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## Exposure experience of the families with MS patients to the disease: Struggle for admission of disease

Farzaneh Roshangaran<sup>1\*</sup> and Reza Masoudi<sup>2</sup>

<sup>1</sup>Master Student, Nursing Faculty, Isfahan (Khorasgan) Branch, Islamic Azad University, Isfahan, Iran

<sup>2</sup>Assistant Professor of Shahr-e-Kord University of Medical Sciences (SKUMS), Nursing Department, Rahmatieh, Shahr-e-kord, IR. Iran

Corresponding Email: [fa.roshangaran@khuif.ac.ir](mailto:fa.roshangaran@khuif.ac.ir)

### ABSTRACT

Multiple Sclerosis (MS) is a chronic and degenerative disease of the central nervous cells that upon onset of symptoms makes family faces with serious and disturbing challenges; so that experience of sudden exposure to MS leads to an unpleasant experience. The present study was conducted aims to explain exposure experiences of families with MS patients. This study was conducted by a descriptive phenomenology method in 2015. Sampling was done targeted to information saturation from 14 families of patients with MS admitted to Ayatollah Kashani Hospital. The method of the study was deep unstructured interviews. The findings from interviews were analyzed by the seven-step Colaizzi. 375 first level code, 13 second level code and 4 main concerns theme due to the unknown disease, permanent stress tolerance, confusion and family conflict and diagnosis bow were obtained from the explanations and experiences of participants including 14 people (10 women and 4 men) 19-55 years old with the education of fifth elementary to bachelor. The findings indicate that families have low awareness about the disease at early diagnosis and it leads to their severe stress and confusion about treatment, conflict, concern and family conflicts. It is hoped that findings of this research could play a leading role in the manner of families in time of exposure to the disease challenges.

**Keywords:** Multiple Sclerosis, exposure experience, phenomenology.

### INTRODUCTION

Multiple sclerosis or MS is a disease which is associated with progressive demyelination of central nervous system due to immune system problems that is one of the most common neurological disease in humans and of the most disabling disease at the young age [24]. According to the report of Multiple Sclerosis Society of America in 2014, this disease has infected more than 3.5 million people worldwide and 200 people are added every week [25]. 400 thousands people are diagnosed with MS in the United States [24]. According to the report of Multiple Sclerosis Society of Iran, around 40 thousands people were diagnosed with MS in the country and evidence indicate that the prevalence of this disease is 30 to 35% in Iran's population [5].

Care of patients with chronic diseases creates a lot of tension for the family of patient and often change the family dynamics. Undoubtedly, family as the most fundamental element of the society is responsible for providing suitable and proper health care for the patient and his entourage [1]. In the care of a patient, the family needs to have a true

understanding of the disease. The nurse needs to help the family of the patient to raise hope and trust in addition care of patient [7]. This approach leads to improve family health and welfare. However, reaction to this disease is different from a family to another as each family has their own unique way in life [4]. This disease makes permanent challenges for the family and causes energy depletion and impact on the speed of movement and activities of the family and is a costly disease in various aspects [33]. Increasing pressure on the caregivers has some consequences such as family isolation, disappointment of social supports, disruption of family relationship and insufficient care of patient that will be followed by drop the patient [43].

Today, the necessity of attention to the families of patients and considering their concerns and challenges is of great importance for optimal care of chronic patients [33]. On the other hand, much attention is not paid to the families in today health care systems and especially in the field of care in Iran and their care concerns is often neglected in their care planning. According to the above mentioned and conducted similar studies, we are going to describe how families with MS patients in Ayatollah Kashani Hospital of Isfahan in 2013, experience. It is obvious that explaining these experiences can help to do more effectively in formulation of holistic care plans which consider the patient's family and support and care patients beside the family [18]. Most important, treatment centers, hospitals caring MS patients, professional consultants, nurses and especially families of MS patients can benefit from the findings of this research [26,37].

## MATERIALS AND METHODS

### *1.2. Research question*

One of the approaches of qualitative studies is phenomenology. The aim of phenomenology is description of life experiences as they occurred [10].

In this study, researchers attempted to understand the experiences of families with MS patients with regard to this point, phenomenology is an appropriate method for this study.

The statistical population of this study is included all families with MS patients who are living in Isfahan during this study.

By referring to the health and treatment center of Ayatollah Kashani Hospital, the researcher explained a brief of study and research objectives to their physician and the physician transferred these explanations to the patients and their families and in case of acceptance, a written consent was taken to participate in the interview. The interview place was a quiet room in the MS clinic of the hospital by cooperation with the director of hospital and educational supervisor.

In this study, participants were selected based on objective sampling method with the conditions such as willingness to voluntarily participate in the study and interview, being a first-degree relative with the hospitalized patient and or having care experiences of MS patients and a definite diagnosis was done according to the medical records.

In this study, researcher has continued sampling until data saturation that means 14 families with MS patients who had the encountering experiences from the beginning of the disease and the interview process has been stopped by data saturation.

In this study, data were collected through deep open unstructured interviews. Participants' conversations were recorded by MP3 recorder and notes taken and typed word by word after the interview. Time of interview was between 30 to 90 minutes in average. The interview was started with a general question like "what is your experience when you found and the physician confirmed that one of your family member has multiple sclerosis?" And as interview continued, more specific questions were asked based on the outcome of initial interviews and main classes in the direction of research's objectives.

Seven-step Colaizzi method was also used to analyze data.

Seven-step Colaizzi method includes below seven steps:

- 1- Studying all talks between participants
- 2- Studying data accurately and extracting keywords by underlying method.
- 3- Evoke a concept from each important sentence which is called formulated concepts.

4-Organizing the developed concepts into broad categories or main topics.

5-Integration of results and making larger categories called a clear and comprehensive descriptive and developed theme of the studied phenomenon

6-Referring to each sample and asking about the findings

#### *4. Research findings*

The findings of the study were collected through deep unstructured interviews regarding "encountering experience of families with MS patients from 18/5/2015 to 21/7/2015 with 14 people who had MS patients in their families, in Ayatollah Kashani Hospital. 10 and 4 people of 14 participants were women and men, respectively. Their education is from primary fifth to the bachelor's degree and age range of participants was 19-55.

First, the researcher, asking a main question "explain your experiences since the beginning of dealing one of your family's member with MS", more questions were designed during the interview and according to the conditions and participant's explanations and or during word by word writing of explanations and listening to them.

The first stage of Colizzi: at the first stage, the recorded explanations of participants were listened for several times and written on the paper word by word and sufficient insight was created toward the interview. The results was considered accurately [6].

Second stage: at the second stage of Colizzi, we referred back to each explanations and important and related sentences to the phenomenon were studied and determined by underlying method in order to extract the significant information. The underlined sections are the most important phrases which seems to be extracted from these explanations [9].

Third stage: at the third stage of Colizzi, raw information were reviewed for several times to convert related and important concepts into abstract concepts and it was attempted to know how much these produced meanings are related to the primary phrases of participants [11]. This stage is introduced as formulating meanings. To do this stage according to Colizzi, the researcher tried to make concepts from the extracted meanings. In this stage, initial codes from the important related sentences to the discussed phenomenon which were been clear by underlying bottom were extracted [13,14]. For example:

Participant No. 1

First stage:

My aunt's daughter was single 4 years ago. My aunt was very involved in Maryam's disease. They did not let others know that her disease is MS. They did not like the others know about that. They were very frustrated and confused due to nobody had such disease before in the family and it was a shock for us..

Second stage:

My aunt's daughter was single 4 years ago. My aunt was very involved in Maryam's disease [1]. They did not let others know that her disease is MS. They did not like the others know about that [2]. They were very frustrated and confused [3] due to nobody had such disease before in the family [4] and it was a shock for us [5]

Third stage:

- 1- Involving family in MS disease
- 2- Hiding the sickness from the others
- 3- Being frustrated and confused
- 4- Not having the same position in the family
- 5- Being shocked from the disease

And so on, 376 initial codes were extracted from the interviews from the seven-step Colizzi analysis at the third stage. At the fourth stage, based on the mentioned method, the researcher integrated the initial codes based on the common points and placed in categories and topic clusters and so on, second level concept codes were obtained as well as 13 set concepts from these stages. For example in **table (1-1)**:

**Table (1-1), the example of level 1 to 2 level code**

Sub-category (level 1 code)	Category (level 2 code)
Avoiding pity and sympathy of strangers and relatives	Pity aversion
Not-paying attention to the patient's situation	
Hating the feeling of pity	
Being upset from compassion and other's help	
Recommending relatives to treat correctly without compassion and pity	
Deteriorating conditions of disease with sympathy and pity	
Being upset of special greeting with compassion	
Not-wanting help from others to prevent sympathy	
Not-indicating problems to avoid sympathy	
Toxic sympathy for patients	
Avoiding displaced caring of the patient	

Following this stage, the results of each case were considered and gathered as a comprehensive explanation of topics and larger categories were formed which are called theme. So that, topic categories were integrated for several times and formed larger categories. This stage is shown in **in table (1-2)**:

**Table (1-2) - categorizing level 2 codes and theme**

Category (level 2 code)	Theme
Pity aversion	
Insufficient knowledge	Concerning about unknown disease
poor social context	
Secrecy	
Reactions upon exposure	
Anxiety	
Feeling bad	Constant stress tolerance
Internal unrest	
Understanding the threat	
Family conflict	Confusion and involvement of families
The suddenness of exposure and disorganizing family	
Colorful diagnosis	Passing diagnosis shop
Multiple treatments	

## DISCUSSION AND CONCLUSION

5.1. What was mentioned on the previous section were the concepts which were obtained from the experiences of families with MS. Here, discussing the findings of recent researches by other researchers, will mention the final results of the research and discuss about them.

### 5.1.1. Concerning about unknown disease

According to the experiences of participants, one of the main obtained concepts in this study was concern about unknown condition of this disease that itself is included sub-concepts of pity aversion, inadequate knowledge, poor social context and secrecy. Concerning about unknown condition of disease was of experiences of participants at the first of diagnosis. They indicated that unawareness and lack of adequate knowledge of disease causes much stress in family and following that secrecy and what they did to hide this disease from others [15]. According to their explanations, poor social context and lack of enough support of such these families and patients lead to isolation of family and patients. Thus, lack of knowledge of disease causes problems and several challenges [37,41]. Participant number 1: (..we never like others know and we did not say any body. We did not want to make nobody happy or sad...).

Participant number 13: (..when I saw its symptoms, it seemed to be anemia, I did not take it too seriously, but when we know that it is not anemia by some laboratory tests, I was worried, we did not ever know what MS is to guess about that..).

Families with chronic patient were worried due to anxiety and fear of clinical condition future of their patient and lack of adequate knowledge and providing information will help their understanding of disease and the future changes [13].

Combined clinical, operational, cultural and behavioral methods of care aims to put the needs of patients and families based on their situation and relationship compassionately, causes reducing their pain and suffer [16,39].

Also, Michael 2012 in his study on the elderly people with MS showed that they tended nobody knows about their disease except their first-degree families and definite diagnosis of MS by the family is known as a big challenge [38,23].

#### 5.1.2. Constant stress tolerance

The second obtained theme from this study is the constant stress tolerance which is included the sun-concepts of restlessness at the time of diagnosis, anxiety, feeling bad, internal unrest and understanding the threat. Most of participants indicated that caring these patients will change the way of life and the family involves in this disease permanently. Stress of caring and future of disease and lack of definite treatment are the highlights and important points in the explanations of participants [42].

Participant number 5: (..first, I thought what if my sister becomes paralyzed like my aunt's daughter? Now that my aunt's daughter is passed away, I am worried about my sister. My mother has become sick because of my sister's disease, she cries and is really worried..).

Participant number 10: (..our spirits have become weak because of my sister's MS, we all fucked up, mother is very sad and I think we become annoyed more than the sister and are in a very bad situation and we really do not know what is happening..).

In Masoudi et al study in 2014 entitled care challenges of families with MS in caring patients which was a descriptive exploratory qualitative study, the results showed that one of the stress resources is multiple care, occupational and familial responsibilities that this complexity of their responsibilities causes distress and tolerating harsh conditions. Also, conflict and contradiction with MS patients is indicated as one of the special care challenges of care givers [34].

Buchmann 2010 also believes in psychological symptoms of MS disease and its cognitive disorders are associated with caregivers' distress [6].

Halper 2007 in his study believes in that the family caring a MS patient feels angrier and is more responsible for their patient as he is a member of them. So that this process will lead to heavier burden on them and wear them out [10].

#### 5.1.3. Confusion and conflict in the family

The third obtained theme is confusion and conflict of the family which is the sub-category concepts of family conflicts that composed of suddenness of exposure and family disorganization.

From the view point of the participants, at early diagnosis, families have been involved and confused because the lack of real understanding of disease, high costs of treatments, lowering family travels because of the patient were the issues which were indicated. A situation that they could not recognize good and bad for their patient and pass a difficult period to be able to cope with the disease [13].

Participant number 11: (..I have only one sister and I confabulated with her before the disease, but after that I knew she has MS I could not tell her much my words, I could not tell her about my problems to have her guide. I became alone when she was sick due to if I told her about my problems, she became upset too. I could not tell her much words. Sometimes I say God why sister among a lot of people??!!..).

Masoudi et al 2014 in his study about the challenges of family caregivers of MS patients found that its unstable nature and complicated conditions is one of the most effective challenges on the activities of caregivers and the family is affected [32].

In Sadat et al study in 2011 regarding phenomenological evaluation of familial and social relationships of patients with multiple sclerosis showed that when all family members are sick, those involved may not be able to participate in the activities previously enjoyed and it often changes dynamic and mobility of the family [38].

Also, MS patients often have low and very low monthly income. Disease has depleted the family's financial resources and creates economic problems (Godizloug et al, 2008).

#### 4. Diagnosis rainbow

Another participant' experiences was passing the diagnosis store which is included colorful diagnosis and several treatments. From the perspective of participants and their experiences, this disease cannot be diagnosed and or physicians misdiagnosed and following that wrong treatments were done that have no effects on disease improvement, so they changed their physicians and followed several treatments. Participant number 7: (.we received a call from my daughter's office, they told me that she was bad and transferred to the hospital. Her father and I went in a very bad mood. Doctor told us that our daughter had a stroke. We were very bad and worried. We changed her doctor. He said that her spinal fluid should be drawn up to determine what has been happened. My daughter was hospitalized in the hospital for 18 days..).

In the conducted study by Michael entitled a path to research, qualitative, personal management which includes elderly people with MS, denying and acceptance of disease was so that families did not believe their thoughts about accepting MS and they did not accept it [26].

### CONCLUSION

Come back a little bit. In this study, we evaluated the findings obtained from deep unstructured interviews aimed to indicate the experiences of families with MS patients. Findings of interviews were analyzed using seven-step Colaizzi method and results were discussed mentioning the findings of other researches.

At the end, it seems that confusion and involvement of the family with this disease and created challenges after infection with this disease is of the family concerns and also constant stress and its tolerance is very difficult due to this disease has no definite treatment and continuously causes family involvement in the treatment and stress of caring these patients. Also, families complained the public attitude and inappropriate social context, misplaced sympathy of people and inappropriate behavior of people and therefore do not tend to inform others about the disease of family member. Families experience stress in time of diagnosis as well as severe discomfort because of low awareness about this disease and continuously stresses that leads to reduced quality of family and patient's lives. Continuous concerns and anxieties about the uncertainty of the future of this disease is a major challenge for them.

It is hoped that the findings of this study can help health care personnel to make patients and their families ready to cope and adapt quickly with this issue and their greater efficiency in their care. Revision in educational programs of target groups and workshops about this disease for families can solve many problems in this regard. Economic needs are the associated problems with this study that is better for families to be covered by financial supports and introduced to different organizations to be supported.

Of the limitations of this study, it can be indicated that personal characteristics and intellectual pursuits of participants can affect on how they will respond. And at the end, conducting similar studies in this regard including evaluation of biological experiences of the families with MS patients from the disease adversity of the family member, experiences and vivid emotions, emotional exhaustion of the families with MS patients can enrich the literature in this context and helped to solve the facing challenges of involved families with MS disease.

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