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The Effect of Anxiety on Treatment Adherence among Patients Suffering from Multiple Sclerosis

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ABSTRACT

Multiple Sclerosis (MS) is one of the diseases of the central nervous system which has caused many challenges and difficulties regarding the patients' psychiatric adjustment throughout the world. The aim of this project is to recognize the factors predicting treatment adherence among patients suffering from MS, being members of Iranian MS Society in Tehran in 2013. The research method was the descriptive correlation method. The sample included 120 patients suffering from MS who were members of Tehran MS society and the Iranian Society supporting MS patients which were selected using the convenience sampling method. Questionnaires of demographic characteristics, treatment adherence among MS patients, Sheer public self-efficacy, short NEO-form personality trait, Beck depression, life quality, Kattle anxiety, PANAS positive and negative affection, Philips social support and feedback were filled for all the patients. The gathered data was analyzed using Multivariate analysis of variance, recognition analysis, and logistic regression methods. The findings showed that treatment adherence was significantly different from depression, neuroticism, extraversion, having a conscience, life quality, social support of the family, and anxiety at the level of $\alpha = 0.50$. The results demonstrated that treatment adherence among MS patients had a direct relation with psychiatric factors; psychiatric consultancies must also be sought to better treat these patients, in addition to taking medicine in order to reduce their anxiety and depression and increase their self-efficacy to improve their life quality.

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INTRODUCTION

Multiple sclerosis (MS) is a chronic disease affecting the nervous system and parts of the brain and the spinal cord. Patients suffering from this disease may lose some of their abilities, this disease mostly occurs for smart and active young people of the society. The cause of this disease is not completely known and no definite treatment has been introduced to cure it. Despite knowing the side effects of this disease, knowing the different personality traits of the patients and the supporting activities can be useful in returning these patients back to active life.

MS is an autoimmune disease affecting the brain and the spinal cord; generally speaking, it is the disease of the central nervous system (CNS). In this disease, Myelin cover is damaged; therefore, the speed of the nervous signals is reduced or stopped. This damage can be due to inflammation. Inflammation occurs when one's immune cells attack their own nervous system. This may occur at any time everywhere in the brain, optic nerves, or the spinal cord.

The cause of this difficulty is not known, yet; the most common theory states that a virus or a gene deficiency or a combination of both might be the cause; it must be noted that environmental factors can play a role, too.

The incidence rate is 2-150 per 100000 people. This disease is seen more in women, than men. The most common age to detect this disease is between 20- 40; however, it can be seen at each age. If this disease has been seen in previous members of a family, it may occur among other members of that family with a higher probability.

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The symptoms may be different regarding the location and the severity of the attacks. The symptoms' severity may take for days, weeks, or months; the symptoms may cause or worsen the attacks in these subsequent periods. Relapses are pretty prevalent, although the disease periods may be accompanied with no improvement and even with the increase of attacks and symptoms. Since the nerves in each part of the brain and the spinal cord may be damaged, the affected patients can have the symptoms in many parts of their body, which include:

- Symptoms in Muscles Losing balance, muscle spasms, anesthesia or abnormal feeling in each part, problems in moving arms or legs, difficulty in walking, difficulty in coordination and small movements, tremor in hands or legs.
- Symptoms in Intestine and Bladder Constipation, problem in urinating, frequent urination, and urinary incontinence.
- Symptoms in Sight Squit, problems in sight, fast and uncontrollable movements of the eyes, and losing sight.
- Numbness or Tingling Feeling or Pain Pain in the face, painful muscle spasm, tingling in arms and legs.
- Symptoms in the Brain and Nerves Lack of attention, poor judgment, losing memory, difficulty in reasoning, depression, dizziness, difficulty in balance, and the reduction of hearing power.
- Sexual Symptoms Erection problems, vagina problems, sexual appetite reduction.
- Other Symptoms: Difficulty in chewing and speaking, fatigue.
- Fatigue is considered as a prevalent and annoying symptom of MS disease which becomes more severe at the evenings.

Although no definite treatment has been found for MS, there are several methods to reduce the speed of the disease progression and also stop each attack and reduce the disabilities and the annoying symptoms. Besides, broad researches are being conducted aiming to find effective treatment methods and it seems that newer treatments will be found in the future. Currently, the treatment methods of this disease can be divided into several categories:

1. Treatments which are used when the attacks occur: Metilprednizolon, ACTH, and plasma exchange
2. Treatments which reduce the speed of the disease progression: Different types of interferon beta (avonex, betaseron, rebif) Glatiramer Stat (Copaxone), Fingolimod, Natalizumab (Tysabri), Mitoxantrone (Novantrone).
3. Treatments which result in the reduction of the disease symptoms: Researchers have proved that some exercises and water therapy can significantly reduce the disease progression.

If the treatments are performed correctly and with the right protocol, they can result in rehabilitation, mobility, employment, independence, and self- management among the patients and prevent the occurrence of repeated attacks and the disease progression. Completely adhering to the treatment and paying attention to the consequences of not controlling the disease are of great importance.

In medical sciences, treatment adherence refers to the level a patient follows the medical advices. Generally speaking, adherence is related to treatment and drugs; however, it can be used in case of other situations such as in medical advices, personal cares, personal exercises, and other issues. The effective factor of treatment adherence is the positive relation between the patient and their doctor; although the doctor's prescription plays an important role, too.

Statement of the Problem:

MS is one of the chronic diseases which can cause many disabilities among young and old people. This disease is mainly seen in young adults; it is usually expressed with several pathologic symptoms in the central nervous system. From a pathologic point of view, MS is diagnosed by several areas of the white matter, demyelination, and scar glial in the central nervous system. This disease can range from the benign and with no symptoms to fast progressing and debilitating.

MS incidence rate has increased in the world in the recent years. The main cause of this disease is unknown; however, some resources have stated that its cause is the combined role of genetics and the immune system with the infectious factors, although there is no strong proof to prove this hypothesis.

MS imposes a lot of economic costs on the society and families, such that the U.S National Institute for Special Diseases states that the annual cost of this disease in the United States is more than

5.2 million dollars (Marvin, 2000):

On the other hand, this disease threatens the independence and ability of a person to take part in activities associated with families and society and move them towards feeling the lack of competency and self-confidence; it can distort one's belief in their body and health.

There is no precise information on the number of the patients suffering from this disease in Iran; however, the Iranian MS Society has stated this number to be 70000 people in Mordad, 2013. Despite several treatments, this disease is still known as one of the most debilitating diseases which affects different aspects of patients' lives, especially their life quality and reduces it.

The result of a study performed in Sweden in 2013 showed that Vitamin D can be effective in treating MS.

In a study done in 2013 in Norway, it was realized that the probability of MS occurrence is higher in 50% of the children born in spring, because their mothers' pregnancy had been experienced in autumn; therefore, they received less sun rays and vitamin D which increased the probability of MS occurrence in their children.

The results of another research performed in Iran in 2013 showed that MS patients experience higher levels of stress, anxiety, and depression which increases their number of being hospitalized.

Treatment adherence in chronic diseases is one of the goals of the World Health Organization through which the disability and mortality rates can be reduced. In general, treatment adherence is related with patient's reaction towards the doctor's prescription and the treatment team regarding the time, amount, and number of drug consumption.

The results of a research in 2010 showed that patients who adhere to their treatments are less endangered with the risk of disease progression in comparison with those who do not.

Another research showed that people adhering to treatments have higher levels of life quality.

Lack of treatment adherence includes a broad range of behaviors which can be intentional or unintentional. Some of the factors which can affect the treatment non-adherence are: Depression, literacy level, psychological disorders, recognition disorders, amnesia, anxiety, treatment costs, drug side effects, and long term treatments.

Considering the importance of treatment adherence and previously performed researches on the reasons of treatment non-adherence, it is clear that psychological-social factors affect treatment adherence. As a result, the psychological aspect is studied in this research. The variables under the study are as below:

Social Support It refers to the things done for a distorted person by people such as family members, friends, colleagues, relatives, and neighbors; these things usually include instrumental help, social-emotional help, and information help.

Self-Efficacy It includes the beliefs or judgments of a person on their abilities in performing duties and responsibilities.

Anxiety It refers to the fear of failure which results in the distortion of the mental balance and physiological calmness of the human body.

The results of a research titled as the consideration of the effect of emotion expression in a written manner on the level of anxiety and depression in patients suffering from MS in 2009 on 40 people showed a high level of anxiety and depression in MS patients which was significantly reduced after the treatments.

The Importance of the Research:

Following treatment advices is an issue which has been expressed since years ago on the relation of the patient and clinical specialists; their non-following has always been regarded as an important and multidimensional problem in health issues.

The process of adjusting with the MS and chronic diseases and also adhering to the treatment advices is affected by three categories of factors:

1. Factors related with the disease Adjustment, flexibility, beliefs and attitude, self-esteem, and personal self-efficacy.
2. Factors related with the disease Severity, duration, predictability, and controllability
3. Social Factors Social supports, inter-personal relations

In patients suffering from MS, there are several reasons for treatment non-adherence; they include the side effects of the drugs, repeated and undesired but required dosages, the level of drug efficiency or the relation of the patient with the drug, the person's low self-efficacy, depressed mood, poor social and familial support, physical problems of the patients, consumption of injection drugs by the patient, the pain during injection, skin reactions in injected sites, anxiety problems, and nausea.

Regarding the mentioned problems, treatment adherence is of importance since it can reduce disease progression and patients' disability; it also reduces the probability of being hospitalized and neurophysiological disorders. It must be noted, however, that the level of treatment adherence is different based on the type of treatment and drug.

Another important aspect of this research is its novelty. The novelty of this study in Iran and the possibility of detecting the effective factors on treatment adherence among MS patients are studied for the first time in this research.

In foreign studies, different factors on treatment adherence among patients suffering from MS have been investigated. Some of these factors are: Self-efficacy, feeling, personality, recognition, satisfaction, acceptability, and interdisciplinary cares. But, all these factors have not been investigated in one study. As a consequence, investigating these factors as multivariate study can significantly help treating the patients.

Due to the importance of treatment adherence in MS patients' health, conducting researches to recognize factors affecting the adherence seems necessary; recognizing such factors can help us increase treatment adherence and prevent the negative effects, controlling those factors.

Research Hypothesis:

1. There is a relation between anxiety and treatment adherence and non-adherence among patients suffering from MS.

Research Question:

1. Does anxiety play any role in treatment adherence and non-adherence among patients suffering from MS?

*Treatment Adherence:**Theoretical Definition:*

In medical sciences, treatment adherence refers to the level a patient follows the medical advices. Generally speaking, adherence is related to treatment and drugs; however, it can be used in case of other situations such as in medical advices, personal cares, personal exercises, and other issues. The effective factor of treatment adherence is the positive relation between the patient and their doctor; although the doctor's prescription plays an important role, too. If treatment is not adhered, the patient will suffer from the reduction of life quality, the increase of unpleasantness, and mortality; on the other hand, it will impose extra costs on the country's health care services.

Operational Definition:

It is the score acquired by a person from the Multiple Sclerosis Treatment Adherence Questionnaire (MSTAQ).

*Anxiety:**Theoretical Definition:*

The word anxiety literally means moving, shivering, distortion, beating, impatience, and restlessness.

Anxiety has different meanings in the science of psychology. In a simple definition, anxiety can be defined as the mental restlessness and impatience which are resulted from the risk or failure. Besides, it can be said that anxiety is the fear of lack of success which ends in mental imbalance and the lack of physiological calmness of the human body.

Operational Definition:

The score acquired by a person in Kattle anxiety test.

The Research Methodology:

The present research is a field research of correlation type. In most researches in humanities, since the main goal is to investigate an issue in a field study, it can be said that the present research falls within the applied research category; on the other hand, since library and field research methods such as questionnaire have been employed, it can be said that the present research is a correlation-descriptive research based on data collection method which provides the possibility to achieve generalizable results for the whole statistical population through studying the sample.

Research Process:

This research attempts to identify the factors predicting treatment adherence among patients suffering from MS. In this research, "treatment adherence" is the dependent variable and the predicting variables are: "Depression, anxiety, self-efficacy, personality characteristics (neuroticism, extraversion, having a conscience), positive and negative affection, life quality, social support, and patients' reaction towards the specialist". On the other hand, demographic variables affect the treatment cycle and treatment adherence in this disease which are considered as the predicting variable.

Statistical Population:

The statistical population of the present research includes all female and male patients of the Iranian MS supporting society in Tehran in autumn, 2013. Based on the latest statistics released by the Iranian MS Society, about 70000 people are suffering from this disease of which around 7500 people are members of the Iranian MS supporting society.

Sample, Sample Size, and Sampling Method:

In order to determine the sample size, $n = \frac{z^2(1-\frac{a}{2}) \times p(1-p)}{d^2}$ formula was used; based on $a = 0.5$ and using the studies, the following was calculated: $p = 0.3$ and $d = 0.1$ and its number was 80 people. However, in order to

increase the creditability of the collected data and reduce the sampling error, 120 people of the MS patients were selected as the final sample of the research.

Stratified random sampling was used to select the research's final sample.

Research Instrument:

Demographic Questionnaire:

The demographic questionnaire includes the applicants' personal information such as age, gender, height, weight, marital status, employment status, education degree, living place, race, family members' number, cigarette consumption, and being infected by chronic diseases. Among these variables, those which can affect the treatment cycle and adherence such as age, gender, race, marital status, and eventually education degree can be measured as qualitative independent rank variables.

Treatment Adherence Questionnaire of MS Patients:

Treatment adherence questionnaire of MS patients was made by Paul Wicks in 2011 in the United States. This instrument measures and considers the reasons of treatment adherence which includes the drug type, drug consumption method, injection type, the injector person, the non-consumption of the drug and its reasons, the side effects of injection, the methods used to reduce the side effects of injection, and the patient's feeling towards the treatment and drug during the past 28 days. This questionnaire includes 11 questions. The questions of this instrument are: The first part (the type of the consumed drug, 14 cases), the second part (the method of drug consumption, 6 cases), the third part (the method of drug injection, 4 cases), the fourth part (injection by another person, 5 cases), the fifth part (the drug non-consumption, 2 cases), the sixth part (the numbers of the drug non-consumption, 1 case), the seventh part (the reasons of drug non-consumption, 13 cases), the eighth part (the side effects of drug injection, 10 cases), the ninth part (the strategies to use in case of injection side effects' occurrence, 7 cases), the tenth part (the patient's feeling towards the treatment, 5 cases), and the eleventh part (the patient's idea regarding the treatment, 5 cases). Question 7 is scored using 4-point Likert scale and question 8 is graded using 5-point Likert scale; questions 1-6 are in nominal and definitive forms and question 9 is in the form of yes/no question which assess these patients' treatment adherence. This instrument has been used for the first time in Iran. In order to use this scale in the present research, reverse translation was used. The text was first translated into fluent Persian and then, it was re-translated into English by a specialist in English language. Then, the Persian text was corrected based on the comparison of the two English texts.

Kattle Anxiety Questionnaire:

This scale has been provided by Reymond Kattle in 1957 based on broadened researches; it is probably the most effective instrument which has been presented in the form of a short questionnaire, a questionnaire which can complete clinical diagnoses and end in concrete results with the research goals. The anxiety scale can be used for both sexes at all ages after 14-15 years of old and in most cultures.

This questionnaire includes 40 questions which forms Kattle's 16 Personality Factor scale. Each question is rated in a 3-degree scale (0, 1, and 2) such that 2 shows the most and 0 shows the least level of anxiety in that question. It must be noted, however, that questions 2, 3, 9, 10, 11, 14, 17, 19, 22, 23, 26, 29, 30, 31, 34, 37, and 39 are numbered adversely. In this test, two series made up of 20 questions are presented. The first 20 questions indicate the hidden anxiety and the second 20 questions indicate the apparent anxiety; each receives scores ranging from 0-40; each person can acquire a score ranging from 0-80 in total. After determining the total score, they will be turned into balanced scores by referring to table 3.5.5. Scores 0-3 are related to people who are not suffering from anxiety and are calm. Scores 4-6 indicate a medium level of anxiety. Scores 7 or 8 indicates a person who may be neurotically anxious; and scores 9 or 10 refers to a person who is in need of a consultant in order to improve their conditions.

Table 3.5.1: The Balanced Scores of Anxiety.

The Balanced Scores	Women's Raw Scores	Men's Raw Scores
0	0- 14	0- 10
1	15- 18	11- 14
2	19- 23	15- 19
3	24- 27	20- 23
4	28- 31	24- 27
5	32- 36	28- 32
6	37- 40	33- 36
7	41- 44	37- 40
8	45- 49	41- 45
9	50- 53	46- 49
10	54- 80	50- 80

This questionnaire has been normalized since 1988 by being tested on 977 students of Tehran University (Karami, 2003). The validity of this questionnaire has been calculated in the research conducted by Salari Far

and Pour Etemad (2011) by Cronbach Alpha method for the micro scale of hidden anxiety as 0.59, apparent anxiety as 0.69, and 0.77 for the total scale. In a research performed by Faramarzi, two methods of Cronbach Alpha and division methods were used to determine the validity of anxiety questionnaire which were 0.60 and 0.60, respectively.

The Method to Analyze the Used Statistical Data and Tests:

In this research, the data were analyzed in two forms of descriptive and inferential. Concerning the descriptive indices, frequency, percentage, mean, standard deviation, and maximum and minimum scores were used. In order to consider the research hypotheses, inferential statistical tests such as chi-square test, Friedman test, Pearson correlation coefficient, Spearman's rank correlation coefficient, regression analysis, Multivariate analysis of variance, and detection analysis were used. The statistical calculations in this research were done using version 20 of SPSS software.

The Statistical Description of Kattle Anxiety Questionnaire:

Regarding table 4.44, the following results were obtained.

- The mean of the apparent anxiety was (33.21%) more than the hidden anxiety (20.93%).
- The variety of answers in the apparent anxiety is more than the hidden one. It means that the scores of the apparent anxiety among the repliers has more distance from the scores of repliers for hidden anxiety.
- The least amount of hidden anxiety in repliers is 9 and the most amount is 32. The repliers' scores range from 0- 40 in case of both anxieties.
- The least amount of apparent anxiety in repliers is 8 and the most amount is 35.
- The total anxiety ranges from 0- 80 among the repliers such that the least amount is 18 and the most amount is 66.
- The mean of the total anxiety is 42.26 and the standard deviation is 10.824 among the repliers.

Table 4.38: The Statistics Related to Hidden, Apparent, and Total Anxiety in Kattle Questionnaire.

Scale	The Least	The Most	Mean	Standard Deviation
Hidden Anxiety	9	32	20.93	5.496
Apparent Anxiety	8	35	21.33	6.401
Total Anxiety	18	66	42.26	10.824

The raw score obtained from the total anxiety variable is acquired in terms of men and women's balanced scores in the table related to normalizing the total anxiety score. The balanced score of 0-3 belongs to people with no anxiety. Besides, the scores of 4-6 indicate the medium level of anxiety, scores 7-8 indicate the anxious neurotic, and scores 9-10 indicate the psychotherapist's neurotic temper.

8.3% of the repliers experienced no stress. Among the remained 91.7%, 34.2% had medium level of anxiety, 26.7% had neurotic anxiety, and 30.8% had anxiety needing a psychotherapist.

Table 3.5.39: The Frequency of the Balanced Scores of the Total Anxiety.

	Frequency	Frequency Percentage
With No Anxiety	10	8.3
With Medium Level of Anxiety	41	34.2
Neurotic Anxiety	32	26.7
Anxiety Needing a Psychotherapist	37	30.8
Total	120	100.0

RESULTS AND DISCUSSION

In the present research, factors such as demographic characteristics, depression, personality characteristics, self-efficacy, patient's satisfaction, positive and negative affection, anxiety, life quality, social support, and feedback among the patients suffering from MS in treatment adherence were considered.

Based on the research findings, the following results can be mentioned:

There is a relation between anxiety and treatment adherence and non-adherence among patients suffering from MS.

In order to analyze Kattle anxiety questionnaire data, analysis of variance was used which was considered from different aspects; the results showed that 21.33% of the patients suffered from apparent anxiety and 20.3% suffered from hidden anxiety. Among all the patients, 8.3% had no anxiety, 26.7% had neurotic anxiety, and 30.8% needed to visit a psychotherapist. This amount of anxiety was not significantly different from treatment adherence and its alpha was not significant; however, it proved the existence of anxiety among the patients. These results were in line with the findings of a study considering the prevalence of stress, anxiety, and depression frequency among the patients suffering from MS which reported the amount of anxiety among the patients to be 25.4% at a normal level, 55.4% at a medium level, and 19.2% at an intense level. Furthermore,

these results were in harmony with the findings by Basic *et al*. which reported this amount to be 3.19% among the patients suffering from MS. In the other studies which have used self-report scales of anxiety symptoms, the amount of anxiety prevalence among patients suffering from MS has been between 25-41% which is higher than the anxiety prevalence among normal population.

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