



# Research Paper:

## Experience of Iranian Women With Multiple Sclerosis About Urinary Dysfunctions Consequences: A Qualitative Study



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### Conflict of interest

The authors declared no conflict of interest.

## ABSTRACT

**Background and Objectives:** This study aimed to identify the experiences of women with Multiple Sclerosis (MS) about urinary dysfunctions consequences.

**Methods:** This qualitative study with the content analysis approach included 10 women with MS (age range: 29 to 59 years), who were recruited using a purposive sampling method with maximum variation. Through semi-structured in-depth interviews, the participants explained their experiences of urinary dysfunctions consequences. The obtained data were analyzed based on the content analysis method of Graneheim and Lundman.

**Results:** The content analysis revealed three key themes: Physical consequences, psycho-emotional consequences, and economic consequences.

**Conclusion:** Urinary dysfunctions cause widespread physical, psychological, and economic problems for women with MS. Therefore, treatment staff should address the MS patient's concerns caused by urinary dysfunctions, in a non-threatening atmosphere, and help them to fearlessly manage their urinary problems.

**Keywords:** Qualitative content analysis, Multiple Sclerosis, Urinary dysfunctions, Lived experiences



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### ↑ What is "already known" in this topic:

To provide a patient-centered management of urinary dysfunctions in MS women it is necessary to identify their needs and experiences of their problems.

### → What this article adds:

It seems due to the ineffectiveness of clinicians consultations, a number of Iranian MS women in addition to feeling ashamed of expressing urinary problems, are unaware of urinary dysfunction consequences. Therefore support and non-threatening atmosphere provided by clinicians are needed for helping MS women managing it.

## 1. Introduction

**M**ultiple Sclerosis (MS) is an inflammatory and multifactorial neurological disease with unknown causes and destructs the myelin sheath of the central nervous system [1-3].

Bladder dysfunction is the third most common symptom of MS, affecting 75% of MS patients [4, 5]. Spinal plaques may play a greater role in the development of urinary dysfunctions [6]. Also, increased urinary frequency and mixed urinary dysfunctions are the most common urinary symptoms in MS people. Urinary dysfunctions cause economic problems by imposing the costs of purchasing pads and other urinary management equipment on the individual, as well as the costs of hospital services, nursing, medicine, etc., on the healthcare system [7, 8].

Furthermore, urinary dysfunction affects physical well-being and the psychological and social aspects of life in patients with MS [9]. Chiarelli et al. reported a strong relationship between urinary incontinence and an increased risk of falling due to a rush to the toilet [10]. Moreover, enuresis is one of the most common urinary dysfunctions in MS women; it reduces sleep quality and causes the feeling of fatigue the next morning. Decreased sleep quality is also associated with increased disability and depression in women with MS (WwMS) [7, 11-13]. Besides, fatigue secondary to urinary incontinence negatively impacts daily functions, social and occupational tasks, and the overall health of WwMS [14, 15]. In many cases, patients are unaware of the effects of their urinary disorders on their lives, therefore, it is common for patients to be reluctant to talk about their urinary problems, owing to the fear of social stigma.

Although urinary dysfunctions cause many limitations and problems for WwMS, clinicians often ignore to talk about urinary dysfunctions [7, 16]. According to Koch et al. investigations, only one-third of MS patients with a history of urinary incontinence seek treatment [17]. Also, refusing to talk about urinary incontinence and not receiving treatment at the golden time, often lead to the use of self-made strategies, such as reduced activity or reduced fluid intake, which are often harmful [7].

In 2016, the World Health Organization stated that health services should provide patient-centered treatments that consist of a holistic view considering the disease and the physician's opinions, in addition to paying attention to the patient's opinions and concerns [18-20]. Achieving this goal is not possible without considering the experiences and needs of patients about the disease they are struggling with; these experiences are strongly influenced by the culture of the community in which the patients live.

Currently, the use of qualitative research methods is increasing in medical sciences, because these methods provide a deep understanding of the phenomenon under study. Also, they are the best type of research to investigate and understand human experiences [21, 22]. Qualitative research provides answers to the questions of "why" (to understand and explain the phenomenon) and "how" (to interpret the behavior of the phenomenon). It can reveal the participant's beliefs, behaviors, and feelings. In other words, qualitative research discovers the various facts of a phenomenon [21]. The management of urinary dysfunctions requires medical teamwork; clinicians cannot complete their treatments without considering the patients' experiences and feelings. Therefore, this qualitative study aimed to investigate the experience of Iranian WwMS about urinary dysfunctions consequences.

## 2. Materials and Methods

The inclusion criteria were as follows: being female, having more than 18 years of age, receiving a definite diagnosis of one type of MS by a neurologist, and experiencing at least one type of urinary dysfunction. Also, the patients were included if they got a minimum score of 21 on the mini-mental state examination and a score of between 1 and 8 on the expanded disability status scale. We used the purposive sampling method, and to increase the validity and transformability of the results, the participants were selected with maximum variation. Data collection continued until data saturation was reached. Eventually, 10 women with an average age of 45 years participated in this study. Besides, the average MS and urinary dysfunction durations were 12.5 years (range: 3 to 30 years) and 5.8 years (range: 2 to 14 years), respectively. Table 1 presents the individual characteristics of the participants.

Data were collected using semi-structured, in-depth, face-to-face interviews. The framework of guiding questions was identified from previous relevant research and two pilot interviews. Each interview began with an open question, such as "What do you experience with urinary symptoms on a day and night from the morning you wake up until the next morning?", allowing participants to speak freely about the subject. For the convenience of the participants and building an intimate atmosphere, a female interviewer was selected who was an MSc student of physiotherapy and was trained for qualitative studies. Also, the body language of the participants was completely recorded. All interviews were recorded by a mobile phone recorder with the permission of the participants. Interviews lasted between 30 to 60 minutes and were conducted wherever participants preferred (home, physiotherapy clinic, hospital, etc.), in calm and completely private conditions.

Simultaneous with data collection, the obtained data were analyzed based on Graneheim and Lundman's qualitative content analysis method. The qualitative content analysis is a proper method for discovering human experiences [22]. Initially, the interviews were transcribed word by word. Then, a typed copy of the interview was given to the participant, so that she could correct, clarify, and complete her comments. Next, the research team read the typed interviews to begin the analysis with the coding and classification process. The texts were read several times to achieve a sense of the whole. Then, the meaning units of participants' statements were identified and condensed. The next step was an abstraction where the condensed meaning units were categorized according to the questions and the objective of the study, finally, the main themes were extracted [23].

Credibility, dependability, and transferability are tools for achieving the trustworthiness of qualitative research [23]. In this study, the interviews were typed and reviewed in each session until the emergence of the main themes, which lasted 9 months. These prolonged engagements and persistent observations were done to achieve the trustworthiness, transferability, and confirmability of the data. Furthermore, the participants were selected with the maximum variation of the MS type, urinary dysfunction type, education, age, etc. The interviewer tried to establish effective communication with the participants to create a calm and non-threatening atmosphere and conduct in-depth interviews.

To ensure credibility and increase the accuracy of the study, the obtained data, extracted codes, and analyses were frequently reviewed by the research team, who were experts in qualitative research, especially in the field of neurology. Also, the participants' recognition of findings guaranteed the confirmability. This goal was achieved by showing the data to participants to express their views on the accuracy of the data and to make corrections if necessary. In two of the interviews, corrections were made after the participants' review. The data were then categorized by the research team and reviewed by the other members of the research team to avoid researcher bias. Moreover, transferability was insured with a thick description of the participant selection, data collection, and analysis process. Describing the process of condensation and abstraction, we tried to facilitate judgment about the credibility of the data [23].

Finally, three themes of physical consequences, psycho-emotional consequences, and economic consequences were extracted. Table 2 shows the obtained themes and subthemes.

### 3. Results

The analysis of 10 interviews with the participants yielded three main themes of physical consequences, psycho-emotional consequences, and economic consequences.

**Table 1.** Individual characteristics of the participants

Row	Age, y	Marital Status	Education	MS Duration, y	MS Type	Urinary Dysfunction Duration, y	Urinary Dysfunction Type	EDSS
1	38	Married	Bachelor	17	RR	12	MUI- nocturia	4
2	29	Single	Bachelor	11	RR	2	MUI- urinary retention	1
3	59	Married	Elementary	3	SP	3	MUI	4.5
4	45	Divorced	Diploma	4	RR	3	MUI	2.5
5	36	Married	Diploma	12	RR	10	MUI enuresis-loss of bladder sensation	4
6	51	Married	Diploma	14	RR	2	MUI	6
7	53	Married	Bachelor	8	PR	5	MUI	6
8	54	Married	Diploma	30	SP	14	MUI- urinary retention	5.5
9	47	Married	Diploma	6	RR	3	UI	5
10	38	Single	Bachelor	20	PP	4	MUI	7.5

RR: Relapsing-Remitting; MUI: Mixed Urinary Incontinence; SP: Secondary Progressive; PR: Progressive Relapsing; UI: Urinary Incontinence; PP: Primary Progressive.

**Table 2.** Subthemes and themes extracted from the interviews

Subthemes	Themes
Constipation, kidney stones and urinary tract infections Injuries from falling Inability to perform daily activities	Physical consequences
Decreased self-confidence Depression Increased anxiety	Psycho-emotional consequences
Increased costs Leaving their job	Economic consequences

### Physical consequences

Women in this study suffered from some physical consequences after experiencing urinary dysfunctions. They expressed physical consequences as bodily injuries or disabilities that they faced after having urinary problems. Some of these consequences, like urinary tract infections due to decreased water intake, could trigger the increase of urinary dysfunction in a vicious cycle. The physical consequences of urinary dysfunctions in the participants included “constipation, kidney stones, and urinary tract infections”, “injuries from falling”, and “inability to perform daily activities”.

Some participants experienced constipation, kidney stones, and urinary tract infections after having urinary problems. For example, participant No. 8 said: “I do not drink water and fluids as far as I can tolerate. That’s the reason I got a urinary tract infection. Now my doctor told me that I have to drink a lot of water because of this infection”. Also, participant No. 6 stated: “I did not drink water early in my illness. Because of that, my kidneys had a problem and brought two stones, then, I got an infection. Now I have to drink water all the time”.

Three participants experienced a fall due to a rush to the toilet and the subsequent injuries and fear of falling. Participant No. 4 stated: “When I had to go to the toilet quickly, I fell on my way to there. I also couldn’t control my urine. Both of my legs were bruised. My knee hurt too. I remember once I had an ankle sprain”.

According to participants, the inability to perform daily activities is the final physical consequence of urinary disorders. Participants reported that they were unable to do some daily activities, such as shopping, going out, and washing dishes. In this regard, participant No. 1 mentioned: “I used to do all my works by myself. I used to go shopping, walking, etc. but now I cannot go out for a long time. It bothers me a lot because I have to go to the toilet several times and if it is not available, I may experience incontinence”. Participant No. 5 explained: “It’s very difficult now. I cannot even wash the

dishes. As soon as my hands get wet I feel an urgency. I do not want to be like this. I’ve reduced my activities now”.

### Psycho-emotional consequences

Psycho-emotional consequences are the second category of the consequences of urinary dysfunctions. After experiencing urinary dysfunctions, participants had the feelings of “decreased self-confidence”, “depression”, and “increased anxiety”. Participants stated these feelings as a result of experiencing a feeling of shame and helplessness due to incontinence in public. Also, low self-esteem and depression result in social isolation in WwMS, because they do not want to be judged by their relatives or other people. Participant No. 1 who felt less self-confident said: “Ever since I couldn’t control my urine, I had completely lost my self-esteem. I stay away from gatherings. I am ashamed all the time”. Participant No. 7 stated about depression: “I used to be strong. My doctor once said to me, you are a warrior. But imagine getting wet in front of everyone.... I got depressed. I was very depressed. I was crying all the time”. Also, participants were concerned about issues, such as urinary dysfunctions aggravation with getting older, falling, dependence on others, diapers being visible under their clothes, incontinence in public, etc. Participant No. 9 said: “I’m always afraid of incontinence in public, that’s the reason I prefer staying home and I refuse going to parties or gatherings”. Participant No. 1 also explained: “I will not go to any parties because I’m afraid my diaper would be visible under my clothes. I do not want everyone to notice and understand that I use a diaper”. She also stated: “I’m always afraid of the future, I think I will lose my urinary control completely when I get old and everything will get worse”.

### Economic consequences

The experience of urinary disorders also had economic consequences, including “increased costs” and “leaving their job” for women participating in this study. These consequences impose economic burdens on WwMS, because these women had to purchase expensive MS medications, walking

aids, etc., to deal with the disease. Thus, the increased costs as a result of buying diapers or visiting a urologist and not having health insurance due to unemployment make these women's life harder. In this study, two participants stated an increase in their daily costs as a result of the need for diapers or urine control medications. Participant No. 10 explained: "Our medications for MS are expensive enough. Now that doctor has prescribed me another expensive medicine to control my urine, the problem is doubled. The diaper is getting more expensive each day. Moreover, besides all these costs, we cannot even have a proper work because of our MS-related disabilities". Two participants were forced to quit their jobs because of urinary dysfunctions and related problems, subsequently, they felt economic burdens. Participant No. 4 who was a nurse assistant said: "Sometimes I got a headache when I was at work, then, I didn't have any control of my urine and I fell on the ground, so I got fired. Now I don't have any health insurance and that's really difficult". Participant No. 7 who quit her job because of the stressful atmosphere also explained: "At work, it was always discrimination between me and others, they talked behind my back, I felt so much stress and I was not happy. So, I decided to quit my job. But that wasn't the end of the story. I got depression, I was crying all the time. I didn't have any income or health insurance. That was intolerable".

#### 4. Discussion

Urinary dysfunctions have consequences for WwMS; the identification of these consequences plays an important role in managing urinary dysfunctions. In this study, the content of the consequences of urinary dysfunctions included three categories: physical consequences, psycho-emotional consequences, and economic consequences.

##### Physical consequences

Constipation, kidney stones, and urinary tract infections were among the physical consequences that participants experienced following urinary disorders. These consequences indirectly occurred as a result of either reduced water and fluid intake or using urinary dysfunction management devices, such as diapers and catheters. Consistent with the results of the present study, De Seze et al. showed that urinary disorders lead to the infection of the lower urinary tract and bladder and the urinary tract stones [24]. It is also reported that lower urinary tract infections are more common in people with MS who need catheterization [25]. In preventing kidney stone formation, it is important to consume at least two liters of fluid per day to facilitate the excretion of solid microparticles from the urinary tract [26]. Therefore, the arbitrary reduction of water consumption to prevent incontinence in WwMS can

increase the risk of kidney stone formation, urinary tract infection, and constipation.

Some of the participants had an experience of falling due to urinary urgency and suffered from multiple body injuries. Urinary incontinence is directly related to the increased risk of falling because of a stressful rush to the toilet. Also, nocturnal urinary dysfunctions can increase the risk of falling owing to the lack of sufficient light at night, sleep disturbance, and the rapid change of body position from sleeping to standing and walking [10, 27]. Similarly, Finlayson et al. stated that urinary incontinence is one of the risk factors of falling and the subsequent increased fear of falling, which is another risk factor for increasing the probability of falling [28].

Furthermore, Browne et al. reported that incontinence and leakage disrupted the daily activities of MS patients, including driving and shopping [7]. In this study, some married women complained about "inability to dishwashing", which was not mentioned in similar studies. Participants reported experiencing urinary incontinence when their hands were in contact with cold water. It seems that the ability to wash dishes (along with other daily activities) is important for the married women in this study; this is a cultural belief. In Iranian culture, wives accept the responsibility of most household chores, especially dishwashing, so, women who are unable to wash dishes because of urinary dysfunctions will experience a bad feeling of disability.

##### Psycho-emotional consequences

In this study, women acknowledged that their self-confidence decreased with urinary dysfunctions aggravation. Urinary incontinence may lead to emotional distress, isolation from society, and decreased self-esteem in older women, because of the experience of incontinence in public and an unpleasant feeling of embarrassment due to wetness and the smell of urine [29, 30].

Most of the participants admitted that they had never felt severely depressed because of the MS, but they had become depressed since they had urinary dysfunctions. With urinary incontinence becoming more unpredictable, women are more prone to social isolation and the reduction of activities, which can lead to depression and helplessness [31]. Also, urinary incontinence and its complications may lead to depression, which reduces the patients' motivation to pursue their treatment and the effectiveness of therapies [32]. In Iran, social stigma about urinary problems is also a factor that greatly affects self-confidence and depression in WwMS; it may lead to social isolation and a decreased quality of life.

Dysfunctional beliefs and negative thoughts about social stigma increase the anxiety and distress of people with urinary incontinence [31]. About 50% of people with MS experience anxiety, which can increase the risk of depression and cognitive problems. Additionally, depression, anxiety, and cognitive problems strongly impact the quality of life of people with neurological diseases, such as MS [33]. Participants in this study were anxious about being judged by society and their relatives, because of social stigma and negative beliefs around urinary problems. Most Iranians consider a person with a urinary problem as unclean and filthy, making the affected person feel guilty and anxious. Importantly, clinicians should consider the teaching of stress and anxiety coping strategies in WwMS.

### Economic consequences

In this study, WwMS stated that the costs of urinary dysfunctions were added to the other costs of MS, such as the cost of medication, hospitalization, and the purchase of assistive devices, like wheelchairs, walkers, etc. This made their lives even more difficult because some WwMS were unable to work. Besides, the “increased costs” may lead to not seeking treatment for urinary dysfunctions. Urinary incontinence management not only imposes costs on WwMS (who are often not covered by health insurance) and their families but also puts economic burdens on the public health system by increasing the need for nursing, hospital servicing, and the provision of special drugs [7, 34]. Moreover, some urinary dysfunction therapies, such as biofeedback are not covered by health insurance in Iran and may impose an economic burden on WwMS.

People with MS quit their jobs for many reasons, including motor or cognitive impairments and fatigue, poor workplace ergonomics, and negative attitudes, such as employer discrimination [35]. Having adequate income and health insurance is very important for WwMS, because of the expensive costs of treating MS and its associated urinary dysfunctions. Therefore, leaving the job imposes a heavy financial burden on these patients.

## 5. Conclusion

Urinary dysfunctions cause widespread physical, psychological, and economic problems for WwMS. Also, the inadequate advice of clinicians for the urinary dysfunctions of WwMS and the shame of expressing these dysfunctions lead to chronicity and complex management of the dysfunction. Therefore, treatment staff should address the MS patients’ concerns caused by the urinary disorder, in a non-threatening atmosphere, and help them to fearlessly manage their urinary problems.

## Ethical Considerations

### Compliance with ethical guidelines

The code of ethics for the present study was IR.IUMS.REC.1398.497, which was obtained from the Ethics Committee of the Iran University of Medical Sciences. Besides, the objectives of the study were fully explained to the participants, then, a written informed consent form was given to them. Also, the interviews were recorded only with the permission of the participants.

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The paper was extracted from the MSc. thesis of the first author, Department of Physiotherapy, School of Rehabilitation Science, Iran University Of Medical Science, Tehran.

### Authors' contributions

Conceptualization, supervision: Shohreh Noorizadeh Dehkordi; Methodology: Shohreh Noorizadeh Dehkordi, Ghazal Roshdi; Investigation, writing – review & editing: All authors; Writing – original draft: Ghazal Roshdi.

### Conflict of interest

The authors declared no conflict of interest.

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## تجارب زنان ایرانی مبتلا به ام‌اس از پیامدهای اختلالات ادراری: یک مطالعه کیفی

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### چکیده

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**مقدمه:** هدف این پژوهش، شناسایی تجارب زنان مبتلا به ام‌اس از پیامدهای اختلالات ادراری است. **مواد و روش‌ها:** این پژوهش کیفی با رویکرد تحلیل محتوا، تجربیات ۱۰ زن مبتلا به ام‌اس در سنین ۵۹-۲۹ سال از پیامدهای اختلالات ادراری از طریق مصاحبه‌ی عمیق نیمه ساختار یافته‌ی حضوری جمع‌آوری شد. شرکت‌کنندگان با حداکثر تنوع و طی نمونه‌گیری هدفمند انتخاب شدند. تجزیه و تحلیل داده‌ها به روش تحلیل محتوای پیشنهادی گرانهایم و لاندمن (۲۰۰۴) انجام شد. **یافته‌ها:** پس از تجزیه و تحلیل داده‌ها سه مضمون کلیدی به دست آمد که عبارتند از: "موانع جسمانی"، "موانع روانی-هیجانی" و "موانع اقتصادی". **نتیجه‌گیری:** اختلالات ادراری پیامدهای گسترده‌ی جسمانی، روانی و اقتصادی برای زنان مبتلا به ام‌اس ایجاد می‌کنند که اثرات منفی روی کیفیت زندگی این مبتلایان خواهد گذاشت. اعضای کادر درمان باید با ایجاد فضایی غیر تهدیدآمیز، زمینه‌ای برای کاهش شرم و خجالت پیرامون این موضوع در مبتلایان ایجاد کرده و زمینه‌ی درمان به موقع اختلالات ادراری را فراهم کنند.

### کلیدواژه‌ها:

تحلیل محتوای کیفی،  
مولتیپل اسکلروزیس،  
اختلالات ادراری، تجربه  
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