

Rehabilitation services difficulties perceived by Multiple sclerosis patients, their families and professionals in Iran: A qualitative study

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Abstract

Background: Rehabilitation services for people with chronic illness such as multiple sclerosis (MS) have recently come into focus. Adequate and efficient services should be provided based on a deep understanding of patient's difficulties and unmet needs, from different perspectives.

This study was conducted to identify patient's unmet needs and difficulties that they have encountered during the process of diagnosis, treatment and rehabilitation.

Methods: 35 participants (21 patients, 7 professionals and 8 families) were purposively selected for in-depth qualitative research. Interviews were voice recorded and transcribed verbatim. Transcripts were coded thematically using a content analysis approach.

Results: Results are presented in four categories: prerequisites for rehabilitation, treatment administration, awareness level and modification.

The majority of participants highlighted the significance of the patient-doctor interaction and access to competent experts. Also the teamwork as a sub-category of health care service was important from all participants' point of view.

A low level of trust in physicians more likely reduces the continuity of care and adherence to treatment. The unawareness and inadequate information of people, family and patients about the disease can cause stigma, reduced family support, stress and anxiety, respectively.

Transportation and Architectural barriers were the causes of inducing restriction and making the patients house-bound.

Conclusion: Advocating for a rehabilitation service package to consider the social rehabilitation in MS patients is critical. Also the team work approach could facilitate an understanding of the barriers faced by MS persons, thus facilitating patients receiving the right treatment in the right place at the right time.

Key words: content analysis; Multiple Sclerosis; Iran; Rehabilitation,

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Introduction

Multiple sclerosis (MS) is a common disabling neurologic disease [1] of young adult people [2] which is more prevalent in the women [3, 4]. More than 2.3 million MS patients in the world are reported [5] and Europeans are more at the risk in comparison to Asians and Africans [6]. About 70,000 patients are diagnosed in Iran [7, 8] and its prevalence has had a significant increase from 26.24 per 100000 in 2006 to 44.53 per 100000 in 2011 [3, 9]. Signs and symptoms of disease (fatigue, depression and anxiety) have impact on patients' daily living and social participation [10, 11].

A comprehensive rehabilitation approach in conjunct with medical treatment should be considered in the treatment process. Providing the right services at the right time induces the optimum treatment outcomes. Prerequisites for providing the right services is based on a deep understanding of patient's barriers, difficulties and unmet needs [12] from different perspectives. The unmet needs from the perspective of patients, healthcare professionals and their caregivers [5, 10, 11, 13, 14] are assessed in different studies and various themes related to service provision are revealed such as "lack of information about services", "lack of continuity and co-ordination of care" [11, 13] "support from family/friends", "healthcare services", "managing everyday life" and maintaining biographical continuity [15]. These differences can be related to a mismatch between perceived unmet needs by professionals, families and the patients. It seems that enrolling the different groups such as MS patients, patient's family and professionals to express their experiences, perceived difficulties and needs are necessary [5]. The present study with the aim of explaining patients' difficulties, barriers and unmet needs from the perspective of professionals, family and themselves simultaneously was therefore conducted.

Methods

Participants

In this qualitative content analysis research, 36 participants (21 patients, 7 healthcare professionals and 8 patients' family) were enrolled voluntarily. They were selected through a purposeful and convenience sampling. Patients with definitive diagnosis of MS aged between 24-65 years from Iranian MS Association (IMSA) and Welfare State Organization (WSO) were selected. The healthcare professionals included social workers (n=3), neurologists (n=1), occupational therapist (n=1) and physiotherapist (n=2) with at least one-year experience of work with MS patients. Patient's family members (a child, a brother, three spouses and three parents) have lived with at least one MS patient and were involved in the treatment process. All of the samples were able to express their experiences and needs. Sampling was terminated when no additional information was acquired and data saturation occurred.

Data Collection

Data was gathered through an in-depth interview with flexible and open ended questions. A prototype interview guide was developed based on the literature [5, 11, 12,

15, 16] and the discussion within the research team. A pilot interview schedule was conducted in three patients and some minor revisions were applied to it. All interviews were conducted in a place that the participants preferred. The interviews usually lasted between 30 and 60 minutes and were tape-recorded and transcribed verbatim.

Trustworthiness

To maximize theoretical sensitivity, constant comparison was done by returning to the data several times during the analysis. All authors participated in the discussions throughout the analysis. All of the transcripts and the preliminary sets of codes and categories were checked by two experts within the research team (Peer review) and some of the participants (Member check).

Ethical Consideration

The study was approved by independent ethics committee of University of Social Welfare and Rehabilitation Sciences, Tehran, Iran (IR.USWR.REC.1395.249) and all participants completed an informed consent form. The purpose of the study and confidentiality of information were explained to the participants.

Data Analysis

The interviews were transcribed and then imported into the qualitative software program MAXQDA (version 10) for analysis. Next open text coding included examining each interview, breaking the transcript down into individual units of meaning, and labeling them to identify categories and concepts that were used. After that, evolving concepts were regrouped to form more abstract categories. Categories were systematically sorted, compared and contrasted, yielding increasingly complex and inclusive themes, until saturated. This analytical process was non-linear in nature, with the analyst going back and forth between the different stages of coding. Finally, the findings were compared with the original tapes, ensuring equality between texts and extracted themes.

Results

The Sample characteristics are presented in Table 1.

Four overall categories were identified based on participations' experiences: "Prerequisites for rehabilitation, Treatment administration, Awareness level and Modification." Subcategories of these four categories are provided in Table 2.

Prerequisites for rehabilitation:

Interpersonal interaction, MS specialists' Competency and sufficiency and Teamwork are grouped into this category. Interpersonal interaction describes physician-patient relationship. The patients and their families explained that physicians had not appropriate interaction with them and did not pay attention. The following example highlights this point:

"As I entered the room, he didn't get up from his seat. He didn't even take my pulse. I was saying to him my symptoms and he was prescribing some medicine without paying any attention to my explanation."(MS P4, man)

Table1: Socio-demographic characteristics of the participation

	MS Patients N (%)	Healthcare professionals N (%)	MS patients' family members N (%)
Gender			
Male	11 (52.4)	4 (57.1)	6 (75)
Female	10 (47.6)	3 (42.9)	2 (25)
Age (year)			
20-30	4(19.04)	1(14.2)	2(25)
31-40	8(38.09)	1 (14.2)	1(12.5)
41-50	7(33.33)	2 (28.5)	-
51-60	-	1 (14.2)	-
61-70	2(9.52)	2 (28.5)	3(37.5)
71-80	-	-	2(25)
EDU (years of education)			
12≤	6 (28.6)	-	3(37.5)
13-16	12 (57.1)	3(42.85)	3(37.5)
17-18	1 (4.8)	2(28.57)	1(12.5)
≥19	2 (9.5)	2(28.57)	1(12.5)
Employment			
Employed	3 (14.3)	6(85.8)	2(25)
Self-employed	6 (28.6)	1(14.2)	2(25)
Retired	5 (23.8)	-	3(37.5)
Not working	7 (33.3)	-	1(12.5)
Time since diagnosis (years)			
0-5	4 (19)	-	-
6-10	3 (14.3)	-	-
11-15	6 (28.6)	-	-
16-20	1 (4.8)	-	-
21-25	5 (4.8)	-	-
≥26	2 (9.5)	-	-

MS is multiple sclerosis

Table 2: Categories and subcategories of the MS patients' difficulties

Category	Subcategory
Prerequisites for rehabilitation	Interpersonal interaction
	MS specialists' competence and sufficiency
	Teamwork
Treatment administration	Treatment adherence
	Trust in therapists
	Controversy on the efficacy of medicines
Awareness level	MS Patients' information about disease and services
	Families' information about disease and services
	People's information about disease
Modification	Transportation barriers
	Environmental barriers

Also, telling the diagnosis directly to the patients usually shocked them and it was so unexpected. The patients preferred that the diagnosis was told initially to their family.

"I didn't expect to hear abruptly that. I had MS. I was really shocked. The doctor didn't bother telling the name of my disease after giving me some preliminary introduction". (MS P21, man)

Participants believed that the MS specialists have the key role in the rehabilitation process. They should have enough knowledge and skills to diagnose the disease, treatment and rehabilitation at early stages. Incorrect diagnosis caused a wrong prescription and secondary side effects. For example:

"I had cramp in my leg and I couldn't raise it then I was referred to a practitioner. He told my father that it is muscular spasm and will be relieved by Piroxicam ointment...., my situation got worse every single day,... once my disease was diagnosed, I was walking with difficulty." (MS P14, man)

Moreover, lack of balance between the number of the patients and the specialists is said clearly by the patients such as 10th patient.

"The doctors try to help the patients but the number of patients and doctors isn't comparable...., Even, we don't have one social worker for a hundred patients. How can just one social worker can deal with all the patients' problems." (MS P10, woman)

The following quotation refers to the lack of teamwork as one of the main problems which participants believed is an essential prerequisite in the treatment process while the most of the patients have not experienced it during the treatment period.

"A doctor just recommends taking some medicine. Now, I realize that psychology and occupational therapy are important. Rehabilitation team doesn't make sense here and the doctor is the therapist." (MS P6, man)

Treatment administration

Medication adherence, trust in physicians and controversy on the efficacy of medicines are comprised in this category, all of them were important in continuity of treatment.

The patients did not follow the medical advice and prescribed treatment. For example:

"The examination fee is really expensive, so we referred to doctors less than before. I used to take my wife to physiotherapy clinics but soon after I gave it up as I couldn't afford it. The truth was that I had to spend all my income on my wife's medicine and I couldn't meet any more expenses." (FM1, husband)

Participants explained that most of the patients spent considerable time choosing the best physician which imposed high stress on them. According to the expert 3 changing the physician makes them tired.

It's so important that patients don't frequent different offices to make their companions tired. They must trust their practitioners and follow their treatment under their observation and this will prevent the occurrence of so many difficulties. (E3, man)

The following quotations show the controversy between the patients and physicians on the efficacy of medicines. Physicians believed that domestic medicine has a high quality while patients do not think so.

Domestic medicine is made with the same quality and under the same standards but the patients imagine that they aren't affective. (E3, man)

Iranian medicines aren't effective. ..., when I have an Iranian injection, I get nauseous. I can't bear it. Doctors prescribe all these domestic medicines because people can't afford buying foreign medicine. (MS P1, woman)

Awareness level

This category includes three subcategories: Patients, Families information about disease and services and people's information about disease.

The participants explained that inadequate information about the disease and services are the origin of developed stress and anxiety. For example:

"I didn't know who to refer to. My mother constantly took me to different doctors.

I didn't know what Multiple Sclerosis is. One said "I have Apitherapy. Bee stings are so helpful for you". I was allergic to Apitherapy and as soon as I had it, I was in a coma for three days." (MS P11, man)

Unawareness of the families about the disease reduces their support. The participants explained that the families worried about the patient's conditions. When they have not enough information, they are confused and not able to navigate the challenges of the disease. In this regard MSP 21 said:

"Families don't know anything about the disease. They are worried what changes will happen. Will the patient become wheel-chair dependent in some years? All these factors cause worriedness. If they're informed well, I could be helped by them." (MS P21, man)

Modification

The modification includes two subcategories: transportation and environmental barriers.

Patients described that inadequate transportation facilities have been restricted and made them house-bound. For example:

"If I want to pay a visit to my uncle's house which isn't far, I must get on a vehicle with my wheelchair comfortably. Such a vehicle doesn't exist; therefore, I must call a taxi. Getting in and out of a taxi is so difficult for me, these limitations made me house-bound." (MS P5, man)

Environmental barriers such as unsuitable buildings and non-level pavements have limited the disabled patients from participating in social, occupational and recreational activities. For example:

Many patients used to be potent but they can't steer their wheelchairs. Physical barriers, unsuitable official buildings and their work place, the physical condition of streets pavements have restricted them. (E5, 43 years old, man)

Discussion

The results of 36 interviews showed four categories: Prerequisites for treatment and rehabilitation, Treatment administration, Awareness level and Modification. Some of the difficulties such as physician-patient relationship should be considered before the implementing of the rehabilitation process. This relationship includes respecting each other, spending enough time with patients and sensitive conversation especially in breaking bad news. Similar to the results of Golla et al, spending time with patients as a difficulty, was underlined by most patients [15]. Patients needed empathy from physicians but they did not receive it. Methley et al (2017) similarly have found that the lack of empathy, politeness, respect and active listening skills results in a negative interaction and this negativity challenges the patients' sense of personhood, devaluing them to a number and not taking them seriously.

MS is a complicated disease which leads to extensive unmet needs for the patients but according to our findings, there is a lack of competent MS specialists for appropriate diagnosis, managing and resolving these unmet needs. Moreover, the balance between the patients and the specialist's numbers is also important. The shortage of comprehensive rehabilitation centers and competent specialists were emphasized. Golla et al (2012) believe that the detailed knowledge about the disease nature increases the quality of treatment and the receiving of appropriate care [15].

Neurologists are the professions who diagnose MS but they usually don't refer patients to other professions to assess the other aspects of patients' problems [17]. Patients experience a complex situation thus appropriate care with holistic view is needed which a multidisciplinary team can provide [12, 16, 18]. According to the National MS Society (2015), the treatment goal is to promote comfort, function, independence, health and wellness which can be achieved by a comprehensive, coordinated care system. Unfortunately in our study opposed to the previous research [15] the participants expressed lack of adequate teamwork between the physician and other health care providers such as physical therapist, occupational therapist and social worker.

Poor adherence to treatment, especially during the first months of therapy because of no obvious disease symptoms and experience of relapse or financial distress was another difficulty. Decoo et al, has mentioned that the low quality of life, increased mortality and health care cost are the results of non-adherence. These findings are consistent with our results, where patients reported the increased symptoms, deteriorated health status and increased health cost as a result of non-adherence [19].

MS specialists can explain the importance of accepting and continuing treatment and can play an effective role in resolving the existing barriers if the patients trust them. Furthermore, patient's trust can improve patient-specialist interaction [20, 21]. Our findings showed that unilateral discontinuation of treatment and seeking another physician is the main consequence of lack of trust. Golla et al, have mentioned that lack of trust can hinder constant care [15]. Some other studies emphasized that a low level of trust in physicians is more likely reduce patient satisfaction, continuity of care and adherence to treatment [21].

The efficacy of foreign and domestic medicines is a controversial issue that has not been addressed within the previous studies. From the MS professionals' view the efficacy of domestic medicines is clinically more significant, but this is not confirmed by the patients who experience them. This controversy can raise patients' doubts about the effectiveness of medicines and arbitrarily make decisions to change their medicine.

Our study also highlighted a lack of information about MS disease, its complications and effects on the attitude of people [22]. It also affects patients and families' mental health, stress, anxiety and related decision-making. Understanding the nature of the disease helps the patients and their families to cope much better with it and also in adopting effective interventions [16] and increased empowerment of patients and their family [23].

Methley concluded that the patients who have enough awareness of primary health care services can select the better available care [14].

Another disadvantage of the lack of adequate information about the disease is bad behavior toward the patients such as mocking them, looking compassionately or stigmatizing them as a drunken person. In the long term, unpleasant reactions will cause exclusion of patients and have them stay at home and hide themselves.

The lack of accessibility to environment and appropriate transport facilities, especially for patients with functional limitations, are some of the major barriers. The lack of ramp, elevator and stair-lift, not only restricts their activities but also diminishes their relative's interaction. Existence of accessibility features can decrease the risk of falling and injury, and no participation in social, occupational and recreational activities [24]. Borreani et al, mentioned transportation has a main role in the daily life of patients [10] but handicap transportation and accommodated vehicles are very limited in Iran. So this limitation has effects on the treatment continuity and environment.

Limitation

Inability of the patients' family to leave the patients alone at home to participate in the interview was a limitation. Generalizability of the results to all Iranian MS patients is another limitation of the study.

Obtaining data directly from patients, their families and specialists was the strong point of this study.

Conclusion

Professionals, patients and their family's perspective are essential to gain a comprehensive view on Patients' unmet needs. It seems that improving public awareness and information about MS disease is an effective way in decreasing patients and their family's stress. It seems that team work approach will facilitate the understanding of the barriers faced by patients.

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