

Experiences of Iranian Multiple Sclerosis patients' and their caregivers' regarding care and treatment outcomes

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Abstract

Introduction: Outcomes of care, treatment and management of people with MS have a high priority in health care, today. The purpose of this qualitative study was to explore the experiences of care and treatment's challenges of MS diseases.

Materials & Methods: Qualitative approach, based on a thematic analysis, was used to achieve the aims of the study. Information collected simultaneously through in-depth unstructured interviews with 31 patients, nurses, and family caregivers from Ahvaz in Iran.

Results: Two major themes were extracted from the analysis of the transcripts: "Comprehensive caring commitment" and "Patients' medication grudge".

Conclusion: According to the findings, the nurses are in a unique position to care for people with MS; therefore they should be ready to provide high-quality patient care in MS patients. Patients must be encouraged to study about their condition and medications to know the specific details of their health care coverage.

Keywords: Care, Cure, Outcome, Multiple Sclerosis, Qualitative Study.

Introduction

Multiple sclerosis (MS) is a chronic, inflammatory, degenerative, and demyelination of the central nervous system that is often disabling and axonal degeneration. It is characterized by a gradual loss of nerve function. MS significantly affected the lives of patients and their families (1, 2). There are estimated that; 400,000 patients are living with MS, in the United States, and about 2 million, worldwide. Majority of diagnosed patients with MS, are 20 to 50 years old, although MS may occur in young people, as well as the old people (3).

Outcomes of the care, control, and management of people with MS have a high priority in health care (2). In addition, a better impression and acceptance of the symptomatic care- as a leitmotif- emerged throughout the MS patients' community and MS care professionals. The complicated and lifelong problematic nature of MS requires knowledge, skills, and direct services of health care professionals, as well as neurologists (1).

Nurses often are in a key position to engage patients and their families, so they may be uncertain of the roles, responsibilities, and skills required to provide effective services

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and manage medications to help people with MS (4). According to the information and support given to the nurse, MS Care can be viewed as either the most difficult or rewarding for those entering this specialty.(5) Universal responsibilities of nursing care are creating a therapeutic partnership, comprehensive care coordination, implementing a treatment plan and evaluating the results. Specific requirements in MS nursing care include full awareness of the disease and its physical, functional, and neurological disabilities.

Other requirements include promoting self-care and empowerment for the patients and their families, as well as the ability to advocate for treatments, programs, and services needed by the people and families affected by MS (6).

In the late 20th and early 21st centuries, we have met a promotion in MS care and treatment, excessive using of medication, and a new recognition of the role of MS nurse and others who provide nursing services (3). People with MS, a disease without a specific cause or treatment, look for any medical treatment that may help them. It is important to note that the symptoms of MS are various and may occur in almost any combination and vary widely among individuals.

These complications are managed with both rehabilitation strategies and a range of pharmacologic agents (7). New drug treatment that can change the course of the disease in an uncertain way of certainty have given options to people with MS and their families to manage the disease, however, MS remains incurable. This disease and its complications has no boundaries (8). MS symptoms and its complications are clearly different in each person and may change over

time. Patients experience its variability on a day-to-day basis and have difficulty living with uncertainty. In addition, the effectiveness of the modifying medications for everyone has not proved, yet. Therefore, to argue the financial advantage of expensive medications and interventions in the short run to avoid high costs in the long run can be problematic(9). It's especially important for medications that have either a depressant or stimulant effect on the CNS. Additionally, some medications are used to manage more than one symptom. It is important to note that many, even most, of the medications used to manage MS complications, were first developed for use in other conditions or for the same symptoms in people without MS. As a result, these medications are often used on an off-label basis as exact complex side effect to patients; therefore, they do not have tendency to continue taking this medication (10).

What is clear is that some of the standard medications are not effective because the source of complication is not typical. Also, some of them have negative side effects that led to exacerbation of the disease symptoms (11).

On the other hand, symptomatic pharmacologic interventions do not attempt to modify the course of the underlying disease but to improve one or more manifestations of MS. A study of 4-aminopyridine found no effects on complications among patients with MS. Other agents that have not been shown to benefit cognitive function and other symptoms in MS actually produced reversible worsening (12). Therefore as in any long-term research, the dropout rate was high in the long-term medication prospective follow-up assuming that these patients have had poor outcomes

and therefore switching or discontinuing therapies(13). On the other hand, adherence to the drugs is associated and directly linked to effective long-term therapy.

Adherence is mainly affected by lack of efficacy, efficiency, and adverse effects. Studies of patients treated with MS' drugs demonstrated that 22–51% have stopped treatment because of adverse effects (14). Adverse events and unrealistic expectations of patient's should be anticipated and managed with nursing support and education (15). So, treating a chronic illness such as MS is an art more than medicine and the ultimate goal is treating and managing the disease while optimizing quality of life and hope to find a way to treat MS.

Although most have some form of insurance coverage, most are underinsured and their policies are inadequate to meet the varied and specialized health care requirement in the MS disease(16). It is often perseverance alone that will make a difference in whether a specific therapy or intervention is covered. It is well highlighted that filing appeals and grievances is effective in reversing denials. But people with MS and families are tired and discouraged. It is often the nurse who can encourage people with MS not to take "no" for an answer and to pursue all of their options and opportunities for reconsideration (3).

According to the fact that there is no definite cure for the disease, so there should be an emphasis on health care as the key for difficulties. This study aims to understanding the challenges of patient adherence to medication and nursing care that provide appropriate care for patients. Care experience provides the necessary assistance to improve the quality and value of better care for these

patients by health care providers in the cultural context of Ahvaz.

Materials and Methods

This study is part of the doctoral dissertation that was approved by Ahvaz Jundishapur University of Medical Sciences. This study was conducted with qualitative approach and descriptive explorative method, which aimed to explore the challenges of caring for Iranian MS Patients.

A thematic analysis approach was used.

The study was conducted between February 2012 and March 2013 in Ahvaz, Iran. Participants in the study included 31 nurses, patients, families and caregivers who were purposefully selected. The exploratory research design is a commonly used and well recognized approach to qualitative studies, when there is no enough information about a particular phenomenon (17).

Data collection method in this study was in-depth unstructured interviews and observations. In the purposeful sampling, the interviews were in Persian, and started by asking the core question: "Please tell me about caring problem and challenges?" To enrich the information, Probing questions would be asked based upon the participants answer.

All interviews were conducted in a private and relaxed environment. According to participants' physical and psychological endurance, all interviews were recorded by a digital MP3 and the time varied from 45 to 100 minutes. In order to precise data collection, in addition to recording the interviews, field note taking was used.

Data were thematically analyzed to identify patterns within the text (17). Data collection and analysis were done concurrently and

began after the first interview. The interviews were transcribed in Persian language and were analyzed by the first author. By using data collection and constant analytic comparison, the researcher will be able to ask more probing questions in subsequent interviews (18, 19). First, the transcripts compared to the MP3 recordings to make sure that the words were correctly recorded. Subsequently, the transcripts were coded separately. After that, the emerged codes compared to the previous codes, using constant comparative analysis to examine the similarities and differences (20). Finally, after conducting 31 interviews, the codes' list were merged and the study's themes were saturated.

In order to ensure the accuracy of collected data, multisource data collection method (interviews, observation notes and the behavior of participants in clinical settings) was used. The transcripts of the interviews and field notes were read several times by the researchers to gain a deeper understanding of the data collected.

In addition, the second and third Authors Listened to the recorded audio files and read the written transcripts of each one and analyzed them (21-23). After the constant comparative analysis, almost two months after the first interview, member checking was done to provide time for in-depth analysis of the transcripts. Each of the participants was contacted to come to the MS Society of Ahvaz to read and clarify the interpretations of the transcripts; some cases of disagreement were discussed and appropriate corrections were applied. During the sampling process, the maximum diversities were guaranteed. Moreover, reflective memos were used to enhance the Audit Trial (24). Data collection

process over a long period of time, more than 13 months, helped to have more diversities.

Ethical considerations

After the University Ethics Committee's approval (code of Ethics: ETH-553), participants were informed about the purpose of the research, as well as the data collecting procedures in order to ensure privacy. Participants were assured that taking part in the study is voluntary, and they can cancel proceeding at any time. The location of the interviews was determined to be in a quiet place with privacy and comfort. Before the interview, participants declared their approval via signing a written consent.

Results

Interviews were taken from 31 participants; (average age of care providers was 32 years, range, 20-50 years and for patients was 28 years, with of range, 20-43).

In the first stage, over 1,374 first level codes extracted. After the classification and integration, eight categories were acquired.

Finally, two themes were extracted. The themes were: "commitment to comprehensive care" and "patient medication grudge" (Table1).

The most prevalent demand of these MS patients was comprehensive caring commitment. MS patients expect compassionate support to overcome the treatment complications. Commitment to comprehensive care as one of the major challenges has a favorable effect on nursing care. MS nursing care requires real commitment, to improve the quality of care for patients with MS and other services and treatment goals are crucial to success. The dissemination of care, regardless of treatment

challenges, such as patients' medication grudge, through the nursing program can often have a major negative impact on the person with MS and her/his family. This theme consists of the four categories including: Caring Presence, Education accompanied with evaluation, Responsibility, and Careful examination of the patients' needs.

Careful review of the patient's needs

Patients expressed satisfaction when healthcare staff reviewed and examined their cases in a committed manner:

"...the lady, the senior nursing officer...comes and examines me from head to toe every morning and assesses the slightest changes in my body and the pain I have. This is really important for me and I feel relieved that they have everything under control..." (Patient 8)

Responsibility

Comprehensive understanding of the physical and mental situation of the patients during the treatment process is essential. One of the caregivers said:

"... She really is a very sensitive and delicate person and has a sensitive character. We are keeping an eye on her physical problems while spiritually; we're always by her side and make her hopeful..." (Caregiver 4)

A patient also believed:

"...When they pay attention to our psychological problems as much as our physical problems and listen to our complaints, our problems would be less ..." (Patient 11)

Education with assessments

Patients expressed satisfaction with the measures taken by health care staff. They were accompanied by evaluation and asked for the consistency of such measures:

"...Some of them do their job and go away, while some follow up what they've done to

examine the consequences and ask whether the problem is solved or not..." (Patient 8)

A nurse believed:

"...I injected him a pain killer. After half an hour, I checked on him to see what he was doing. He was delighted and said that his pain was much better. He asked me, if he can message the part of his body. I requested him to massage gently. They tell you the results of anything you do for them and ask you what to do next..." (Nurse 2)

Caring Presence

Patients feel calm and relaxed, while seeing nurses at their bedsides when they encounter a problem.

"... They generally love seeing you by their side. They don't want to think you've left them alone. The moment I stand by his side and speak to him, he gets really relax..." (Caregiver 2)

A fellow nurse said:

"... It was the first time that she was receiving pulse therapy. She rang the bell half an hour after I had connected her IV bag and said: Sister! My body is on fire. Please, don't go away.. When you're not here, I feel something bad might happen..." (Nurse 2)

A patient talks about the moment of saying goodbye to family and the difficulty of being left alone in the hospital:

"... It was extremely difficult for me to find myself in the hospital gown, while my family left me alone, there..." (Patient 4)

"... At times my family would leave me at the hospital and go and I saw myself in the hospital gown, it was extremely difficult..." (Patient 4)

Another factor mentioned by the participants, which was introduced as a challenge in caring was Patients mistrust of

medication and treatment plan. The “patient’ Medication Grudge” is another major theme that emerged from analysis of participants’ experiences. This theme consists of four different categories which include: unmet therapeutic demand, costly medication, abandon medication therapy and adverse effects of drugs.

Unmet demand for treatment

Experience has shown that treatments have not responded well to their needs and have not helped to prevent disease progression:

“...Whatever pills and injections we’ve been given just hasn’t worked, and day by day we get worse ...there has been no recovery at all. They don’t help our problems, they’re useless...” (Patient 6)

Expensive medication

Patients lose their interest in continuing treatments due to the enormous cost of medicine and drugs:

“...The drugs are so expensive...and after using them, you don’t get the result you expect...” (Patient 7)

One family caregiver said that the high cost of my patient drugs affected all of my life dimensions.

“...My family total income is spending on my daughters’ medical expenses. So, sometimes we have to borrow money from the others...” (Caregiver 11)

Abandon medication therapy

The experiences of patients revealed that before receiving an adequate response from the medications, they give up the treatments.

This point was also confirmed during field note taking:

“... The patient on the adjacent bed called me and said that he’s tired from these drugs...he said that it’s 5 years he is taking them and he won’t trust them anymore, because they’re useless. He said he’s been hospitalized, so that he starts a different treatment or something different happens to him and he gets better...”

Side effects of medications

Experiences showed that they are worried about adverse effect of medication that they are using. In this regard, a patient said:

“...Believe me, I’ve tried out and used a number of drugs, but not only I did not get better, I get worse every day and it really pisses me off. I just don’t know what to do...My problems have grown rapidly, since the last time I was hospitalized and I can’t do anything about it anymore...” (Patient 7)

A caregiver also said:

“...When I see whatever I do to make the patient feel a bit better, is useless, I get more confused and I feel terrible. It makes the whole family become worried...” (Caregiver 2)

Discussion

The aim of this study was to explore and describe the experiences of Iranian multiple sclerosis patients and their caregivers about the care and outcomes in Iran led to the identification of two themes:

“Comprehensive Caring Commitment” and “Patients’ medication grudge” that lead to patients’ mistrust of medication and treatment plan.

Table1: Challenges in the care and treatment of multiple sclerosis

Theme	Category
Comprehensive caring commitment	Careful review of the patients' needs Responsibility Education with assessments Caring Presence
Patient medication grudge	Unmet demand for treatment Expensive medication Abandon medication therapy Side effects of medications

When patients are cared for in such an atmosphere without confidence for healing, they will be protected from being grudging as well as disappointed. These are behaviors that patients recognize as care obstacles and consider them damaging and restrictive (25). The presence of nurses is one of the aspects of care that has an important impact on the patient health. The presence of a caregiver by the patient's side causes the patient satisfaction on one hand and reduces professional stress in the caregiver on the other hand (26). Nursing is determined to have a loving and caring nature, and a nurse should be able to create a multi-functional relationship, an affectionate relationship that builds trust between the patients and their families (27).

One of the most important characteristics of nursing is responsibility in facing the patients' situation and offering care services such as efficient medication. It is the essence of nursing profession that will remove many of the ambiguities of nursing care and will add to the quality of care (28-30). Responsibility is a very important presupposition in examining the quality of nursing services (31, 32).

On the whole care for MS patients requires a sense of responsibility in taking appropriate care measures, the participation of the patient

in self-care programs and paying attention to modern and up to date care science. Different studies consider the humanistic commitment in nursing care and the availability of care purposes more important than meeting the physical, psychological, social and spiritual needs of patients (33) and since nursing is a holy career and its aim is to serve humans thus its personnel are individuals that need to be highly motivated, endeavoring and responsible for educating and follow-up caring outcomes (34).

Among the findings of this study, the importance of healthcare staff experience in examining patients with MS and giving appropriate responses based on their own needs is clear. In this study, patients with MS lost their hope and believe that multiple treatments are ineffective. Unfruitfulness treatment and lack of knowledge on the one hand, progression of the disease and the complications and uncertainty about the nature and future of the disease, add weight to the burden of care; As a result, it requires skilled and experienced nurses to care for patients in with a comprehensive commitment in the Iranian care context. Neglecting the patients' problems, such as unmet therapeutic demand, may have negative consequences for the patients (35-37). In this regard, the patients'

confusion and drug treatment program and lack of nurses' knowledge toward the challenges make the nurses deal with issues, such as uncertainty and confusion in facing to the disease. It requires to give the information to the nurses, the healthcare professional make a serious effort to remove these ambiguities and help to the better care of these kinds of patients and their family caregivers.

Commitment to comprehensive care for patients along with paying attention to the patients' complications has a major role to provide better care for the patients (38). A careful review of the patients' needs is one of the important features of nursing care process; paying attention to the education accompanied with evaluation of the patient not only paying attention to his/ her disease and neglecting the patient is among the other important matters of care. Once, a patient who is facing with numerous challenges, feels that he/ she is completely understood by the care staff, will not feel neglecting anymore and when valued he/ she will undergo the treatment process better than before (39).

Undermining the role of nursing has negative consequences on the quality and consistency of nursing services and will harm the process of providing care for patients by creating despair and hopelessness in them (31). While taking care of MS patients, paying attention to solidified as a key to solve complicated problems of patients specially grudge from medications and drugs was found important in this study and paying heed to it prevents the segregation of care measures and the improvement of effective care.

The nurse can play a vital role in ensuring that patients receive the most possible comprehensive medical care. The nurse is the

health care provider with whom many people have the most regular and extensive contact. The nurse can play a pivotal role in facilitating individual and family adjustment to the illness, medication therapy and promoting hope in the face of uncertainty (10). Early signs of new or worsening symptoms may first come to the holistic attention of the nurse for providing opportunities for early intervention and education. In particular, the nurse can recognize the signs of cognitive, emotional, and family problems especially medication grudge, those effects of MS that often go untreated (40). Although, the nurse may not be in a position to provide medication for many of these psychosocial problems, he or she can act as a valuable resource for information and education about various MS-related problems. The specialist nurse will often be the one who makes the referral that will get things back on track.

These challenges mean that patients must be empowered to become self-management, and nurses are in a unique position to help patients to do this. Patients must be encouraged to study their disease situation and medications, to know detail specifics of their health care coverage. They must know when and how to frame an appeal and how to engage health care providers, especially nurses, in that process (41). Nurses who have experience with medication procedures can often assist patients in the process of challenging a denial situation. A nurse can also serve as a powerful source and spokesperson in negotiating with health plan case managers and other decision makers within the health care system.

Conclusion

The findings of the current study indicate that nursing care for MS disease has multiple

dimensions from comprehensive commitment and specialized and target care for manage complex frustration situation, such as preparing drugs and medication. Considering these ranges, increases the effectiveness of care offered by healthcare staff, medical professionals and caregivers to the patients. According to the result of this study, shared goals of care and cure were difficult to achieve in the absence of a positive commitment career. Further verification of the findings is recommended by replication in different clinical settings with a larger group of Iranian patients with MS. Above all, however, the study helps to show the complexity of the interactional processes that comprise nursing comprehensive commitment. We hope that future researches develop the picture of these challenges across different clinical settings and time.

Among the limitations of the current study, one can point out to the information gathering process. Due to the special culture of the research society, that they were mainly Arabs, permission was not granted to continue research through observing the patients' situation outside the hospital and inside their homes. Besides, according to the qualitative nature of the study, the findings cannot be generalized. Therefore, it is recommended that the care concepts of these patients be examined in other cultures, too.

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