

The challenges of healthcare delivery to people with multiple sclerosis in Iran

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ABSTRACT

Background: Multiple sclerosis (MS) is a chronic disease prevalent in young and middle-aged people. Patients with MS often have numerous complicated needs and, consequently, require a broad range of health services. Results of a number of studies indicate that patients' needs are only partially met. **Aims:** This study was conducted to explore the challenges of healthcare delivery to patients with MS in Iran. **Materials and Methods:** In this qualitative case study, 43 participants selected through purposeful sampling were interviewed using semi-structured method in the cities of Isfahan and Tehran in 2012–2013. Besides the interview, documentations relevant to healthcare delivery were collected from different sources, including websites of all Iranian universities of medical sciences, insurance organizations, patients' weblogs, news agencies, the MS Center forum for MS patients, and MS Payam bimonthly. The data were analyzed through the constant comparative analysis. **Results:** The data were categorized into four main categories, including functional challenges (diagnosis problems, failure to pay attention to patient needs, failure to follow-up, and miscommunication), administrative challenges (resource allocation and supervision), policy-making challenges (lack of comprehensive services, bureaucracy, and problems in provision of medications), and structural challenges (difficult access to services, lack of comprehensive centers, space limit, and long wait). **Conclusion:** Despite all attempts of governmental and nongovernmental organizations for healthcare delivery to MS patients, these services cannot satisfy all needs of the patients. In this regard, service providers and administrators should pay more attention to the needs and expectations of patients and their families.

Key words: Health services, Iran, multiple sclerosis

INTRODUCTION

Health is a prerequisite of life and important for all human beings.^[1] The increasing incidence of chronic diseases in the world is a burden on patients and the healthcare system.^[2,3]

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The health system administrators all over the world face with the frightening task of health service management for chronic diseases.^[4] According to the World Health Organization's (WHO's) definition, chronic diseases need constant care for years or decades and cover a vast area of health problems.^[4] Multiple sclerosis (MS) is a chronic,^[5] non-traumatic neurological disease that is common in young and middle-aged people.^[6] Over the past decades, the prevalence and incidence of this disease have increased

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all over the world. Based on the survey of the International Federation of Multiple Sclerosis in 2013, the number of MS patients increased from 2.1 million in 2008 to 2.3 million in 2013, and the global mean prevalence of MS increased from 30 per 100,000 people in 2008 to 33 per 100,000 people in 2013. Although MS exists in all parts of the world, its prevalence rate differs from place to place. Maximum prevalence rates of 140 and 108 per 100,000 people are related to the North America and Europe, respectively, and the minimum prevalence rate is found in Black Africa and East Asia.^[17]

In Iran, various studies examined the prevalence and incidence of the disease in different cities. A study on MS patients registered in Tehran's MS Center estimated the prevalence of the disease in Tehran, Iran, as 51.9 per 100,000 people.^[18] The age- and sex-adjusted incidence of the disease in Tehran increased from 0.68 per 100,000 people in 1989 to 2.93 per 100,000 people in 2008, as the peak incidence was 4.58 per 100,000 people in 2005.^[19] Isfahan's MS association conducted numerous studies on the prevalence of MS in Isfahan and estimated the periodical prevalence of MS as 35.5 per 100,000 people in 2004–2005 and 43.8 per 100,000 people in 2003–2006, and the MS incidence as 9.22 per 100,000 people in 2010–2011.^[10]

MS involves various neurological disorders with relapse and progression periods,^[11,12] which reduce the quality of life and increase the incidence of mental disorders in patients.^[13-16] It is also accompanied with social consequences such as unemployment and divorce.^[17] Lack or reduction of income results in increased financial burden on patients and their families and, ultimately, reduces the quality of their life.^[18] The financial consequences of the disease arise from loss of working capacity, the effects of physical and mental disabilities on young people and the subsequent reduced workforce, hospitalization during relapse, and the need for help to do daily activities and for direct costs of the expensive medications.^[19,20]

MS patients often have numerous complicated needs and, consequently, require a broad range of health services.^[21] The health services provided to patients and their families should be effective and corresponding to the patients' needs.^[22] The mission of the healthcare system is to improve the health status and resolve people's needs in the area of health and sickness.^[23] There is much evidence that the control of the disease by patients is affected by healthcare delivery.^[2] Moreover, the relationship between patients and health service providers is of special importance.^[24] Patients must be the focus of healthcare process and health services must be provided for them, not on them; but unfortunately, most often patients are ignored.^[25,26]

Results of a number of studies conducted in Iran^[27-29] and other countries indicate that patients' needs are only partially met, and that they need to receive comprehensive services. This involved patients with MS, and given the nature of the disease,

they needed comprehensive health services and information by service providers about the disease and treatment process,^[22,30,31] rehabilitation services,^[31,32] social support, access to medical treatment, and home-care services.^[31] Despite all the findings made about the effects of MS on patients, their families, community, and patient needs, full and accurate information about the status of services available to MS patients in Iran does not exist. The researcher's experiences in dealing with patients with MS indicate healthcare system's failure to attend to patients' needs. Patients have to deal with several problems in disease management, receiving services, self-care information, and heavy treatment costs. This study was conducted to explore the challenges of healthcare system to patients with MS in Iran.

MATERIALS AND METHODS

In this study, the researcher chose a qualitative case study approach in order to explore the healthcare system and understand it from different perspectives. The reason was that a case study is used to deeply understand a complex matter in real situations from different aspects,^[33] obtain holistic, meaningful, and contextual knowledge; and realize life events.^[34] Using various data sources, a case study facilitates the examination of a phenomenon in a real situation. Therefore, the phenomenon is examined not only by a lens but by multiple lenses that yield understanding of its different aspects.^[35] The researcher chose the above approach to obtain a holistic perspective of the healthcare system because this system was limited to temporal, spatial, and economic conditions of the society and could not be isolated from its context. Furthermore, the researcher could not control the variables influencing the phenomenon and, consequently, found the case study suitable for examining that system.

In this study, the researcher selected 43 people from Isfahan and Tehran cities in 2012–2013. The participants consisted of three main groups, namely, health service policy makers (4 academic and ministerial senior managers), recipients of health services (20 MS patients and 10 family members), health service providers, including personnel of treatment centers offering healthcare delivery to MS patients (3 doctors and 3 nurses), and personnel of the Welfare Organization and the MS Society (managing director, employees, and consultants).

The inclusion criteria were as follows: The willingness and ability for participating in the study, diagnosis of the patients' MS by a physician, and health service providers' active role in providing services to patients and families. Participants who met the study inclusion criteria were selected with maximum variation in terms of age, gender, education, and marital status, using purposive sampling method. After explaining about the study and obtaining participants' consents, location and timing of interviews were decided according to patient's preference. In this study, the interview locations included MS clinics in Isfahan, neurology wards of hospitals affiliated to Isfahan University of Medical Sciences, Isfahan MS Society,

Isfahan Welfare Organization, Isfahan city parks, and the Ministry of Health and Medical Education. The researcher conducted the first interview with an MS patient, and based on the analysis, subsequent interviews were conducted with maximum variation. The data were collected using a semi-structured interview. Based on the participants' position, the following questions were asked: What services have been provided to you? What services do you need? What is the status of the services provided to you? What services do you provide to the patients and their families? What services do the patients and their families need? What is the status of the services you provide? What are the policies of healthcare delivery to the patients and their families? How are the policies implemented? What organizations are involved in implementation of the policies?

Participants were selected once approval of the Ethics Committee of Isfahan University of Medical Sciences was obtained. After introductions, explanations about study objectives, and obtaining written informed consents, interviews with participants were conducted by the researcher. Before the interview, the researcher informed the participants that their talks would be recorded, their recorded voice along with their personal information would be confidential, and they could stop the interview whenever they disliked continuing. The interview was held for 29–120 min in a quiet and comfortable place. Collection of data continued until data saturation was reached and new codes were not obtained.

In addition to the interview, the researcher collected documentations relevant to healthcare delivery (forms, instructions for diagnosis and treatment of MS, and instructions for service provision), news, contents of patients' weblogs, discussions among patients in the MS Center website, and contents of MS Payam bimonthly. Moreover, websites of all Iranian universities of medical sciences, insurance organizations, and MS societies were explored in terms of their services.

In this study, data collection and data analysis were performed simultaneously. The data were analyzed using the constant comparative analysis, which is a general method used in different qualitative studies.^[36,37] The researcher first transcribed the recorded interviews verbatim, then reviewed the transcripts several times, examined the data sentence by sentence and word by word, and encoded the key concepts and sentences in each paragraph or line. The collected documents were analyzed in the same way as the transcribed interviews. In this study, the researcher reviewed the data collected from the interviews and documents several times and compared them with each other in terms of their similarities and differences in order to form main categories and subcategories. For instance, the main category of functional challenges was formed as follows. Initial codes including inadequate training about pulse therapy, no training about chemotherapy medication, no training about diet, no information about the trend of the disease, lack of attention to patient's psychological needs, lack of attention

to family's psychological needs, and stereotypical advice were extracted from interviews after documenting and reviewing the interview texts several times. In the second stage, the second level codes were created by comparison among initial codes which included: Lack of attention to education needs about the nature of the disease, lack of attention to education needs about management of the disease, lack of attention to patient's psychological needs, and lack of attention to family's psychological needs. The subcategory of "lack of attention to needs" emerged from comparison of the second level codes in terms of similarities and differences, and together with the subcategories of diagnosis, lack of follow-up, and inappropriate communication, it formed the main category of functional challenges.

Various data collection methods, including the interview and collection of documents related to healthcare delivery to patients, were used to increase credibility of the data. The researcher held the interviews for a long duration in order to obtain a deep perception of each participant. Prolonged engagement with participants in the field of study helped the researcher to gain their trust and obtain a better understanding of the subject. For the sake of feedback, interpretations from interview texts and initial codes were returned to participants to compare and confirm concurrence of ideas that emerged from data with their own experiences, and if needed, codes were modified.

The interviews and documents were examined and discussed by co-researchers for peer check. The researcher had his collaborators examine confirmability of the data. For transferability of results, the researcher described the process of the study and the activities performed in this regard accurately and purposefully.

RESULTS

The study participants included 20 MS patients, 10 family members, 9 service providers, and 4 service policy-makers, with age ranging from 22 to 63 years. 67.44% of participants were male. 50% of patients had university education, 25% had high school diplomas, and 15% had primary school education. Health service providers' education level ranged from bachelor's degree to PhD. 70% of family members were the patients' spouses, 20% were their mothers, and 10% were their children. In this study, patients and their families were faced with difficulties in receiving health services.

The challenges were categorized into four main categories: Functional, administrative, policy-making, and structural challenges. The categories and subcategories are shown in Table 1.

Functional challenges

The services provided to MS patients in public hospital clinics for MS or special diseases included free outpatient injection (pulse therapy and interferons), teaching how to inject interferon, and patients' appointments for

Table 1: Categories and subcategories

Category	Subcategory
Functional challenges	Diagnosis problems
	Failure to pay attention to patient needs
	Failure to follow-up
	Miscommunication
Administrative challenges	Resource allocation
	Supervision
Policy-making challenges	Lack of comprehensive services
	Bureaucracy
	Problems in provision of medications
Structural challenges	Difficult access to services
	Lack of comprehensive centers
	Space limit
	Long wait

neurologists. Besides neurologists, clinical nurses and nurses of pharmaceutical companies provided health services to patients in MS clinics. Moreover, physiotherapy, plasmapheresis, and magnetic resonance imaging (MRI) were provided to the patients free of charge in hospitals affiliated to the university.

One of the challenges faced by the patients and their families was the performance of service providers. This was divided into subcategories of diagnosis, failure to pay enough attention to patient needs, failure to follow-up, and miscommunication.

A challenge experienced by the patients was the misdiagnosis or delayed diagnosis of the disease. The patients had experienced symptoms of the disease for a long time and visited various doctors following misdiagnosis and failed treatments, or doctors might have referred them to other doctors by mistake. In this respect, the patient was diagnosed with MS after a long time.

“I visited a general physician, an orthopedist, and an internist, but none of them diagnosed my MS. I mean, they didn’t guide me. My cousin told me to visit a neurologist. She guided me; doctors didn’t help me at all.” (A 38-year-old woman suffering from MS for 15 years).

Besides misdiagnoses and improper referrals, some participants were not satisfied with the manner of expressing the diagnosis at the beginning of the disease. The diagnosis had not been disclosed to them or only a brief description of the diagnosis was revealed for them. Those patients experienced much stress at such a situation because they did not have any information or experiences about MS or they might have had some incorrect information.

“The doctor looked at images, encephalogram, eye, and MRI, then looked at the nurse and said, ‘I guessed it right. It’s MS.’ I asked the doctor, ‘What do you mean? What’s MS?’ She said, ‘I’ll explain it to you later.’ Then she left. I didn’t how they injected me cortisone.” (A patient’s weblog).

Another challenge was the service providers’ failure to pay enough attention to needs of the patients and their families. In this regard, some patients had changed their doctor due to the service providers’ inattention. Some participants were dissatisfied with doctors who were in hurry or accepted several patients at the same time during visits.

“I had just started to talk when the doctor had written the prescription and given it to me. When he was writing the prescription, I wondered if it was useful to talk anymore because he wrote everything he wanted to say. He didn’t pay attention at all.” (A 38-year-old woman suffering from MS for 12 years).

The service providers’ failure to pay enough attention to patients’ mental needs was also a problem for the patients and their families.

“One thing, I think, very important, especially for newly diagnosed patients, is consultation that I didn’t see. I wish someone had given me such a service at the beginning of my disease, I mean, someone had talked to me about the disease. Such a service couldn’t be just done physically, mental consultation is much more important.” (A 29-year-old woman suffering from MS for 7 years).

Another challenge was the service providers’ failure to pay enough attention to instructional needs of the patients and their families when the disease was diagnosed. In this regard, patients’ lack of enough information made them concerned mentally and visit the doctor frequently.

“Maybe the doctor can clarify it a bit more because it’s some time my leg hurts. So, I visited the doctor and was examined twice, but the doctor said it’s nothing special. Maybe I need to be briefed more to know it doesn’t really matter.” (A 25-year-old woman suffering from MS for 6 months).

The patients’ failure to follow-up was another problem the patients and their families had experienced. In this regard, patients had stopped their treatment arbitrarily and exacerbated the disease that had caused more severe symptoms because they did not have enough knowledge or practiced unusual treatments.

“He didn’t continue, well, he was sure he was OK. Not this way, they have to, no, they have to convince us that if we are OK, we should follow up, we shouldn’t ignore. They should warn us.” (An MS patient’s 41-year-old wife).

The participants also complained about the service providers’ miscommunication. They expected the service providers to understand patients and their families, and reduce their suffering.

“Some helpless people can’t even come here, they can’t talk to anyone, and they don’t know how to complete forms. For example, some providers are offensive, they mistreat patients.” (A 46-year-old man suffering from MS for 3 years).

According to the participants' experiences, problems of diagnosis, failure to pay enough attention to patients' needs, failure to follow-up, and miscommunication influenced receiving services.

Administrative challenges

The participants also faced with administrative challenges, including resource allocation (such as human resources and hospital resources) and supervision.

The shortage of human resources was a problem of the service providers such as MS clinics and neurology wards. It resulted in providing services hastily and failure to pay attention to the needs of patients and their families on one hand, and personnel burnout on the other hand.

"Well, the personnel can't pay enough attention to patients. For example, they can't brief patients and familiarize them with the condition, or support them. If there are enough nurses, for example, each nurse has five patients, she can pay attention to all of them and help them." (A nurse working in a neurology ward).

Another problem related to human resources was the shortage of nurses specialized and educated in MS. Moreover, there were no training courses on MS for nurses, and the nurses themselves were trying to acquire relevant information from books and the internet.

"I think all nurses in this field should be specialized. It's very good. See, for example, we can't expect nurses specialized in burns act like nurses specialized in MS. This can help a lot." (An MS patient's 41-year-old wife).

Besides the shortage of specialized nurses in centers providing health services, families of bedridden patients with various physical problems faced with difficulty for care of those patients and receiving nursing advice. The reason was that there were no nurses specialized in MS in the society, and this problem exposed the patients' families with a great challenge, especially when they could not care for the patients for some reasons.

In all units providing services, human resources only consisted of nurses and neurologists who could not satisfy all needs of patient regarding the impact of the disease on all aspects of human beings.

Problems related to the resource allocation, which was a responsibility of the management and related to the structure of healthcare delivery, included lack of suitable environment for receiving services and inappropriate facilities in such places. The unavailability of medications was another problem for some patients where the services were provided, as the patients or their families had to get those medications from other centers.

"You don't know how much we suffered when we wanted only to move up on the bed. These beds aren't suitable for patients. Well,

for pulse therapy, the patient must lie higher on the bed, but an MS patient can't put his foot on the footstool." (A 40-year-old man suffering from MS for 17 years).

Another administrative challenge was lack of supervision on personnel's performance. In this regard, some participants believed that lack of supervision on personnel's performance was the result of their failure to pay attention to patients and their miscommunication. According to the administrators, lack of supervision on personnel's performance was due to the failure to regulate the organizational chart for service providing units, job description, and forms pertaining to the supervision.

"Hospital does not monitor MS patient care. They didn't inspect here at all. They didn't come to see how the patients are cared for here. Of course, it's much better to have supervision." (A nurse working in the neurology ward).

"We have problems because there's no supervision. Management should have sympathy to really manage these problems, to realize I don't just have a cold, I am dependent. The guy comes in, and doesn't really know what he should give to whom. Well it's incomplete, what is the poor guy supposed to do? They just come in and sit over there; it has become so mundane for them. They should insist that they do the work, and they should know their duties, and if they don't do their job, they ought to be warned and monitored." (A 46-year-old male patient with 3 years of history of MS).

Therefore, it seemed that the administrative challenges experienced by the participants, including the challenges related to resource allocation and supervision, could affect the performance of health service personnel and the manner of receiving services.

Policy-making challenges

Problems related to policy-making included lack of comprehensive services, bureaucracy, and problems in provision of medications. The policies of healthcare delivery to MS patients were made in Treatment Deputy and the Food and Drug Administration of the Ministry of Health. Measures taken by the Treatment Deputy of the Ministry of Health included the formation of a National Committee for MS; preparation of MS service package; development of instructions for providing services related to paying the franchise fee for diagnosis, treatment, and rehabilitation services, and submitting it to all Iranian universities of medical sciences; allocation of budget to the universities of medical sciences to offset costs of free services provided to patients; establishment of the patient record system; negotiating with insurance organizations to reduce franchise fees of services; and communicating with the Food and Drug Administration to supply patient's medications. The Food and Drug Administration supplies patient's medications and negotiates with pharmaceutical companies for pricing medications.

One challenge of policy-making was the policy makers' attention devoted only to the physical aspect of the disease

and supply of relevant services that could not satisfy all needs of MS patients regarding the various symptoms of the disease and the effects of the disease on the entire course of their life. Moreover, bedridden patients could not easily satisfy their needs, although they received some services from the Welfare Organization. However, these services could not resolve all their needs. The Rehabilitation Deputy of the Welfare Organization covers bedridden MS patients upon their registration in the organization and approval by the medical commission. The Welfare Organization provides services such as allowances for purchasing equipment (wheelchairs and air mattresses), medication allowances, sending mobile medical teams, and introducing patients to 24-h care centers.

“Nowhere in Iran, except a center in Tehran (Kahrizak), services are provided to bedridden MS patients. I mean MS patients don't receive rehabilitation services at all. There is one charitable MS care center only in Tehran. Well, families can't care for these bedridden MS patients at home.” (A neurologist).

The MS patients also complained about the bureaucracy of receiving services. They believed that the bureaucratic process for receiving services should be managed in a way that the patients and their families would not have to do numerous procedures and go to different organizations for receiving services.

“I went to the hospital ..., I waited from the morning to noon only for a shot of interferon, I sat there from the morning to noon. I thought they would treat us well, that they would inject the interferon right away. Also, there was a special paper work; for example, they told me to go to the insurance office, to go... to take my medication, or to have the doctor sign this...” (A 46-year-old man suffering from MS for 3 years).

Another problem experienced by the patients was related to the supply of medications. The patients were satisfied with free Iranian interferons, while the patients using foreign medications were concerned about the cost and unavailability of the medications, which was stressful for them.

“Prices of our medications are so jumpy. We have to use them permanently and sometimes we can't find them.” (A 27-year-old man, in an interview by IRNA news agency).

Lack of comprehensive services, bureaucracy, and problems in provision of medications were the policy-making challenges affecting the manner of receiving services.

Structural challenges

The difficult access to services, lack of centers providing integrated comprehensive services, space limit, and long wait were the structural challenges influencing the quality of healthcare delivery. It was difficult for the patients living in small towns and villages to access to services because services were only provided in big cities, and the patients and their families had problems such as commuting to treatment centers for receiving the services. Furthermore, the patients

suffering some degrees of disability or acute symptoms of the disease and living in big cities had difficulty due to the limited number of service providing centers.

“It's difficult for many patients, they can't come alone. They can't make somebody take a day off work to come here. We can't have just one or two centers, even neighboring cities must have such centers.” (A neurologist).

The long wait for receiving service was among the challenges of healthcare delivery due to the limited free services provided in public hospitals. In this respect, patients had to spend costs for services provided in private centers.

“Last year, I wanted to take an MRI in the 10th month. They told me it would be more than 200 USD (at a private center). I went to a hospital. They told me I should be admitted or take a turn for the next 2 months. So I had to go to a private center.” (A 39-year-old woman suffering from MS for 5 years).

The patients also encountered dispersion of service providing centers, as they had to go to various centers in order to buy medications, take MRI scan, do tests, visit the doctor, inject medications, and receive consultation and rehabilitation services. This condition was annoying for MS patients, especially those with motor problems.

Space limit was another structural challenge resulting in poor-quality healthcare delivery and, consequently, patients did not receive the necessary care.

“I mean we need a much larger space, we have patient overload here. The day clinic can hold six beds, but we admit 10 to 15 patients on average.” (A neurologist).

Based on the participants' experiences, the difficult access to services, lack of centers providing integrated comprehensive services, space limit, and long wait were the structural challenges influencing the quality of healthcare delivery and faced by the patients and their families.

DISCUSSION

The results of this study revealed the challenges for healthcare delivery despite the efforts of governmental and nongovernmental organizations. The Iranian governmental and nongovernmental organizations have tried to provide services to MS patients despite the high cost of their treatment. These efforts included: Measures taken by the Ministry of Health and universities of medical sciences for uniforming healthcare delivery, such as development of instructions for healthcare delivery through consulting with the National Committee for MS, paying subsidies for free services, providing free services in public hospitals, including diagnosis, rehabilitation, outpatient services, and providing Iranian interferons; measures taken by the Welfare Organization related to healthcare delivery, such as providing mobility aids and paying pension and nursing costs to

bedridden patients; and measures taken by nongovernmental organizations, such as MS societies, in order to cover the socioeconomic aspect of the disease.

The functional challenges were among the healthcare delivery challenges. One functional challenge was the misdiagnosis and delayed diagnosis of the disease that made patients visit various doctors and resulted in diagnosis of the disease after a long time. Moreover, some participants were not satisfied with the manner of being informed of the diagnosis. Results of Ytterberg *et al.*'s study in 2008^[22] and Jassens *et al.*'s study^[38] showed that MS patients preferred that their disease had been diagnosed early.

The service providers' failure to pay enough attention to patient needs was also a functional challenge that made the patients and their families dissatisfied and visit various doctors in order to make a better communication with them. The patients were content with those personnel who understood their needs and empathized with them. The results of Egger *et al.*'s study on MS patient needs in Switzerland revealed that the most important needs of the patients and their families comprised their need to have more information about their disease and its treatment, mental support, and consultation.^[39] Matti *et al.*'s study also indicated that the doctors provided little information to the patients who were willing to receive more information from the doctors.^[40] The results of the studies by Somerst,^[41] Forbes,^[31] and Sweet^[42] showed that the patients needed more information and psychological support.

The patients' lack of information about the disease process and receiving unofficial information about a definite treatment for the disease resulted in patients' failure to continue being treated by service providers and, consequently, exacerbating the disease after a while.

The administrative challenges involved the shortage of human resources in service providing places and the need for nurses specialized in MS in treatment centers and the society. Based on a survey by WHO, the number of MS nurses in the world ranged from 0 to 0.07 per 100,000, with the maximum number of nurses in European countries.^[43] However, according to Somerst^[41] and Forbes,^[31] patients preferred to be in contact with nurses specialized in MS.

The unfavorable equipment and space limit of the service providers were the other administrative challenges. The patients with motor and sensory problems had difficulty when they wanted to lie on bed due to the inappropriate equipment. Brandon also examined hospital equipment.^[44]

Another administrative challenge that was mentioned by the participants and administrators was lack of supervision on personnel's performance. This challenge resulted from the failure to regulate the organizational chart for the related units and, consequently, lack of job description and supervision forms. The service providers' physical- and

treatment-oriented approach and failure to pay enough attention to rehabilitation and mental needs of the patients, especially bedridden patients, and their families were among the administrative challenges. According to a WHO survey on the services provided to MS patients in the world, 21% of countries do not have home visits. In 30% of countries, life support equipment or technical support was not provided, and 11% of countries did not provide information necessary for patients' families and care givers.^[43] The results of Hampton's study also showed that 64% of the patients needed psychosocial services.^[45] Ytterberg *et al.*'s study revealed that about half of the patients required psychosocial support and consultation and rehabilitation courses. A high percentage of patients needed physiotherapy and occupational and rehabilitation therapy. One-third of patients complained about their rehabilitation needs not being met.^[22] Forbes also revealed that the patients required rehabilitation therapy and home care.^[31]

Other challenges of service providing were the concerns about supplying medications due to the high cost of foreign medications, lack of insurance coverage, their scarcity, and changes in their prices. International sanctions and their associated problems were influential in scarcity and raised price of the medications that troubled patients and the Food and Drug Administration.

The difficult access to the services was another challenge of healthcare delivery, as it limited the patients, especially those with motor problems, in using services. Results of Hampton *et al.*'s study on the health service needs of women with neurological disorders also indicated that the patients did not receive adequate service due to lack of easy access to service providing centers. According to these patients, inaccessible service providing centers and difficulties in going to these places were the most significant environmental barriers.^[45] A study conducted by Finlayson *et al.* also showed that 36% of the patients had never used physical treatment services, and that an influential factor in using these services was their accessibility, as the patients living in urban areas had used services more than others.^[46] Results of Pohar's study also showed the inaccessibility of services as the reason for not meeting patient needs.^[47]

The long wait for receiving free service in public centers was another challenge of service providing, as the patients had to spend costs of services provided in private centers. Results of Pohar's study on health service in Canada also revealed that the long wait was the main reason for not meeting MS patients' needs.^[47] Moreover, results of Markwick *et al.*'s study on the physiotherapy services provided by the British National Health System showed that the patients complained about the long wait.^[48] In Brandon's study, patients were dissatisfied with the long waiting list.^[44]

The factors affecting performance of personnel, receiving services by the patients, and control of the disease included lack of a defined structure for service providing centers, the

failure to regulate job description in these centers, lack of holistic centers for healthcare delivery, the shortage of human resources, failure to instruct human resources for providing services, lack of supervision and one-dimensional approach in service policy-making, and paying attention only to the physical aspect of the disease. In this regard, the patients and their families had experienced difficulties in the course of diagnosis, the attention paid to their needs, follow-ups, and supplying medications.

The strong points in this study include collection of data from several sources to gain deeper insight on the subject and emergence of possible recommendations to reform the status of services provided for patients with MS. In this study, only a few patients, family members, and health service providers were investigated, which can limit generalizability of the results.

CONCLUSION

Despite service providers' every effort at different levels of health system, patients and their families were faced with challenges in receiving services, which involved every dimension associated with providing services, including policy-making, structure, performance, and management. It is therefore necessary that policy and provision of health services be based on the needs of patients and their families; they should be the focal point of the process of providing services and should have an active role. Additionally, an opinion survey of patients and service providers should be conducted on the quality and quantity of services, and results should be used in designing services.

Regarding the centralized decision-making in the healthcare system in Iran, it seems that the health service policy makers should modify some service delivery policies. Moreover, policies should be made on the basis of epidemiological field research and patient needs, secondary and tertiary prevention, all physical and psychosocial aspects, and the sociocultural and economical context. An appropriate structure for service providing centers must also be embedded in the policies. In medical universities, the administrators should supervise the performance of personnel working in health service centers and promote personnel's performance through holding short-term training courses besides implementing policies.

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