

**Original Article**

## **Urinary Incontinence and the Quality of Life in Women with Multiple Sclerosis**

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**Abstract**

**Purpose:** Urinary incontinence in patients with multiple sclerosis is one of the most important problems having a negative impact on the quality of life in patients. The present study aims to analyze the relationship between urinary continence in women with MS and quality of life.

**Method:** The present study has a descriptive research design conducted with 100 female patients with Multiple Sclerosis having urinary incontinence problem who applied to the Neurology out-patient clinic of a university hospital. The data were obtained using the Multiple Sclerosis Patient Inquiry Form (MSPIF), the Incontinence Severity Index (ISI) and The Incontinence Quality of Life Instrument (I-QOL). SPSS (22.0) program was used in data analysis and in addition to descriptive statistics, the student's t-test, one-way analysis of variance (ANOVA) and the Pearson Correlation Coefficient were used.

The mean age of women with MS participating in the study was found to be  $37.85 \pm 11.29$ . It was determined that as urinary incontinence types, 50.0% of them had Urge (urgent) incontinence, 42.0% had Stress incontinence and %.8.0% of them had Mixed incontinence. It was identified that the mean of Incontinence Severity Index in women with MS participating in the study was at a moderate level ( $3.80 \pm 3.69$ ). In addition, the following findings were obtained: the total mean score of the Incontinence Quality of Life Instrument was  $72.7 \pm 22.9$ , the mean score of the Avoidance Limiting Behavior subscale in the I-QOL was  $65.4 \pm 24.4$ , the mean score of the Psychosocial Impacts subscale was  $79.0 \pm 22.5$ , the mean score of the Social Embarrassment subscale was  $72.2 \pm 25.1$ , and the total mean score of the I-QOL was  $72.7 \pm 22.9$ . It was found that the perception of quality of life was above average in women with MS having incontinence. When the relationship between Incontinence Severity Index and Incontinence Quality of Life in women with MS, it was found that there was a statistically significant relationship between the Avoidance and Limiting Behavior, Psychosocial Impacts, and Social Embarrassment subscales and the Incontinence Severity Index.

**Result:** Multiple sclerosis increases the incontinence severity in women, and the urinary incontinence problem has a negative impact on patients' quality of life. In line with these results, it is important for healthcare professionals working with women who have MS to examine patients routinely in terms of urinary incontinence and to plan suitable nursing activities for its prevention. Within the scope of these projections, it is recommended to raise awareness in women with suitable training on the subject-matter in order to provide rehabilitation in women.

**Keywords:** Multiple Sclerosis, Quality of Life, Urinary Incontinence.

## Introduction

Multiple Sclerosis (MS), characterized by axonal damage related to inflammation and demyelination processes in the central nervous system, is a chronic, progressive disease that causes major limitations in the physical, emotional, social and cognitive functions of the individuals (Etemadifar et al. 2006). MS is seen between the ages of 20-40 and approximately twice as prevalent in women as in men ( Mirza 2002; Turner, Kivlahan and Haselkorn 2009;). The fact that it is seen at young ages, that it affects those in productive ages in the population, that it is long-term and leads to disability, that it has a negative

impact on self-care and quality of life in the individual increase the importance attached to the disease ( Kocer et al. 2011; Yahia et al. 2011; Zwibel 2009).

Central nervous system demyelination in multiple sclerosis (MS) causes many symptoms to appear. Among these symptoms, bladder problems occupy an important place (Yahia et al. 2011). In the majority of patients diagnosed with MS, the sensory, motor and sphincter functions of the bladder are affected and often cause sudden urination, frequent urination and urinary incontinence problems (Duffany et al. 2011). In studies, it was reported that the frequency of urinary incontinence in patients with MS is at a rate of 52-97%, it appears as the first symptom in 5% of patients and its frequency increases as the disease progresses (Gulick 2011; Hsiao, Chang and Chen 2012).

Urinary incontinence reduces quality of life by having a negative impact on the social, professional, and sexual life of the individuals (Bonniaud et al. 2008; Gulick 2011; Hsiao, Chang, and Chen 2012; Moore, Tawadros and Betts 2011). In the study conducted with a case and a control group, Tarhan et al. (2007) stated that patients with high urinary incontinence had low quality of life. In a study conducted with 143 female patients by Murphy et al. (2012), it was found that 55.9% of women experienced stress-related urinary incontinence and that this reduced quality of life in individuals.

Healthcare professionals have important responsibilities in preventing various problems in women with MS and improving daily life

activities of patients (Tulek 2016). In particular, in addition to medical services related to the prevention of its progression, healthcare professionals should use their educational roles effectively in evaluating incontinence in patients with urinary incontinence, in being a consultant on making lifestyle changes and in strengthening pelvic floor muscles (Kaplan and Demirci 2010). Moreover, healthcare professionals may offer effective strategies related to treating and preventing urinary incontinence with these roles they undertake, and thus, they can actively take actions in order to improve health (Abali and Sahin 2010; Sen 2011).

In summary, urinary incontinence, which has become a more and more common problem worldwide, is a health problem that is seen as four times in women as in men and that has a negative impact on all kinds of quality of life such as professional life, social life, personal relations, and sexual life in individuals. Studies on urinary incontinence are included in the literature; however, studies on female patients are rather scarce, even though it is common in patients with MS. In this context, the present study aimed to identify urinary incontinence in women with MS and its impact on quality of life. Thus, it is thought that the results of the present study will focus attention on urinary incontinence in women with MS, that they will lead to an increase in studies on controlling incontinence and that they will contribute to studies related to improving quality of life.

## Method

### Study participants

The research was conducted as a cross-sectional descriptive study in the MS Outpatient Clinic, Neurology Clinic of ..... University Hospital. In this process, 213 female patients ( $\geq 18$  years old) diagnosed with MS applied to the polyclinic. Patients with urinary incontinence problems were identified by asking them the following question: "Do you have a urinary leakage problem?" Since 104 of these female patients replied "Yes" to this question, they were included in the study. Since four of the patients with urinary incontinence refused to participate in the study, the study sample was composed of 100 individuals. Written consent was granted by the Non-

Invasive Clinical Studies Ethics Committee of ... and by the hospital management for the present study. In the data collection process, patients were informed on the subject-matter of the study, and they provided written and oral consent forms stating that they voluntarily took part in the study. Interviews were conducted using the face-to-face interview technique by the researcher in order to ensure patient privacy.

### Data collection

The patients were firstly informed about the subject-matter and aim of the study. After informing them, data collection forms were applied to female patients who volunteered to participate in the study using the face-to-face interview technique in a suitable room of the neurology polyclinic between the researcher and women with MS. The total duration of the questionnaire forms was between 15-20 minutes. The data were obtained using the Multiple Sclerosis Patient Inquiry Form (MSPIF), the Incontinence Severity Index (ISI) and the Incontinence Quality of Life Instrument (I-QOL).

**Multiple Sclerosis Patient Inquiry Form:** It is a personal form developed by the researcher after the literature review process in order to obtain information and collect data on the patients' sociodemographic characteristics and on the disease (Ozkan Tuncay and Mollaoglu 2017; Sen et al. 2015; Ustun 2006). This form is composed of 25 questions containing information on sociodemographic characteristics (age, level of education, employment status, marital status, place of residence, level of income etc.), clinical characteristics, urinary incontinence status, and training status in female individuals with MS.

**Incontinence Severity Index (ISI):** "ISI" developed by Sandvik, Espuna, and Hunskaar (2006), by applying it to women with urinary incontinence complaint is a universally-accepted, easily applicable, short and simple index.

The validity and reliability of the 2-question scale in Turkish was conducted by Hazar and Sirin (2008). There are 4 items of the question "How often do you experience urinary leakage?" There are 3 items of the question

"How much urine do you lose each time?" The score is calculated by multiplying the scores in the first and the second question. The severity index score is accepted to be 1-2 points= Slight, 3-6 points= Moderate, 8-9 points= Severe, and 12 points= Very Severe (Hazar and Sirin 2008).

**Incontinence Quality of Life (I-QOL) Instrument:** It was developed by Wagner et al. (1996) to identify the quality of life in patients with urinary incontinence. The scale is composed of 22 questions and three subscales. These subscales are Avoidance and Limiting Behavior (items 1,2,3,4,10,11,13,20), Psychosocial Impacts (items 5,6,7,9,15,16,17,21,22), and Social Embarrassment (items 8,12,14,18,19). In the I-QOL, all items are scored as 5-point Likert-type response (1=extremely, 2=considerably, 3=moderately, 4=slightly, 5=not at all) and in order to better understand the total score, Likert-types are recalculated and scored between 0-100 points (Schurch et al. 2007). In our country, the validity and reliability study of I-QOL was conducted by Ozerdogan, Kizilkaya Beji, and Yalcin (2004). The Cronbach's Alpha coefficient for the overall I-QOL was 0.96, while the Cronbach's Alpha coefficient was 0.88 for the Avoidance and Limiting Behavior subscale, 0.92 for the Psychosocial Impacts subscale, and 0.90 for the Social Embarrassment subscale. Each subscale is scored between 0-100 points. High scores indicate that the quality of life is better.

### Ethics Consideration

The research was conducted with approval of the Ethics Committee in an university. Moreover, participating in the survey was on a volunteer basis. Those who wanted to participate in the survey were briefly informed about the research and why it was conducted. In this context, participants were asked to fill in questionnaire.

### Statistical Analysis

When the data obtained in the present study were uploaded into SPSS (22.0) program and parametric test assumptions were achieved in the data evaluation (skewness and kurtosis values being and not being between 1.96 and -1.96), it was decided that student's t-test would be applied in independent groups while

comparing two independent groups, and Analysis of Variance would be applied while comparing more than two independent groups. Since skewness and kurtosis values varied between 1.96 and -1.96 in the study, student's t-test and One-Way Analysis of Variance, which are two different parametric tests, were used for independent groups.

## Results

The average age of women with MS in the study was  $37.85 \pm 11.29$ . 35% of these women are university graduates and 33% are primary school graduates, 76% are married. 69% of women with MS were unemployed and 63% of them were housewives. The clinical characteristics demonstrate that 30% of women with MS had 6-10 years of MS diagnosis and that 67% of them had Relapsing-Remitting MS. 51% of them had MS attacks once a year and 32% of them had MS attacks twice a year (Table 1).

Investigation of Urinary Incontinence types in women with MS demonstrated that 50% of

them had Urge (urgent) incontinence while 42% of them had stress incontinence. Findings on the Incontinence Severity Index revealed that the mean score of ISI was  $3.80 \pm 3.69$ . A total score between 3-6 points in the Severity Index indicates that there is a moderate urinary incontinence problem in patients (Table 2).

When results on the I-QOL were analyzed, it was observed that the mean score of the Avoidance and Limiting Behavior subscale was  $65.4 \pm 24.4$ , that the mean score of the Psychosocial Impacts subscale was  $79.0 \pm 22.5$ , that the mean score of the Social Embarrassment subscale was  $72.2 \pm 25.1$ , and that the total mean score was  $72.7 \pm 22.94$  (Table 3).

In the correlation between ISI and I-QOL, there was a negative and statistically significant relationship between the Avoidance and Limiting Behavior, Psychosocial Impacts and Social Embarrassment subscales of the I-QOL and ISI ( $p < 0.05$ ). Urinary Incontinence problem have a negative impact on patient quality of life (Table 4).

**Table 1.** Characteristics of Women with Multiple Sclerosis

	n	%
<b>Age:</b> Min:19, Max:76, Mean:37.85 Standard Deviation:11.29		
<b>Educational Status</b>		
Not literate	3	3.0
Primary school	33	33.0
Middle School	10	10.0
High school	17	17.0
University	37	37.0
<b>Marital status</b>		
Married	76	76.0
Single	24	24.0

<b>Working Status</b>		
working	31	31.0
Not working	69	69.0
<b>Occupation Status</b>		
Housewife	63	63.0
Worker	6	6.0
Officer	18	18.0
Free	4	4.0
Farmer	9	9.0
<b>Disease Duration</b>		
> 1 year	13	13.0
1-5 years	31	31.0
6-10 years	30	30.0
11-15 years	16	16.0
≤16 years and over	10	10.0
<b>MS Type</b>		
Relapsing-Remitting Form	70	67.0
Secondary Progressive Form	11	11.0
Primary Progressive Form	13	13.0
Progressive Relapsing Form	3	3.0
Bening multiple sclerosis	3	3.0
<b>MS Attack Frequency</b>		
No attack in the past year	6	6.0
1 attack / year	51	51.0
2 attacks / year	32	32.0

> 3 attacks / year	11	11.0
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**Table 2.** Mean of Urinary Incontinence Type and Incontinence Severity Index in Women with MS

	<b>n</b>	<b>%</b>
<b>Urinary Incontinence Type</b>		
Urge incontinence	50	50.0
Stress incontinence	42	42.0
Mix incontinence	8	8.0
Incontinence Severity Index; mean (SD); min-max. 3.80 (3.69): 1-12		

**Table 3.** Evaluation of Incontinence Quality of Life Scale in Women with MS

	<b>Minimum</b>	<b>Maximum</b>	<b>Mean</b>	<b>Standard Deviation</b>
Avoidance and Limiting Behaviour	20.0	100.0	65.4	24.4
Psychosocial Impacts	24.4	100.0	79.0	22.5
Social Embarrassment	20.0	100.0	72.2	25.1
Total of Incontinence Quality of Life Scale	24.4	100.0	72.7	22.94

**Table 4. Correlations between Incontinence Severity Index and Incontinence Quality of Life Scale**

Incontinence Quality of Life Scale	Incontinence Severity Index	
Avoidance and Limiting Behaviour	Pearson Correlation  Sig. (2-tailed)  n	-.680 .000 100
Psychosocial Impacts	Pearson Correlation  Sig. (2-tailed)  n	-.693 .000 100
Social Embarrassment	Pearson Correlation  Sig. (2-tailed)  n	-.612 .000 100
Total of Incontinence Quality of Life Scale	Pearson Correlation  Sig. (2-tailed)  n	-.655 .000 100

## DISCUSSION

Urinary incontinence is one of the major health problems in women with MS. In studies conducted on the female population and in the wide population-based prevalence studies on urinary incontinence caused by different factors, it has been reported that the mean frequency of urinary incontinence in women varies between 18% and 45% (García-Pérez et al. 2013; Jokhio et al. 2013). There are studies reporting that the prevalence of urinary incontinence in women in Turkey varies between 9.6% and 25.8% (Kocak et al. 2005; Beji et al. 2010).

In the present study conducted on female patients with MS, urinary incontinence was found to be 46.9%. Studies analyzing the urinary incontinence problem in female patients with MS are rather limited in the literature (Massot et al. 2016). Even though there are urinary incontinence studies conducted on women in Turkey, no study on women with MS could be found. Urinary incontinence is an expected symptom in women with MS due to the fact that the sensory, motor, and sphincter functions of the bladder are affected.

However, in the present study, urinary incontinence was diagnosed based on patients' self-report. The question "Do you have urine leakage?" was asked to female patients diagnosed with MS and applying to the polyclinic for routine checks, and those who said "Yes" to this question were diagnosed. No diagnosis was specified in their medical records suggesting that they had urinary incontinence.

However, it is stated that female patients see this problem as a private one, and they experience some emotions such as embarrassment and dread and try to hide these emotions (Ozdemir, Ozerdogan and Unsal 2011). Therefore, they may not have told the truth to the doctor and nurse who examined them. Hence, it is thought that the frequency of incontinence may be higher in our study. It is necessary to raise sensitivity in healthcare professionals towards the problem and to check the urinary incontinence symptom routinely.

After diagnosing incontinence in the patient, it is important to manage treatment and rehabilitation studies individually using objective and subjective diagnostic methods. The investigation of urinary incontinence types in women with MS in the present study demonstrated that 50% of them had urge (urgent) incontinence while 42%

of them had stress incontinence. In their study, Sen et al. (2015) concluded that 37.5% of patients had a urinary incontinence type with an urgent feeling. In a study conducted on 30 patients, Gunduz et al. (2006) found that 77% of patients had frequent urination and urge incontinence, while 60% of them had urinal leakage problem. In their study conducted with 143 female patients, Murphy et al. (2012) found that 55.9% of women had stress urinary incontinence.

On the other hand, the incontinence severity of female patients with MS was found to be moderate in the present study in which the Incontinence Severity Index was used. In their study, Goris et al. (2010) concluded that urinary incontinence problem in female patients with MS was important and that patients had moderate-severe urinary incontinence index. In studies identifying the incontinence severity in women, it was found that multiple sclerosis was a major risk factor for urinary incontinence (Can Guler and Yagci 2006; Yavuz 2008). In the statistical analysis of the present study, the fact that the most common urinary incontinence type in patients was urge incontinence demonstrated that incontinence severity was perceived more. In fact, other studies support this result.

In their study, Hägglund et al. (1999) reported that urge (urgent) and mixed incontinence types affected psychological, physical, and social functions more than stress incontinence. It has been reported that the reason behind this is that urge urinary incontinence appears at the moment of urinary need without any chance to go to the toilet, that it cannot be postponed, that it causes more urinary leakage than stress urinary incontinence and that it causes frequent night urination (Ozerdogan, Beji, and Yalcin 2004; Sivaslioglu 2011).

Urinary incontinence is one of the major health problems affecting quality of life in individuals. Another dimension of the present study is to analyze the quality of life in patients with urinary incontinence. In the present study, the Incontinence Quality of Life Instrument was used in order to evaluate patient quality of life.

According to the instrument, it was found that the quality of life in cases was above the mean score. No study in which the Incontinence Quality of Life Instrument was used could be found in the literature. In their study conducted with MS patients, Janssens et al. (2003) used SF-36 quality

of life scale and reported that patients had low quality of life.

Henriksson et al. (2001) found a strong relationship between MS disease and quality of life in their study, while Janardhan and Bakshi (2000) found a moderate relationship and O'Connor et al. (2001) found a weak relationship between these two. In the present study, it was determined that quality of life in patients with high incontinence severity was negatively affected even though the quality of life in female patients with MS was found to be above the mean score. In their studies, Ozerdogan, Beji, and Yalcin (2004) and Tennstedt et al. (2007) reported that the quality of life decreased in women as the urinary incontinence severity increased.

Turner, Kivlahan and Haselkorn (2009) reported in their study that the fact that Multiple Sclerosis appears at young ages and that it causes physical limitations in patients have a negative impact on quality of life in patients even though the mortality of MS is low. Bonniaud et al. (2008) stated in their study that one of the most common problems in MS patients is urinary incontinence and that this problem has a negative impact on the quality of life in patients. In the study conducted with a case and a control group, Tarhan et al. (2007) stated that patients with high urinary incontinence had low quality of life.

Murphy et al. (2012) found that the life quality of patients with a urinary incontinence problem was negatively affected. Urinary incontinence may distinctively disrupt the quality of life and may cause the disruption of social relations, psychological troubles related to embarrassment and disappointment, disruption of skin integrity, and hospitalizations related to urinary infections (Langa et al. 2002).

It is considered important that healthcare professionals take an active role in training and consultancy services regarding the prevention and elimination of urinary incontinence and strengthening the pelvic floor muscles (Aslan 2002; Kok, Senel and Akyuz 2006; Nas Acar 2010).

Prevention and elimination of the urinary incontinence problem, which may have a negative impact on quality of life in individuals and is a common health problem, requires multidisciplinary teamwork.

In conclusion, urinary incontinence, which may have a negative impact on quality of life in

individuals and is common health problem, is common in female patients with MS. In the present study, it was concluded that the most common urinary incontinence types in female patients were urge and stress incontinence and that they had moderate urinary incontinence. As the urinary incontinence severity increases, patient quality of life decreases.

Urinary incontinence studies as a routine check in all MS patients are incontestable. However, studies have reported that female patients cannot express this problem due to factors such as embarrassment, dread, and privacy.

Therefore, it is important to test the presence of urinary incontinence in female patients with medical conditions that may cause incontinence, especially MS, and to conduct required consultancy and effective rehabilitative practices.

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