

Explaining the Individual Challenges Experienced of Women Affected by Neuromyelitis Optica and Multiple Sclerosis: A Comparative Content Analysis Study

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Abstract

Introduction: Multiple Sclerosis (MS) and Neuro-Myelitis Optica spectrum disorder (NMOSD) are an autoimmune condition. Both of them have unexpected and acute relapses. The aim of this qualitative study was explaining the individual problems experienced of women affected by NMOSD and MS.

Method: Sixteen NMOSD patients and eighteen MS patients completed a face to face deep semi-structured interview. Participants were recruited from the MS ward in Sina hospital. After typed the interview, the data were analyzed using conventional content analysis, as recommended by Graneheim and Lundman (2005). Data analysis is managed with MAXQDA2018 software.

Results: In this study, a common theme for both disease groups was identified as "challenges arising from personal problems". The categories are named after each other and have many similarities, which in the NMOSD group include four categories including: "From uncertainty to the perception of threat", "Living with limitations", "Active coping until normalization" and "Facilitators of personal problems" appeared. In the group of patients with MS, five categories emerged: "perceived threat", living at a bottleneck, trying to deal with negative experiences, "facilitators of personal problems" and "problems related to physical rehabilitation".

Conclusion: This qualitative study showed that the individual problems of the two groups of NMOSD and MS patients are somewhat similar. Also in the present study, people with MS need longer-term rehabilitation care than people with NMOSD, which should be considered and examined, a need that was less seen in people with NMOSD. The unpredictability of attacks in NMOSD and MS can have a profound effect on the daily lives of these people. Therefore, educating patients and staff about how to manage life in such diseases can be an important help to improve patient's health.

Introduction

Autoimmune diseases such as multiple sclerosis (MS) and neuromyelitis optica spectrum disorder (NMOSD) [1] are chronic, inflammatory diseases of the central nervous system which usually affect young adults, and are a growing public health threat [2]. Tehran, the capital of Iran, is faced with an increasing incidence of MS and prevalence of MS and NMOSD [3, 4]. Cases of MS and NMOSD have been distinguished in all races, cultures, and regions. Although the sex distribution of MS and NMOSD is variable in different races and women are more affected than men, the female-to-male ratio is generally higher in NMOSD than in MS [2, 5], and they differ in the course and pathology of the disease [6]. The patients' experience of having chronic diseases is often hard to generalize to other diseases, and there is reason to accept that it can never be fully shared with other people [7]. However, by examining people's descriptions of the experience of morbidity, it is possible to gain a deeper understanding which can, in turn, be crucial for the provision of better care and nursing and enhancing the quality of care [8]. Research concerning the lived experience impacts on care provision and ongoing professional development in

nursing and treatment should not be underestimated when it comes to satisfying the needs of MS and NMOSD patients in daily life [9, 10].

MS and NMOSD considerably change people's everyday life and alter the power/capacity to meet the personal expectations of themselves and their care-givers [11]. People living with MS and NMOSD have a lower quality of life (QoL) than those living with other chronic diseases because the effect on daily life is greater in MS [12, 13]. Managing daily life can be difficult when unpredictability and lack of control are a part of the everyday life of patients living with MS [14]. Living with chronic diseases such as MS and NMOSD can involve giving up usual activities. Daily life difficulties, feeling sad and frustrated, denial of the diagnosis, fatigue, and not following or stopping treatment are common experiences these patients; however, little is known about the meaning of these experiences for women with MS and NMOSD [15, 16]. Therefore, this topic needs investigation for gaining a deeper insight into the provision of care and support of women with these conditions.

Since it is possible to study personal perspectives and experiences through qualitative research, the present qualitative study aimed to describe individual problems experienced by women who have MS and NMOSD for the first time in Iran. In this way, the experiences related to personal problems can be elucidated.

Methods

Study Design

This study was a qualitative study with the conventional content analysis approach, conducted in Sina Hospital (Tehran, Iran). Women with MS and women with NMOSD participated in this study.

Conventional content analysis is generally employed with a study design which aims to describe a phenomenon, in this case, the emotional reactions of in-patients. This type of design is usually appropriate when the existing theory or research literature on a phenomenon is limited [17].

Participants and Setting

The participants included women with NMOSD and MS who visited Sina Hospital (tertiary care referral center in Tehran, Iran) and were selected by purposive sampling. All the patients were interviewed at the MS/NMOSD clinic. The interviews were conducted by people who had received sufficient training in this field and were scientifically and practically competent. Each interview lasted 35 to 65 minutes. The inclusion criteria were: 1) being older than 18 years, 2) being literate, 3) having NMOSD/MS for more than a year, 4) speaking Persian, 5) and having received a definite clinical diagnosis of MS)based on 2017 McDonald criteria([18] or NMOSD [19]. The exclusion criteria were 1) the presence of limb fracture, 2) head injury and surgery at the time of research, or 3) pregnancy. The sample size in the qualitative study was not known before the study, and we continued the research until reaching data saturation. Finally, 18 MS patients and 16 NMOSD patients were included.

Data Collection and Interviews

This study was conducted from May 2020 to December 2020, and the data were collected using in-depth, semi-structured, face-to-face interviews by a trained interviewer. The interview analyses were continued until data saturation, which meant that no new piece of data was obtained from the interviews, and no new category or subtheme emerged.

Initially, the researchers explained the purpose of the research to the participants over the phone, and invited them to participate in the study during the patients' visits to Sina Hospital for receiving care and treatment. The participants visited the hospital in-person and were interviewed face-to-face in a private room.

Instruments for data collection:

The scheduled interviews comprised open-ended, nondirective questions and included main and follow-up questions [20, 21]. Examples of the main questions are given below: (please see appendix1)

- 1) How did you feel when you found out that you have been diagnosed with MS/NMOSD?
- 2) What changed in your life with MS/NMOSD?
- 3) What pleasant/unpleasant experience of treatment do you have with MS/NMOSD?
- 4) What experience of physical problems do you have with MS/NMOSD?

The processes of reflecting and probing were adopted to ensure that each participant directed the content of her interview. The sequence of questions for each interview was unique and depended on the interview process. The interviews were record, transcribed verbatim, and then coded to extract the themes. Based on the research needs, observations were also made by the researcher (SA), and were considered in the analysis of the transcripts.

Data Analysis

MAXQDA2018 software was used to manage the data collected in this qualitative study. Conventional content analysis and the inventory of Graneheim and Lundman (2005) were used for data analysis by the expert author (MS). According to this method, first, each typed manuscript was read and reviewed several times. The data (sentences) were broken down into meaningful segments and received a conceptual label (codes). The codes that were semantically similar were grouped into a category. The interviews were analyzed concurrently. The extracted codes and categories were compared constantly with other interviews. Finally, themes emerged to describe the aim of this study.

Results

The mean age (SD) of the participants was 39.13 ± 11.14 years in the NMOSD group and 44.83 ± 8.76 years in the MS group. Most of the women in both groups were married, and half of the women in both groups lived in Tehran. The majority of the patients had a bachelor's degree in the NMOSD group and a high-school diploma in the MS group. The mean (SD) duration of NMOSD was 8 ± 3.98 years and the mean duration of MS was 9.55 ± 5.11 years. Table 1 lists all the characteristics of the two groups.

A common theme for both groups was the "challenges of personal problems". The categories were named after each other and had many similarities. The categories belonging to the NMOSD group were grouped under four categories: "from uncertainty to the perception of threat", "living with limitations", "active coping until normalization", and "facilitators of personal problems". In patients with MS, five categories emerged: "perceived threat", "living at a bottleneck", "trying to cope with negative experiences", "facilitators of personal problems", and "problems related to physical rehabilitation" (Table 2).

The first category in the NMOSD group and MS group was, respectively, "from uncertainty to the perception of threat" and "perceived threat". The majority of NMOSD patients stated that they had suffered a lot before being diagnosed with the disease, and had experienced many problems due to lack of diagnosis:

"Both my doctor and my family thought I had a mental illness and could not believe my eye problems and pain. I even went to a psychologist and, because of my late diagnosis, my illness progressed." (NMOSD patient #2)

Most NMOSD patients were happy with the diagnosis. However, MS patients talked less about the complexity of diagnosing the disease and more about the fatigue caused by the disease before diagnosis. These people usually lived in remote cities that did not have access to magnetic resonance imaging (MRI). Most of the MS patients experienced a gradual onset and continuous progression of signs and symptoms without any recurrence:

"I had MS for a while and I didn't know it. The first time I went to the doctor, I told him the problems I had. He said, 'You only have a stomach problem.' Our city did not have MRI equipment, or a good doctor. First I got weaker. I went to Kermanshah [the center of Kermanshah Province]. The first doctor I visited ordered an MRI. Then, he said, 'You have MS.'" (MS patient #7)

The sub-category of "emotional reactions" was common to both groups and included crying, sadness, grief, and anger. The sub-category "feeling threatened by individual and social life" was also common to both groups:

"I was worried I might not be able to get married because of MS." (MS patient #8)

"Living with limitations" and "Living at a bottleneck" were two similar categories in NMOSD and MS patients, but had slightly different sub-categories. In NMOSD and MS patients, social and economic constraints included exposure to harassment from others, isolation, changes in work and education, and the financial pressures of the treatment. Examples are given below.

Drug-related problems in NMOSD and MS patients included a shortage of medicine and the high price of medicine. One of the patients said:

"Our medicine is very expensive. I spent about 9 million rials on one medication, and this put me under financial pressure." (MS patient, #7)

Limited physical health in NMOSD was another sub-category that included items such as feelings of overwork and fluctuating dependence on others; reduced housework, leisure, and activity; quitting sports; and reduced sex.

"I am not as active as I used to be, and I go out less. I don't go to the gym because I may fall down. When I'm entertaining a guest and because my hand goes numb, I spill hot tea and burn my hand..." (NMOSD patient #14)

Annoying cognitive disorders was another sub-category. Many patients with MS and NMOSD reported cognitive impairment. Similar to NMOSD patients, MS patients suffered from memory impairment:

"Sometimes I forget that I have to go to work in the morning, and they remind me." (MS patient #15)

NMOSD and MS patients also faced family problems:

"When my husband found out that I was sick, he said that the cost of treatment and medicine was high and that he couldn't pay it, and so we got divorced." (NMOSD patient #16)

Another category was "from active coping until normalization", which emerged in the NMOSD group. There were similarities and differences between the two groups in the subgroups described below.

Awareness seeking was common between the two groups. The NMOSD patients had no knowledge of their disease when they heard the word NMOSD, and some called it pseudo-MS. With the help of Internet searches and asking doctors and nurses, they managed to obtain more information. Patients with MS, like patients in the NMOSD group, sought information and even used the radio and television to complete their information.

"As soon as the doctor said that I have NMOSD, I began searching the Internet to see what the disease was, what made it better, and what made it worse." (NMOSD patient, #3)

Motivational promoters were another sub-category in both groups. Patients tried to motivate themselves by considering worse conditions and by paying attention to motivation enhancers.

People tried not to lose hope in various ways and sought to find motivation to continue living. Some had tried to give themselves hope and motivation by continuing to exercise, learn more, compare themselves to unsuccessful cases, or successful role models and improved patients.

"I felt hopeful to see that people who used to sit in wheelchairs could now walk. I thought they could never walk after the attack." (MS patient #8)

Participants protected themselves by seeing a doctor, by avoiding stress, negative thoughts and people, and having more rest. The following codes emerged: "self-preservation" sub-category in NMOSD patients, but "self-care" in MS patients. Loss of energy and fatigue made MS patients learn energy conservation techniques, so codes such as activity planning, lifestyle changes (elimination of bad habits, improvement of eating patterns), adaptation of the environment, and exercise resulted in the self-care subcategory.

"I had a lot of wrong habits; I quite everything to keep my energy and stay healthy. For example, I stopped taking a shower with hot water or did many exercises to improve my physical condition." (MS patient, #7)

Normalization was another sub-category. The participants talked about being indifferent to the disease, getting used to the pain, normalizing, understanding the disease, not taking the disease seriously, not having negative thoughts, and equating themselves with healthy people. However, MS patient tried to gain self-confidence and preserve their independence. Hence, "do not give up" emerged from the codes.

"I tried to increase my self-confidence by ignoring my disabilities and paying attention to my abilities, so that I would not get lost." (MS patient, #4)

"I no longer feel sick at all; I got used to it. I even take care of my leg." (NMOSD patient, #5)

Spirituality was in common between the two groups. The majority of participants found a deeper connection to God following the illness. Prayer, trust, and appealing to the Imams (saints) were the themes that formed the sub-category of spirituality.

"At first, it was as if something had happened to me. I was constantly praying, and I didn't even listen to music." (NMOSD patient, #12)

"Trying medical supplements" and "using any method for recovery" were two sub-categories that were similar for NMOSD and MS patients. The only difference was that patients with MS used more methods to improve their body, e.g., turning to traditional medicine, acupuncture, and bee therapy.

"My husband took me to a friend, and he said that if I tried bee treatment, I'd feel better. But it didn't work at all." (MS patient, code 9)

The category "facilitators of personal problems" emerged in both groups of patients. In the NMOSD group, this category included personal conditions (i.e., marriage, family support, beliefs) and support from others. In the group of MS patients, it included personal conditions, support from others, and access to high-quality medical services. Support from others meant support from people other than the family. Donations from charities, colleagues, friends, and distant relatives were among the contributions mentioned by the participants.

The sub-category of "benefiting from high-quality medical services" in people with MS emerged due to the frequent use of occupational therapy and physiotherapy services by most of these patients.

"My husband helps me a lot, and he is the only one who can calm me down – after God, of course." (MS patient, #17)

Finally, the sub-category of "rehabilitation-related problems" existed only in the group of MS patients and included a) lack of community support for rehabilitation, b) the complex nature of the disease (i.e., recurrent disease, time-consuming diagnosis, young age, and chronicity), and c) lack of information (i.e., family and patient's poor and incomplete information about care, insufficient information about the disease, and inadequate community views.)

It seems that the reason for the existence of this category only for this group of patients is the large number of disabled people, the community's little information about disability, and lack of equipment for the disabled, lack of government support for patients in accessing care services, absence of insurance services, and unsafe streets.

"There is no one to follow me up and check why I couldn't come for treatment. Also, MS treatment centers are small and far away." (MS patient, #8)

Discussion

A comparison of personal problems experienced by NMOSD and MS patients showed some similar sub-categories and categories. In the NMOSD group, these includes four categories of "living with limitations", "active coping until normalization" and "facilitators of personal problems". In the patients with MS, five categories emerged: "perceived threat", "living at a bottleneck", "trying to cope with negative experiences", "facilitators of personal problems", and "problems related to physical rehabilitation".

"From uncertainty to perceived threat" was one of the categories in the NMOSD group, which was similar to the "perceived threat" category in MS patients. The only major difference was the pre-diagnosis uncertainty reported by NMOSD patients, which was reported by some MS patients living in remote cities without facilities; therefore, such late diagnosis codes belonged to the category of physical rehabilitation inhibitors. Moghadasi stated that the diagnosis of NMOSD is important but difficult. If the diagnosis is wrong, it can even be life-threatening [22], which could be because of no proper attention paid to NMOSD.

In our study, "perceived threat" emerged as a category in MS patients. The perceived threat category in the study by Ghaffari et al. on patients with MS is similar to the present study, except that, in the mentioned study, the participants were not just patients but also families and healthcare providers. In addition to the sub-category of the present study, they also reported a sub-category of understanding the consequences of ignorance, including negative feelings and ambiguity about the future [23].

After diagnosis, people with MS and NMOSD described a continuous struggle to maintain an everyday life which, despite their illness, would look like their normal life. The NMOSD and MS patients had

emotional reactions such as feeling negative, anxiety, depression, and aggression. Sung Shin et al. found that MS and NMOSD patients had emotional problems. MS patients had depression, anxiety, aggression, paranoia, interpersonal sensitivity, self-regulation problems, stress vulnerability, and poor QoL compared with NMOSD patients, but NMOSD patients were more hopeless [24].

"Living at a bottleneck" was another category that emerged in the patients with MS, and, with a little of difference, "living with limitations" emerged in the patients with NMOSD. In NMOSD patients, this category included social and economic constraints, drug-related problems, limited physical health, cognitive impairment, and exposure to family trauma. These themes were similar to those reported by Huang et al., who concluded that the disease affects various aspects of the QoL, including physical, emotional, psychological, economic, and social aspects [25].

A qualitative study was conducted Mutch et al. on the experiences of people with NMOSD, and the theme of diagnosis and treatment was similar to some sub-categories of the present study [15]. In the study by Mutch et al., the theme of "the effect of symptoms on daily life" was similar to "limited physical health", "cognitive impairment" such as memory impairment, and "drug-related problems" such as side effects emerging in the present study [15].

There were also bottlenecks in the lives of patients with MS. The sub-categories included social and economic constraints, drug-related problems, from physical limitations to loss of independence, cognitive impairment, and family trauma. The category of "living at a bottleneck" was similar to the category of "decline in the totality of one's existence". Its sub-categories were also similar to the sub-categories of disability and physical limitation, tolerance of annoying cognitive disorders, family trauma, and social isolation in the qualitative study by Ghaffari et al. on MS patients [23].

"From active coping until normalization" emerged in the NMOSD group, with the sub-categories of awareness, motivating factors, self-preservation, normalization, spirituality, and trying medical supplements. The equivalent of this category in the MS group was "trying to deal with negative experiences" which included sub-categories of awareness-seeking, attention to motivators, self-care, non-surrender, spirituality, and the use of any means of healing. A study by Shaygannejad et al. which evaluated coping strategies adopted by NMOSD and MS patients showed that both groups used similar coping strategies [26]. A qualitative study by Mutch et al. on the experiences of people with NMOSDs also revealed that people with NMOSD lacked knowledge. Participants could not plan due to disease recurrence [15]. The sub-categories of the study by Ghaffari et al. included searching for information about MS and treatment, hopefulness, spirituality, and the ability to learn about MS, which were similar to the present study [23]. Patients with MS and NMOSD expressed feelings of not being listened to and fighting against the illness alone. The search for information and knowledge about the illness were described as crucial, due to patients' regarding knowledge as a way to maintain control [27, 28].

The category "facilitators of personal problems" was present in both groups of patients. In the NMOSD group, this category included personal conditions (marriage, family support, beliefs), and support from others. In the MS patients, it included personal conditions, support from others, and access to high-quality

medical services. The emergence of the sub-category of benefiting from high-quality medical services in people with MS was due to the frequent use of occupational therapy and physiotherapy services by most of these patients.

Two themes in the study by Mutch et al. were support and identity. They showed that good family support is highly effective in helping the patients cope and improve their mood [15]. The code in the identity theme also included beliefs similar to the personal conditions sub-category in the present study.

Finally, the sub-category of "rehabilitation-related problems" existed only in the MS group and included a lack of community support for rehabilitation, the complex nature of the disease, and a lack of information. This sub-category was similar to the "healthcare services" category in the qualitative study by Galushko et al. on MS patients. Sub-categories such as information and access to similar care services existed under the categories of this study [29].

Conclusion

This qualitative study showed that the personal problems of two groups of NMOSD and MS patients are somewhat similar. The patients with MS need longer-term rehabilitation care than do people with NMOSD, which should be considered and examined. The unpredictability of attacks in NMOSD and MS can exert a profound effect on the daily lives of these people. Therefore, educating patients and staff about how to manage life and improve the QoL in such diseases can be an important step to enhancing patient's health.

One of the limitations of this study was that NMOSD is a rare disease, and there was no sample selection in this study; therefore, the diversity of the sample in this group of patients was not discussed. It is recommended that a similar study be conducted on men to compare sex differences.

Abbreviations

MS: Multiple Sclerosis; NMOSD: Neuro-Myelitis Optica spectrum disorder; MRI: Magnetic Resonance Imaging.

Declarations

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Authors' contributions

The design of this sub study was done by MSh/ShE. MSh created the analysis plan, in close correspondence with ShE /SA. The interpretation was done by all authors. The manuscript was drafted by

NM/MSh. All authors read, critically reviewed and approved the final manuscript.

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Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Ethics approval and consent to participate

The research is ethically reviewed and approved by the MS Research Center Research Ethics Council, but since the MS Research Center belongs to TUMS, the ethics committee of TUMS re-examined and revised the codes of ethics and finally, ethics approval with a number of IR.TUMS.NI.REC.1399.012 was obtained from TUMS. The Declaration of Helsinki Ethical is considered in our work. Before conducting the interviews, all patients were informed that participation in this study is voluntary and they could refuse to participate or withdraw from the study at any time for any reason. Also, they were persuaded that their identities and responses will be kept confidential. From patients who agreed to participate in this research were requested to sign an informed consent form.

Consent for publication

not applicable to this study.

Conflict of interest

The authors declare that they have no competing interests.

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Tables

Due to technical limitations, table 1,2 is only available as a download in the Supplemental Files section.

Supplementary Files

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- [semistructureinterview.docx](#)
- [Table1.jpg](#)
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