

The Perspectives of Iranian Patients With Multiple Sclerosis on Continuity of Care: A Qualitative Study

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ABSTRACT

Background: Continuity in multiple sclerosis (MS) care has been cited as a critical feature of this care and necessary to improve medical outcomes.

Purpose: This exploratory and descriptive research attempts to identify continuity of care from the experience and perspective of patients with MS at two teaching hospitals and the MS Society in Ahvaz, Iran.

Methods: In this study, 23 patients with MS were selected through purposeful sampling. Data were collected through in-depth and unstructured interviews and were analyzed using an inductive thematic analysis approach.

Results: Four main themes emerged from the analysis: human-oriented attention, the necessity of purposeful planning, importance of responsibility, and caring with empathetic sensing.

Conclusions/Implications for Practice: Because of the importance of professional caring practice to continuity of care for patients with MS, we suggest that healthcare providers should include these aspects in care planning.

KEY WORDS:

multiple sclerosis, care, qualitative study, continuity, Iran.

expects to receive care that is delivered in a manner that respects his or her dignity and human value (Watson, 2011).

Care of patients with MS includes the assistive, supportive, and facilitative measures that are taken to meet the potential and actual needs of the patients and their families to ultimately improve their quality of life (Karaoz, 2005). Caregivers should make an utmost effort to discover and understand the feelings and inner concerns of their patients to help them improve self-efficacy. This builds trust in the patients and leads to their greater understanding (Watson, 2008a). Every human being is unique; therefore, the care that he or she receives requires special consideration and understanding (Watson, 2011). The nursing and healthcare system should be based upon humanistic values and consider the welfare and understanding of patients (Watson, 2008a, 2011).

Despite the vast measures that have been considered to provide healthcare to chronic patients, there remain many shortcomings in the quality of care offered to these patients (Cumbie, Conley, & Burman, 2004). The complex symptoms of chronic diseases such as MS often create problems in the daily life of both the patients and health professionals (Blank & Finlayson, 2007; Hyde, Skirton, & Richardson, 2011).

Review of the Literature

Factors affecting the quality of care in Iran include tasks beyond daily routine, cooperation, promotion of an effective

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Introduction

Multiple sclerosis (MS) is the most common debilitating neurological disease among the young adults worldwide (Lublin & Miller, 2008). The number of afflicted individuals is on the rise, exceeding 2.5 million globally and 50,000 in Iran alone (Elhami, Mohammad, Sahraian, & Eftekhari, 2011; Moriya & Kutsumi, 2010). There is currently no medical cure for MS, and the key to solve many problems associated with this disease lies within the definition of care. Understanding the needs of patients is one of the prerequisites of sufficient care (Watson, 2008b), and the basis of comprehensive care rests in paying adequate attention to the patient. Every patient must be considered a unique individual that is worthy of respect and who

relationship, and updating education. The concept of providing qualified nursing care in Iran is contextually complicated and needs to change to achieve high-quality care (Molazem, Ahmadi, Mohammadi, & Bolandparvaz, 2011). On the other hand, most studies conducted on MS in Iran are limited to the epidemiology of the disease (Elhami et al., 2011; Ghandehari, Riasi, Nourian, & Boroumand, 2010; Saadatnia, Etemadifar, & Maghzi, 2007) and apply interventions to control the problems related to this disease (Ghafari et al., 2008). All of these studies have taken a quantitative approach to MS, and there are no studies that have adopted a qualitative approach to explore the experiences of caring for these patients.

It is necessary to define continuity of care and quality of care and their relationship to each other. Continuity of care is the process by which the patient and the caregivers are cooperatively involved in ongoing care management with the goal of high-quality and cost-effective care (Saultz & Albedaiwi, 2004). Continuity of care is a main criteria and an essential element of nursing care and is consistent with quality patient care. The continuity of care helps nurses and caregivers gain their patients' confidence and enables them to be more effective advocates for the patients and their families (Haggerty et al., 2003). Continuity of care further facilitates the nursing role as a cost-effective coordinator of the patient's health services by making early recognition of problems possible. Continuity of care is rooted in a long-term patient–nurse partnership in which the nurse knows the patient's main concern from experience and integrates new insight and decisions from a holistic-patient perspective efficiently without extensive investigation (Saultz & Albedaiwi, 2004). On the other hand, quality of care refers to delivering the best possible care and achieving the best possible outcomes for patients every time they deal with healthcare providers or use healthcare services. Essentially, continuity of care means doing the best possible function with the resources available. In evaluating quality of care, we must treat the management of the process of care as being equally important to the outcome of care (van Servellen, Fongwa, & Mockus D'Errico, 2006). Evaluations of the quality of care, especially by patients and family caregivers, are likely to place significant emphasis on the continuity of care delivered by nurses in terms of both qualitative and quantitative considerations. There are no studies that have investigated continuity of care in the context of patients with MS, a group for which this type of care is perceived as highly important.

A review of studies on continuity of care and quality care outcomes for patients with chronic conditions conducted by van Servellen et al. found that the focal point of most interventions was on functional outcomes, quality of life, and patient satisfaction. However, the cases studied in this review study were not specifically patients with MS. Because of the nature of their disease, patients with MS require greater attention than patients with other chronic diseases (van Servellen et al., 2006). Healthcare teams have a responsibility to adjust their opinions about each patient to reflect the culture, quality of life, experiences and understanding of healthcare definitions of the patient. The goal of caring is to change the health concepts

from nursing point of view. However, quality of care should be carefully investigated from the patients' perspective regarding their life experiences and understanding of care concepts (Aghamohammadi-Kalkhoran, Valizadeh, Mohammadi, Ebrahimi, & Karimollahi, 2012). As there is inadequate information on the quality of care provided to patients with MS in Iran, this study was designed to explore the experiences and perspectives on continuity of care of Iranian patients with MS.

Methods

Study Aim

An exploratory and descriptive research design was used to identify the perspectives and experiences of Iranian patients with MS regarding continuity of care. A thematic analysis approach was used.

Ethical Consideration

This study received approval from the ethics committee of Ahvaz Jundishapur University of Medical Sciences. The participants were provided with information about the purpose and method of the study. They were further informed that participation was voluntary. All of the participants were guaranteed anonymity, confidentiality, and the right to refuse to answer any question or withdraw from the study at any time. They were also asked to consent to have their interviews audiotaped. Informed written consent was obtained from all the participants. The location for the interviews was a mutually agreed-upon place that afforded adequate privacy and comfort for the participants.

Participants

This study is part of the researcher's doctoral dissertation and was conducted between January 2012 and February 2013 in two teaching hospitals and the MS Society in Ahvaz, Iran. Twenty-three patients with MS were chosen using purposive sampling. Choosing participants from various settings helped the researchers to capture a wide range of potential perspectives. The inclusion criteria were having a diagnosis of MS confirmed by a neurologist, having medical records at the MS Society, being able to communicate in Persian, over 18 years old, and willing to provide written consent. Reasons given for nonparticipation in the study included being too ill, feeling too exhausted, and being unfamiliar with the Persian language.

Data Collection

In-depth, unstructured interviews were used to collect data. The interviews started by asking the core question: "Please describe how you spend a typical day with regard to your MS disease?" Probing questions were then asked based upon participant answers to enrich the data. The interview sessions lasted between 45 and 100 minutes. The tempo of the dialogue

was flexible, and the conversation proceeded based on the physical and mental conditions of the participants and their tolerance.

Data Analysis

A thematic analysis approach was used to identify patterns within the text (Kazemi, Nasrabadi, Hasanpour, Hassankhani, & Mills, 2011). Before data analysis, the interviews were transcribed verbatim, and the transcripts were reviewed rigorously several times to ensure data immersion. The first author used face-to-face interviews to gather data. Data collection and constant comparative analysis allow a researcher to ask more probing questions in the next interview (Birks & Mills, 2011; Corbin & Strauss, 2008). The analysis continued by reading the text several times to determine the differences and similarities. Eventually, after conducting all 23 interviews, the list of codes was merged into themes, with the analysis continuing until all the thematic categories had been saturated. In other words, there was no new apparent concept remaining to be identified, and all designated categories were coherent or meaningful (Khosravan, Salehi, Ahmadi, Sharif, & Zamani, 2010). Field notes (Strauss & Corbin, 1998) were the primary tool used to gather data.

Trustworthiness

To ensure accurate data collection, this study used a multi-source data collection technique (interviews, field notes, and observations). The transcripts of each interview and the field notes were read several times by the researcher to gain a deeper understanding of the collected data. The second and third researchers listened to the recorded audio files and studied the written transcripts. Analysis of all transcripts was done by all of the authors (Charmaz, 2009; Lincoln & Guba, 1985). After constant comparative analysis, member checking was done nearly 2 months after the start of the interview process to provide adequate time for in-depth analyses of the transcripts. During the sampling process, prolonged engagement and maximum variation were ensured. Furthermore, reflective memos were used to enhance the audit trail of decision making during the research process (Mills, Bonner, & Francis, 2006).

Results

The participants were 20–50 years old (mean \pm SD = 27 \pm 4.7 years), with a disease duration of 2 months to 19 years (mean \pm SD = 7 \pm 3.5 years). Eleven participants had a post-high-school degree, 10 had a high school education, and two had an elementary education. The concept of continuity of care used in this study is more general and encompasses a range of the factors that affect quality of care. This may be considered as a spectrum from this continuum; therefore, this section explains the concept of care as perceived by patients with MS and provides the factors affecting continuity of care (Figure 1).

Four main themes emerged from the data analysis, including human-oriented attention, the necessity of purposeful planning, importance of responsibility, and caring with empathetic sensing. We generated 25 subcategories, eight categories, and four themes from the 1,374 unique codes derived from the continuity-of-care experiences of patients with MS.

Human-Oriented Attention

This theme of continuity of care ranges from a human orientation to a disease orientation.

The necessity of human-oriented care

The experiences of patients show that they highly valued and appreciated the intrinsically altruistic and humanitarian behaviors of care teams:

We really appreciate them because they respect our dignity and treat us as human beings (Participant 12).

Another expressed:

It's really important to maintain human dignity. The staffs treat their MS patients as members of society; as Saadi (the famous Iranian poet) says: "Human beings are members of a whole; as they have been created from one essence and soul. If one member is afflicted with pain, other members will be uneasy." They are paying close attention to the patient, as if it is their own problem (Participant 3).

A comprehensive physical and psychological understanding of the patient is necessary during the caring process. One of the participants said:

I am really delicate and have a sensitive personality. Nurses keep an eye on both my physical and spiritual problems. They are always by my side and giving me hope (Participant 5).

Avoiding disease-oriented care

The participants believed that their disease has eclipsed their human dignity:

The entire thing is this disease, not me. Anyone who sees me asks me how's your problem? Are you better? Nobody asks me how you feel yourself. The disease has taken my place and it's all about "it".... (Participant 2)

The patients' experiences revealed that their disease cast a shadow over all aspects of their individual and social lives:

It's affected all of our lives. Anywhere we go, anything we want to do, it's all about the disease and its problems. We can't go to the park, we can't

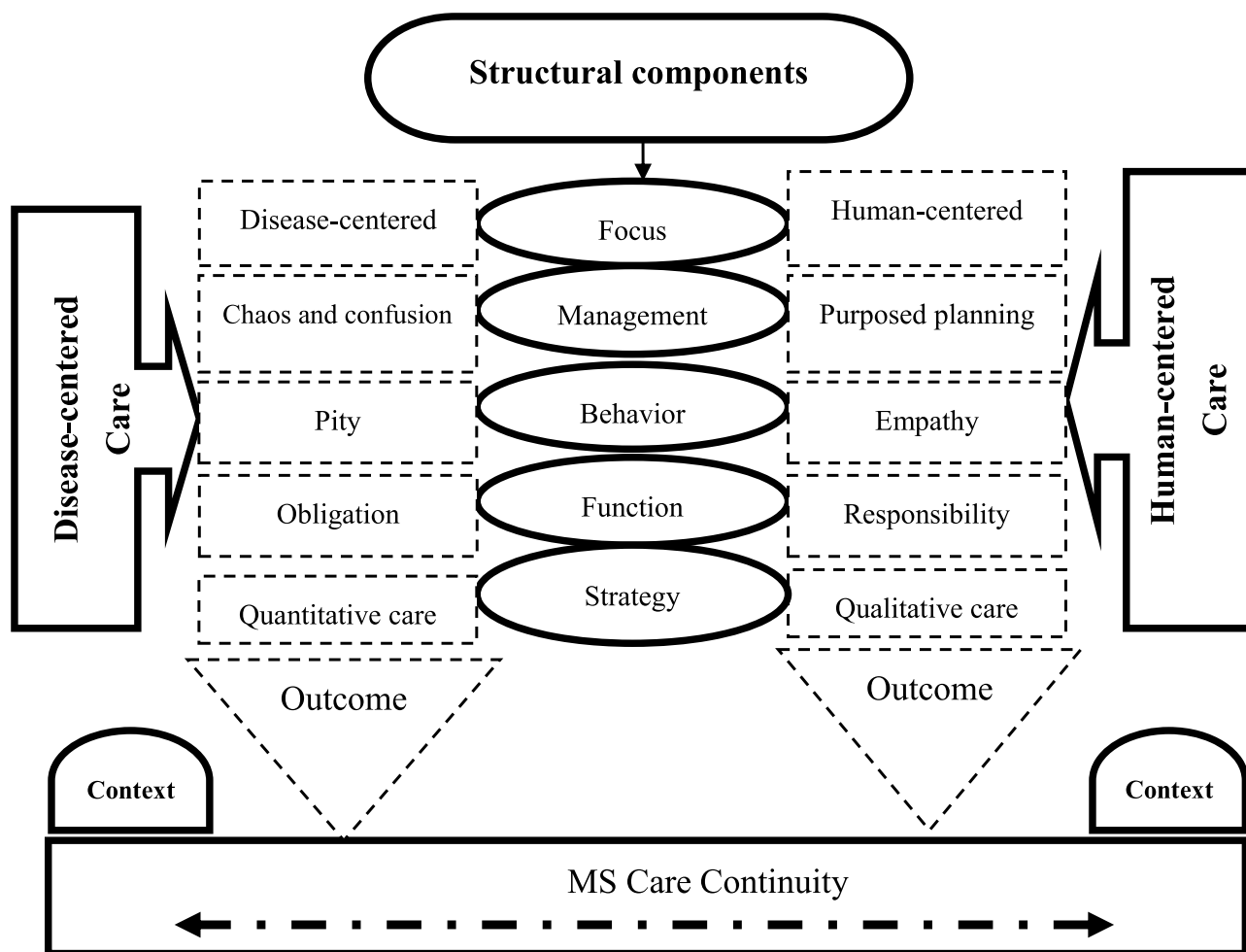


Figure 1. The continuity and structural components of caring: the experience of Iranian patients with multiple sclerosis (MS).

travel. It has tied our hands and legs like a chain
(Participant 10).

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 (Participant 8).

The Necessity of Purposeful Planning

Management of caring in this theme of continuity ranged from purposeful planning to chaos and confusion.

Caring with purposeful planning

Participant experiences showed that they need experienced and qualified staff to provide care:

An experienced nurse will know about the kinds of problems I suffer from; at least she will be aware of the visual and external problems like imbalance, relapse and impatience, but inexperienced ones do not.... (Participant 10)

The patients expressed satisfaction with the care staff as staff reviewed and examined their cases in a committed manner:

The lady, the senior nurse, comes and examines me from head to toe every morning, and assesses the

Management of chaos and confusion

The participants expressed concerns and uncertainty about the unclear nature of their disease and their treatment and related that they asked many questions about their disease:

I don't know what's going to happen later on and I'm really confused. When you don't know what's going to happen in the future, it's really difficult. Your mind is always busy thinking about it (Participant 11).

The experiences of patients showed that their confusion grew as their disease progressed:

Believe me, I've tried out everything there but not only I am not getting any better but every day I get worse. This really pisses me off and I just don't know what to do.... My problems have grown rapidly since the last time I was hospitalized and I can do nothing about it anymore (Participant 7).

Importance of Responsibility

The function of caring in this theme of continuity varies from sense of responsibility to obligation.

Sense of responsibility

The participants expressed general satisfaction with the measures taken by the care staff in response to their evaluation and asked that all staff be consistent in the measures taken:

Some of them do their job and go away, while some follow what they've done to assess the consequences, and ask whether the problem has been solved or not (Participant 8).

Following their need for care measures, the participants were willing to participate with the care staff in the care process, to use their self-care abilities to control the situation, and to find the necessary readiness to care for themselves at home:

Many times, my doctor asks my opinion or the nurse says: Eat your food on your own. I am sitting with you and will help if necessary (Participant 11).

The participants also expressed particular willingness to be taken care of by care personnel who were aware of recent advancements in care:

When my nurse told me that if this medication doesn't work on you, there is another type too; I got really happy. She even told me that it's okay if you can't afford to buy plasmapheresis, there are other treatments available. It really gave me comfort and nobody else had told me this point before (Participant 2).

Obligation as an insufficient function of caring

The patients complained about the insufficient training provided by their nurses related to their disease problems and difficulties:

They haven't given us any training regarding our diet or told us that warm weather and eating fish are bad for us. On the whole, they don't spend much time teaching us and we have to go read and study ourselves (Participant 6).

In some cases, there were gaps between the requests of patients and the measures taken by the nurses:

Because I wanted the flow in my IV to slow down, I had to argue with them for hours and, at the end, they said: Do whatever you want. She couldn't see that my body's on fire. She claimed the doctor ordered that the IV bag should be finished in 4h, and so 4h it was. She would open the flow clamp to speed up the flow (Participant 1).

The patients expressed unhappiness at the staff's inattention to the educational needs of their families:

They don't spend time training my family members... Perhaps it's not even their fault because the ward gets really busy and they send the patient attendants out. So it's not possible to train my family. There isn't any other place in the hospital we can go to educate our families, which is really worrying (Participant 5).

Caring With Empathetic Sensing

Caring behavior in this theme of continuity varied from empathic understanding to the expression of pity.

Necessity of empathetic understanding

Receiving sufficient and normal care and attention were among the main requests of the participants:

When I feel bad and want to walk, my family tries not to help me. They just bend and put their hands forward. If I want, they'll help; if not, I walk on my own. They let me ask for help first before giving it to me. I'll be unhappy if they push me (Participant 17).

The participants expressed feeling calm and relaxed upon seeing the care staff at their bedsides when problems arose:

I generally love seeing him by my side. I don't want to think that he has left me alone. The moment he stands by me and speaks to me, I really get calm (Participant 19).

Avoidance of pitiful reactions

Pitiful behavior exists across the continuum of patient care.

The participants talked about their experiences of pain eliciting sarcasm from others:

My relatives and friends throw it in my face. It is harder for me as I am a woman. Unfortunately, most of the MS patients here are female and they receive a lot of sarcastic remarks from others (Participant 16).

The participants complained about other people's sense of pity toward them and described it painfully:

They feel pity towards us when they see us in this situation. They start crying or don't let you speak. They whisper to each other and look at us with pity and shake their head in grief (Participant 3).

They also expressed feeling dissatisfied at being the center of attention:

When my sister in law comes to visit, she tells me not to move at all, and that it is bad for me. She won't even let me get out of my seat, which makes my body go stiff. She does all my work and makes me feel bad. I am not that disabled (Participant 9).

Discussion

This study provides insights into continuity of care from the perspective of Iranian patients with MS. The results suggest that the participants enter their care units with a community of empathetic understanding versus pity, sense of responsibility versus obligation, purposeful planning versus chaos and confusion, and human-oriented versus disease-oriented care.

Human-oriented care and humanity coupled with attention to the patients' troubles play significant roles in creating a relationship with patients and providing them with quality care (Adriaansen, Van Achterberg, & Borm, 2008). A complete physical and psychological understanding of patients with MS is one of the important qualities of care for these patients. Paying due attention to the patient's human dignity and not just to his or her disease is another important element of care. Once a patient who is facing numerous challenges feels that he or she is completely understood by the care personnel, he or she will not feel neglected anymore and will be more inclined to accept the treatment process. It is worth mentioning that one of the main problems of patients with MS is that their disease casts a shadow on all dimensions of their lives in a way that their human aspect is forgotten. Therefore, nurses should pay due attention to the concept of humanity rather than focusing singularly on the disease. Being cared by supportive and caring nurses who easily relate to patients has a positive effect on treatment effectiveness. Thus, humanity and a human-oriented approach to care should replace disease-centeredness, a phenomenon that is undermining and disabling.

One of the most important characteristics of nursing is the feeling of responsibility toward the situation faced by the patient. It addresses the fundamental essence of the nursing profession. Paying attention to this issue removes much confusion from nursing services and enhances quality of care (Clancy & Svensson, 2007; Gallagher & Rowell, 2003; Roussel & Swansburg, 2006). Responsibility is a very important presupposition to examining the quality of nursing (Bolton et al., 2003; Schluter, Seaton, & Chaboyer, 2011). Obligation-centeredness leads to the emergence of disorganization and negligence in training, empowering the patients, and forgetting the importance of seeking the assistance of the patients' families in facilitating care. These instances lead to conflict and opposition between the patient and the caregiver. Wakimizu, Fujioka, and Yoneyama (2010) believe that families feel confused when initially facing the challenges of disease and thus need to be supported by the nurses. Upon receiving this support, they share their experiences and undertake the problems associated with the disease in the next stage (Wakimizu et al., 2010). Dealing with the problems related to their disease, pa-

tients with MS and their families feel confused. The progression of the disease and failure to receive adequate support from caregivers lead to their feeling troubled. In the Iranian healthcare system, there exists a dire need to provide fundamental support to patients with MS. Those in the relevant support systems must understand that the situation cannot be ignored and that they must provide capable and sufficient manpower motivated by a sense of responsibility. Thus, care services must be provided proportionate to patient needs (Mahmoodishan, Alhani, Ahmadi, & Kazemnejad, 2009). On the whole, the care of patients with MS requires that healthcare providers have a sense of responsibility to take appropriate care measures, encourage the participation of the patient in self-care programs, and pay appropriate attention to recent advances in scientific care (Lee, Hsu, & Chang, 2007).

One of the findings of this study was the important role played by nurses' experiences in providing accurate examinations or assessments of patients with MS and in giving appropriate patient-needs-based responses. When nurses were not by their bedside, many of the participants reported that they tended to conceal their needs and requirements. A nurse who is responsible for taking care of a patient with MS should have the necessary scientific and practical skills to attend, treat, and fully understand the patient in accordance with her or his physical and psychological symptoms. The nurse should be able to characterize the patient's care needs and fully meet them. In this study, the patients with MS had lost hope in the care process and talked about the multiplicity of ineffective and unsuccessful treatments. The ineffective treatments on the one hand and the insufficient care knowledge, the progression of the disease and its problems, and the confusion and uncertainty about the nature and future of the disease on the other exacerbate the complexity of care. Therefore, proficient and experienced nurses are needed to take care of these patients. Inattention toward the problems of patients threatens negative consequences for the patient (Brämberg, Dahlborg-Lyckhage, & Määttä, 2012).

Empathetic understanding of rather than feeling pity for patients with MS is one of the effective concepts of care for these patients. Studies show that meeting human needs through attention and empathy is one of the main duties of caregivers (Burhans & Alligood, 2010) and that constructive respect and compassion between the care staff and patients increase the effectiveness and efficacy of care. As a result, the patients will be shielded from the pity of others as well as from hateful behaviors and other behaviors that patients recognize them as obstacles, damaging, and restrictive.

The nature of nursing is loving and caring. Nurses should be capable of creating multipurpose relationships that allow affection that builds trust between the nurses, the patients, and the families of patients (Mahmoodishan et al., 2009).

The findings of the current study indicate that the nursing care of patients with MS ranges from specialized and targeted care to low-quality and maintenance care. The effectiveness of care offered by the nurses and medical professionals may be significantly improved by considering this issue.

Limitations

As is the nature of qualitative studies, the results of this study may be generalized only to Iranian care settings. To increase knowledge regarding this topic, we recommend that the care concepts of patients with MS also be examined in the context of other cultures.

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