

*Original Article***Experiences of patients with multiple sclerosis from group counseling**

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**Abstract**

**BACKGROUND:** Group counseling is one of the most important methods in somatic and psychological rehabilitation of the multiple sclerosis (M.S.) patients. Knowing these patients' experiences, feelings, beliefs and emotion based on learning in group is necessary to indicate the importance of group discussion on quality of life of the patients. This study was done to achieve experiences of M.S. patients from group training.

**METHODS:** This was a qualitative study using phenomenological method. The samples were selected using purposeful sampling. Ten patients from M.S. society who had passed group training were included in the study. The group training was done through seven sessions weekly and voluntarily. The participants were interviewed using in-depth interview. The average time of each interview was between 30-50 minutes which has been recorded digitally and moved to a compact disc to transcribe and analysis.

**RESULTS:** The data analyzed using 7-step Colaizzi method. The data were transformed into 158 codes, 12 sub-concepts and 4 main concepts including emotional consequences, communication, quality of life and needs.

**CONCLUSIONS:** M.S can lead to multiple problems in patients such as somatic, behavioral, emotional and social disorders. Group psychotherapy is one of the methods which can decrease these problems and improve rehabilitation of the patients. Group discussion helps patients to overcome adverse feelings, behaviors and thoughts and guides them to move in a meaningful life. It also can improve quality of life and mental health of the patients.

**KEY WORDS:** Life experience, multiple sclerosis, group counseling, qualitative research.

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Pain and illness were always considered as one of the main health problems since human being life started and rehabilitation and taking care of sick or disable people were greatly taken into account since then. One of these weakening chronic diseases is multiple sclerosis (M.S.).

Multiple sclerosis (M.S.) is a chronic progressive and degenerative disease of central nervous system which creates small plague in patient's brains and spinal cord. Attacking nervous system, it involves different parts of the body.<sup>1</sup> Due to involvement of different parts of the central nervous system in people suffering

from M.S., it has several symptoms; therefore, multiple sclerosis is called "multiple faces".<sup>2</sup>

M.S. may infect all the races and socio-economical groups and it can be seen all around the world;<sup>3</sup> but the disease may spread more in some geographical areas. Frankel believes that its incidence is more than 150 and 50 in every 100,000 people in both North and South America respectively.<sup>4</sup> In 2004, it was announced by head of multiple sclerosis society that at least 30,000 patients were suffering from M.S. in Iran.<sup>5</sup> Moreover, a survey was done by Dr. Etemadifar et al at the same year and according to his findings, around 1014 patients have enrolled

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voluntarily in the multiple sclerosis center of Isfahan. Comparing the total population of Isfahan province, the number of them was almost 25 to 30 people in 100,000.<sup>6</sup>

Multiple sclerosis is among those weakening chronic diseases which include psychological dimensions. Generally, around 20-25% of the patients suffering from chronic diseases would experience all the symptoms of psychological problems. A wide range of psychiatric symptoms may be seen in patients with M.S. the most common in which is mood disorder (particularly depression). Depression makes disease disability worsen. In addition to mood disorder, all the diseases which cause damage myelin such as multiple sclerosis generates a wide range of heterogeneous psychiatric symptoms like psychosis, anxiety and cognitive problems.<sup>7</sup>

It is clear that a chronic disease may cause changes in roles, disability in performance of the roles, losing income, spending longer time to treat, decrease patient's activity and social functioning. All of the mentioned problems make patient to search for treatment and it may generate tension, stress and fatigue for him/her and all of them influence his/her psyche and spirit negatively.<sup>1</sup>

Each patient would definitely earn some experiences during the disease and treatment period that they may be valuable for the other patients. On the other hand, most of the patients behave in variety of ways and it is completely different from what physicians know or believe in.<sup>8</sup> Understanding the experiences is as important as expressing patients' experiences from different clinical activities which will help in developing the related knowledge. Regarding this case, Benner, Tanner and Chelsa pointed out that restating the life experiences and realities can be considered as the main axis (factor) to learn and develop clinical skills. Reminding these types of experience is much more valuable, lasting and practical than information that had not been experienced.<sup>9</sup>

In order to evaluate the patients' condition and the effect of applied treatment methods, their behavior and motivation must be recognized; so that their effects on patients' quality of

life and better interventions be done. Showing respect to patients' experiences would develop the science and create new ideas.<sup>1</sup> Niven (2002) believed that asking questions about people's direct and objective experiences is an important approach to know about their insight into reality of a person or phenomenon. He considered the acquired concepts of this method were more reliable than indirect methods.<sup>10</sup> In order to recognizing people's behavior, emotion, experience and all the available materials in their lives, researches preferred to use qualitative approach.<sup>11</sup> Among all of the qualitative methods, the descriptive phenomenological approach relying on depth of the experiences is useful in the research because it develops our understanding of life experiences.<sup>12</sup>

One of the important and helpful methods in physical and mental rehabilitation of M.S. patients is group counseling. it has some positive point such as sharing personal experience, depression and anxiety treatment, understanding affective aspects of the patients problem and discovering their adaptive mechanisms. Group counseling helps patients to overcome their feelings, annoying behaviors and thoughts and guides them toward a purposeful life.<sup>13</sup>

The objective of describing the experiences of patients with multiple sclerosis of group counseling, researcher hoped to depict and make tangible patients' experiences to recognize positive and negative points. Moreover, she wanted those who were in charges of mental health to improve the quality of care and rehabilitation of all the chronic diseases and support patients by promoting their information and skills in this field.

## Material and Method

This study aimed to evaluate the M.S. patients' experiences of group counseling that had qualitative and subjective nature and cannot be measured by quantitative methods. Therefore qualitative method was used.

The more the qualitative methods focus on human experiences and its meaning, the more it provides extended insights and deeper wisdom of human complex behavior for the researcher.<sup>14</sup>

Because the research meant to study people's experiences, the phenomenological method was used, which its aim was to understand the main structure of the human phenomena experience to analyze the oral descriptions of all the participants.<sup>15</sup>

The study population included all the patients with multiple sclerosis who referred to multiple sclerosis society of Isfahan in 2007. Inclusion criteria included membership in M.S. society, physical ability to participate in the group counseling sessions, and having motivation to interview, ability to express the feelings and ideas, being at the same cultural level.

The researcher started proposal sampling and continued until the saturation of the information i.e. not receiving any more new information.<sup>16</sup> Only the patients who had experienced group counseling (experienced phenomena) and were able to express their experiences verbally were chosen. Group counseling with cognitive-behavior approach was done for patients who voluntarily liked to attend (16 subjects) in seven sessions weekly which each session lasted for 1 hour or 1.5 hours. In order to get maximum variation, those who attended were from different age groups and duration of suffering. The total number of those who took part in the current research was 10. Because most of the volunteers were women, men did not attend regularly; therefore those who were chosen for interview were patients who were attending regularly in the sessions.

The most common method for collecting the data in qualitative approach is interview, observation and researcher's creative tools.<sup>17</sup> In order to collect data in-depth interview was used, and patients were interviewed about 20 days after the group counseling sessions for 3 months. All the patients consciously took part in the interviews. In addition, their personal information was confidential. The interview started with a general question about patients' experiences about group counseling and considering their possible answers, other questions were asked. For example, at the beginning of the interview the following questions were asked: what is your experience of group counseling? Or what

is his feeling like at the end? In order to encourage participants to continue and complete their speeches about their experience, probing approach was applied and they were questioned to explain more and express their feelings and ideas. For example, if the interviewee in answering of the first question said: the group counseling is good, she was asked how did she get? Or why those sessions were good? Each interview lasted for 20-30 minutes and all of which were recorded by a MP3 player. At the end, the researcher listened to the recorded files to check their quality, understandability and necessities. Then she wrote, codified and analyzed the interviews and made them ready for the next interviews. The seven-step Colaizzi method was used to analyze the data as the following:<sup>18</sup>

- 1- The researcher read all the important descriptions and findings of participants and tried to sympathize with them.
- 2- In order to extract some important sentences, the researcher found related words, phrases and sentences.
- 3- All the important extracted sentences were given clear meaning.
- 4- The participants' descriptions were reviewed and shared concepts were put in the related sections. In order to make them reliable, the researcher studied the main descriptions again. Having any possible differences, she disregarded those which were not related.
- 5- All of the inferred ideas were changed into complete and comprehensive descriptions.
- 6- The phenomenon was changed into a real description.
- 7- At last, in order to clarify the acquired ideas and make them reliable, she talked to the participants again.

Rigor of research: to guarantee the credibility which was confidence to the correctness of the data, after analyzing each interviews, the researcher talked to the participants again that made sure that all the data were correct and changed them if necessary.

Researchers tried to collect the data based on experience; it could approve the trustworthi-

ness of the data. In order to increase transferability of the findings to other groups or occasions, the participants were from different social-economical levels and disease condition. Moreover, most of the current research findings were proved in other similar researches.<sup>18</sup> All of the research steps were approved by the professor of school of Nursing and Midwifery and one of the experienced professors in qualitative researches field.

## Results

In order to reach the study objective, the researcher interviewed with 10 M.S. patients who took part in the group counseling sessions; their characteristics are shown in table 1. All the acquired data were analyzed according to suggested method of Colaizzi and 154 cods and 12 sub-concepts were obtained. All of them could be summarized in 4 main factors: mental outcome, communication, quality of life, and need. The results are shown in table 2.

*Mental outcome:* One of the emotional outcomes of taking part in counseling sessions, is the created changes in psycho-mental conditions and annoying feelings of disease which all of the participants focused on several times. Participant No 4 talked about her experience:

- ❖ "I often was impatient and I was not in a good mood to talk with other people. Talking part in the counseling sessions helped me to open up. I learned that the condition was somehow were illogical and not real."

In relation to reduction of anxiety and stress of M.S. patients, participants reported that theirs were clearly reduced. Regarding to this matter,

Participant No 4 said:

- ❖ "I was afraid of my future. I thought with myself if my disease get worse, I could not be pregnant anymore and my family does not pay attention to me anymore. But now I feel better and I can be pregnant too."

Being doubtful, confused and especially angry are mental reactions that all of patients had been experienced. Participant No 7 described her anger:

- ❖ "I am irritable and easily offended. It makes my friends angry. But using the suggested methods, I can control my anger greatly."

Another obtained concept of participants' experiences in the study is adaptation. Participant no 5 said:

- ❖ "No one knows about my disease except my parents. In order to keep it secret, I prefer not to meet the relatives or friends."

Group counseling helps patients to be informed and admit their diseases. Moreover, they can play active roles in the treatment. It can be clearly seen in ideas of participant No 3:

- ❖ When I learned about my disease, I became really sad and secluded. I quitted my job and I just thought about my disease while crying. But now I accept the situation and I am going to start to work again."

*Communication,* group counseling means to improve your connection with other people. Human is a social creature and is in need of communication with others. Multiple sclerosis and its outcomes will disturb people's life and especially their family relationship. Participant No 3 described her experience of group counseling as the following:

**Table 1.** Participations' characteristics

job	education	age	disease duration (year)	Marriage status	gender	No
retired	B.A	48	3	married	woman	1
homemaker	diploma	30	2	married	woman	2
employee	B.A	26	6 m	married	woman	3
employee	B.A	33	6	married	woman	4
student	diploma	21	1	single	woman	5
homemaker	diploma	34	8	married	woman	6
homemaker	diploma	36	14	married	woman	7
homemaker	B.A	27	2	single	woman	8
homemaker	diploma	32	5	single	woman	9
homemaker	diploma	31	3	married	woman	10

**Table 2.** Main concepts and Sub-concepts deductive of experience participants

Sub concept of third level	Sub concept of second level	Sub concept of first level	Main concepts
	depression		
fear	worry		
anxiety	angry		
treatment	hope	change	
Period of disease	Period of treatment		Mental outcome
	disease	adaption	
partner			
children	internal		
parents		family	
relative	external		communication
		social	
		spiritual	
	personal	activity	
	social	hobbies	
		sleep	quality of life
		Self-care	
		nutrition	
	group	awareness	
	personal		
In family	affective		need
Out of family	financial	supporting	

❖ “I did not have a friendly relationship with my family. Paying no attention to my disease, my parents agreed to my younger sister to get marry. But now I learn that I made a mistake and it showed I was selfish.”

Regarding the point, participant No 8 said:

❖ “Multiple sclerosis made me inactive and unsociable. I couldn’t communicate with others. Joining the group helped me to learn some communication skills.”

One of the important and effective factors in human life is spiritual dimension which affects mental health positively. About her experience, participant No 10 said:

❖ “I failed to do my religious duties before. But now I pray to God and it makes me relax.”

*Quality of life* is one of the main and important results of taking part in group counseling sessions. All of the participants mentioned it several times. Group sessions and empathy members with each other especially talking with the head of the group and his/her teaching make

all of the patients active and improve their quality of life. Regarding the point, participant No 1 said:

❖ “These kinds of sessions and discussions made stimulate the patient and made her active. I can do my social activities again; because I think my false thoughts made me limited more than my disease. But now I try to overcome them.”

Moreover participant No 10 said:

❖ “I did not like to go anywhere; I preferred to stay home being alone. I joined the group and I met some people. It helped me to improve my social communication.”

In all the groups, interactions and discussions patients learn to use experiences of others and taught techniques about their sleeping problem. They learned to control the problems without taking drugs and were safe from possible side effects of it. About this point, participant No 4 said:

❖ “I was insomniac and I used to sleep late. I

was anxious during the day. Applying the relaxation method taught in the group sessions, improved my sleep.”

*Need*, all of participants believed that group counseling was a kind of need. Need to gain knowledge leads patients to the way confront with their different needs and caused them always look for some approaches to solve their problems. Participant No 1 talked about some positive points of informing patients:

❖ “Information exchange and teaching in the sessions are helpful; at least they were good for me and I learned about the suitable confronting methods. Now I can overcome the possible problems better.”

Group sessions make empathy that it helps patients to share their ideas about problems and how to deal with them. Participant No 7 explained:

“Empathy in the group sessions helped us to be more energetic and made other people pay attention to us.”

## Discussion

Life is full of mental fluctuation. When the process of life changes and because of a chronic disease falls down, it definitely makes people confused and their function become disturbed. People adapt differently to the changes happened on their health.<sup>19</sup> Considering the participants’ ideas and results of other studies, it can be concluded that group counseling had many emotional outcomes. According to the results of the study done by Mokhtari (2005), group cognition-behavioral therapy would greatly reduce patients’ depression.<sup>20</sup> It approved the results of the current study which was in accordance with the mentioned study.

Multiple sclerosis like psychological disorders, not only involves patients’ understanding of themselves, but also makes the brain less active. The disease makes the patients worried about their future, ability to be economically and physically independent, and their ability to control a family.<sup>8</sup> One of the advantages of participating in group counseling sessions was that they could express their feelings and asked their questions. Most of the time, asking and answer-

ing the questions revealed some important information about members and help them to identify their feelings and how to confront with them. Then, they learned how to reduce their anxiety and to be calm.<sup>21</sup> Regarding the reduction of the anxiety and stress in M.S. patients, Barak (2000) conducted a study titled as “group gestalt therapy”. The results of this study showed that patients’ anxiety reduced significantly after eight sessions of group counseling.<sup>22</sup> In the present study, participants believed that their anxiety and mental stress have been greatly reduced.

Doubts, confusion and particularly anger are among mental reactions of the patients’ experiences. Anger is a common reaction to missing opportunities. It is really important to be able to know and understand the feelings.<sup>8</sup> Study results of Langenmayr and Scholttes (2000) showed that there was a meaningful correlation between friendly relationship and reduction of the anxiety.<sup>23</sup>

Hopelessness is one of the mental outcomes of the chronic disease. In multiple sclerosis, chronic period of disease, long-time treatment and physical disability make patients hopeless. But they thought that taking part in group counseling sessions would lead them towards hope. Hope has an important role in treatment process and group counseling sessions can provide them to reinforce primary worthies such as admission and trust to others. Patients would gain self-respect, self-esteem and self-confidence in group interactions; therefore they actively try to improve their health.<sup>13</sup>

Whenever someone comes to realize that he/she suffers from M.S. disease, he/she becomes exited and anxious. The patient families along with themselves try to keep the disease secret; so it makes them worried and prevents the patients to have close relationship with the relatives.<sup>24</sup> Group counseling helps patients makes themselves free from feelings such as ambiguity, confusion, pain, inefficiency and inferiority and learned how to live better and admit their physical and mental changes resulting from their disease.

Human is a social existent and is in need of communication with others. He/she exchanges feeling, attitudes and emotions through communication and provides his/her with psycho-physical needs.<sup>25</sup> Multiple sclerosis disease and its outcomes disturb patient's life especially his/her family relationship. Streak (2000) said M.S. often makes marital break in link especially if relationship between couples is weak. It can be considered as an excuse for all of the sexual, emotional and communication problems.<sup>26</sup> M.S. disease may impact children so that they think they are the main reason of disease or they may feel they are neglected.<sup>27</sup> The patients who participated in the current study believed group counseling meant "to communicate". It helped them to express/show their feelings/needs to their family members, how to moderate their expectations, how to pay attention to other family members' needs particularly children and in general how to behave in relation to other people to have a friendly relationship with them. In fact, in order to eliminate all the conflicts, well-adjusted interactions pattern were evaluated. Social relationship is one of the communicational aspects which is necessary to improve people's health. Therefore, patients with M.S. need to make themselves free from isolation. Because of their physical disability, patients will be reclusive but to keep their social security, it is necessary to learn how to communicate and make it into practice. With providing necessary qualifications for role playing, group counseling sessions help them how to communicate and it considerably affect their psycho-social performance.

One of the important factors in any person's life is spiritual dimension which affects their mental health positively. In fact, spirituality is a psycho quality. When someone meets emotional problems or a chronic and severe disease, with emphasizing the dimension and increase to pray, he/she will be hopeful and relaxed and enjoy his/her life. Participants in the current study believed that group counseling could reinforce their relationship with God. The sessions will clarify the role of God, pray in pa-

tients' life and it helps them to be well adjusted with their disease.

M.S. as an incurable disease affect patients' life negatively and decrease their quality of life.<sup>28</sup> Patients' problems limit their daily activities. Comparing healthy people, even those with mild kind of disease, have less daily activities.<sup>29</sup> According to the studies done on M.S. patients, most of them experienced some types of changes in their career and daily social activities as the results of symptoms and outcomes of the disease. Not only these symptoms and outcomes limit their activities, but also disturb their cooperation and affect different aspects of their quality of life.<sup>8</sup> Making empathy with the patients and each other and especially making empathy leader of group with them and his/her teachings during group counseling sessions make patients more active. They need to be guided by physicians, nurses and those who were involved. Overall understanding of the psycho-social outcomes created due to disease and progressing approaches to deal with them will improve M.S. patients' quality of life. Consequently the entire above mentioned are possible and practical through group interactions.

Patients with M.S. do not have strong desire to follow the things they love. It makes them inactive and they may be isolated.<sup>30</sup> Therefore, one of the ways to return patients to the social interactions, abandoning solitude and making motivation for following their hobbies is to participate in group interactions. Regarding this problem, group counseling can help them.

Sleeping is an important item in people's life and it is necessary for their growth and health.<sup>31</sup> Etemadifar (2004) declared: most of the patients with M.S. complain about insomnia or changing in their sleep pattern. They face with insomnia because of the secondary problems such as stress, anxiety, depression or being inactive.<sup>32</sup> During group interactions and discussions, patients learned to use other experience and new techniques to sleep. It will definitely keep them safe from side effects of the sleeping problems.

Multiple sclerosis affects all aspects of the patients' daily life negatively and changes their physical activities. Therefore they need to do

some activities which make them independent.<sup>33</sup> 10-15% of the patients suffer from intense physical disability and they must be taught to do the self-care.<sup>34</sup> Self-care means: being able to do primary personal activities without asking for help. Suitable self-care independent of others will improve the patients' psycho-mental health and it can be considered as an essential need.<sup>8</sup> Participants of this study emphasized on effects of group counseling sessions on self-care several times. Applying the self-care has positive effects on patients' quality of life, family, social interactions and economical condition. Training self-care can decrease progression problems as a result of disease, improve optimum life and help families learn how to solve their own problems.<sup>28</sup> All of the patients who participated in the study complained about their physical inability, but participating in group counseling sessions helped them to be independent as much as they can. Therefore forming some supportive and teaching groups will provide patients with self-care activities.

Today, there are lots of scientific evidences which show the important role of nutrition in improving the health of M.S. patients. For controlling, slowing down the progress and stopping the disease, nutritional changes are necessary. Although all of them are general advices and everyone should observe them, also there are some special emphasized techniques in patients with M.S.<sup>35</sup> Participating in group counseling sessions would help patients to be informed about it.

Need is a motivation which makes people do the activity. It is not only physical but also psychological matter. If need becomes intense, psychological conditions would become more intense and when it is satisfied, affective conditions would become more relaxed and peaceful. Need to gain knowledge refers to how someone uses her/his abilities and talents and it makes them to affect their own life directly.<sup>8</sup> In addition, need to gain knowledge will lead patients to learn how to react with different needs and makes them to look for appropriate solutions. From patients' experience, group counseling

was their important need and teaching in these sessions reduced their stress, fear and worry, and some tensions between patients and family members and also adapting patients with their own disease. Different studies revealed that all the patients need to have information about various issues such as psychological and psychiatry treatments, how to adapt with their life, supportive groups and etc. All of them can be provided with participating in the group counseling sessions. Essential needs of all the people are need to be loved and belong to a group; they need understanding and acceptance of others and feeling of belong to friends and community. Human is a social creature and needs to belong to a place or groups and be accepted by others. These patients thought it could not be met, and they felt they were alone.<sup>8</sup>

Need to be supported include all psychological, educational, financial and physical aspects i.e. to protect patients against available and possible injuries. Human being would live if he/she feels safe physically, psychologically, emotionally and economically.<sup>8</sup> One of the human's needs -which all of the participants mentioned- was emotional support; taking part in group counseling sessions which helped them to feel better and learned to share their experience with each other for increasing ability of problem solving. Kiessling, Weiss and Raudies (1990) showed that the M.S. patients need to be supported more so that they can cope with their chronic disease.<sup>36</sup>

Group counseling sessions can be greatly helpful; because patients learn how to encounter with their financial problems and make correct decisions about them. On the other hand, when the sessions are held in charities like MS society, it is not only a financial support but also reduces negative mental outcomes of the financial needs.

The obtained results of the current study and other studies <sup>20,23,28,37-40</sup> showed that group interventions had a positive role in depression, anxiety and stress reduction and it also helped patients to overcome their psycho-mental problems. Moreover, it made them more active in their treatment processing and learned how to

improve their independency, self-care, adaption and quality of life.

The study showed that single medicinal or pharmacological treatment is not that appropriate to control M.S. progress and eliminate patients' needs. In fact, pharmacological and non-pharmacological treatments such as psychotherapy and group counseling are necessary and complementary toward each other; because psychotherapy has very effective role in the patients' rehabilitation. Therefore the people who supported the patients can have an active role in this field too and provide them with group counseling sessions. Moreover, they can encourage patients and their families to attend there regularly.

Because one of the objectives of every study is presenting and applying its results and findings in order to promote community health level, the results of the current study can be used to prevent and treat physical and psychomental problems of the patients who were suf-

fering from chronic disease. In addition, all the findings of the present study can be used in all the levels of prevention to reduce some negative effects of this disease. Therefore, it is suggested in addition to use some of the usual or common ways of treating for patients with M.S., group counseling sessions added to it as a part of their program treatment.

### **Ethical considerations**

The following considerations done in order to observe ethical considerations:

Receiving letter of introduction from Research Manager of Isfahan University of Medical Sciences for his presentation to the research and to receive permission of group counseling and interview, introducing herself to the participants; explaining objectives of the study, data collection methods and receiving written testimonial consent form from the participants.

The authors declare no conflict of interest in this study.

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