with no hospital history had higher hopes, but people who had been hospitalized more than ten times for MS reported greater self-efficacy. In addition, patients admitted less than twice had less intolerance of uncertainty. Although the study found that the self-efficacy was enhanced with increasing frequency of hospitalizations, but frequent and prolonged hospitalizations following

chronic illness cause a decline in physical strength, a decrease in the ability of individuals to engage in daily activities, a reduction in life expectancy, and an increase in depression (43). The results of this study showed that people with regular exercise have more hope, while the studies of Wall et al. (2000) and Sung et al. (2019) on cancer patients revealed that exercise had no effect on patients' hopes. However, it is recommended that a combination of exercise, training and emotional programs can reduce stress in patients (44, 45).

The present study showed that self-efficacy increases in highly educated individuals. As in the present study, Saeidinejat et al. (2014) and Tol et al. (2017) also expressed that the self-efficacy in patients with type II diabetes increases with elevating academic level (36, 38). However, Danilai et al. (2016) did not achieve such a result in MS patients; however, they considered educational interventions to increase patient awareness (35).

Conclusion

Nursing has a comprehensive focus on the patient, and pays attention to the integrity of the clients in their care. The results of this study can help nurses to be careful in assessing the psychological problems of MS patients and provide more appropriate services in this area. Due to the increasing prevalence of MS in Iran and the incidence of this disease at a young age, it is important to pay close attention to the psychological issues affecting this disease and help patients to increase their adaptation to the disease. By increasing hope, the patients can increase their capacity to overcome the problems and conditions resulting from the disease and thus expand their adaptation. In addition, by enhancing self-efficacy and self-care behaviors, they can overcome the disease more effectively. In general, due to the fact that the course of the disease in MS is not predictable and preventable, it is normal for a person to experience anxiety, worries and uncertainty in the face of the disease and its symptoms. Therefore, increasing hope and self-efficacy can help these patients reinforce their

tolerance of uncertainty and overcome the disease and its symptoms.

Some of the limitations of this study are the lack of high generalizability due to sampling exclusively in the MS community and the type of self-report of the disease stage. Additionally, it was impossible to orient the observed relationships due to the descriptive-analytical nature of the study. Extensive studies are proposed to understand the relationship between different psychological dimensions of MS patients. It is also recommended to perform these studies in other chronic diseases such as cancer, diabetes and rheumatoid arthritis.

According to the present results of this study, it is recommended that the authorities should consider measures to employ and increase the monthly income of these patients in order to increase their hope and self-efficacy. Given that hope, self-efficacy, and overcoming complex problems and issues can be achieved through learning and training, healthcare providers are advised to hold workshops and training classes to promote these issues in MS patients, thus increasing the compatibility of these patients with the disease and overcoming the problems caused. Teaching problem-solving techniques, strengthening patient adaptation strategies and cognitive-behavioral therapies can also be effective.

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