



Patients With Multiple Sclerosis and Their Dignity

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Abstract

Introduction. Multiple sclerosis is a chronic, inflammatory, demyelinating, and neurodegenerative disease of the central nervous system with a variable and unpredictable clinical course, affecting approximately 6,500 individuals in the Republic of Croatia. Untreated, the disease irreversibly leads to severe neurological impairment and over time, may cause disability in daily life, potentially resulting in feelings of indignity among patients.

Aim. The aim of the study is to examine the expectations and satisfaction of individuals with multiple sclerosis regarding the respect for their dignity in daily healthcare. Special emphasis was placed on differences regarding the duration of the disease, as well as the method and frequency of therapy application.

Methods. The study included a total of 150 individuals with multiple sclerosis and was conducted at the Neurology Clinic of the University Hospital Centre Zagreb. A hospitalized patients' dignity scale, consisting of 21 questions, was used. The questions assess patients' expectations and satisfaction regarding the behavior of doctors and nurses in the hospital. Satisfaction and expectations of patients were evaluated across four domains: respect for the individual as a human being, personal feelings, independence, and privacy, in relation to the disease duration and the method and frequency of therapy administration.

Results. The results indicate that patients with a disease duration of less than 5 years report higher satisfaction in the domain of independence. There is no statistically significant difference in expectations and satisfaction based on the method of therapy administration, i.e., between patients not receiving any therapy and those receiving therapy in the form of tablets, injections, or infusion solutions. There is no statistically significant difference in the expectations and satisfaction of patients receiving therapy at intervals shorter than 2 weeks compared to those receiving therapy at intervals longer than 2 weeks.

Conclusion. The study suggests that the expectations of patients regarding the mentioned domains, in relation to disease duration, therapy modality and frequency, are met, and their dignity is preserved. Due to the lack of publications on the dignity of patients with chronic diseases in Croatia, further exploration of this topic is recommended.

Introduction

Multiple sclerosis (MS) is a chronic, inflammatory, demyelinating, and neurodegenerative disease of the central nervous system with a variable and unpredictable clinical course, affecting approximately 6,500 individuals in the Republic of Croatia. Untreated MS irreversibly leads to severe neurological impairment, including physical and cognitive decline that impacts the quality of personal and professional life (1). A range of medications is available for this disease, administered in various forms, from tablets to injections and infusion solutions. The type, method, and frequency of therapy administration can influence patients' expectations and satisfaction (2, 3, 4).

Among the most common symptoms are diplopia (double vision), visual impairment, limb weakness, urinary and bowel control disorders, balance issues, and coordination difficulties. The most frequently described movement disorders in MS include restless legs syndrome, tremor, ataxia, parkinsonism, paroxysmal dyskinesias, chorea and ballism, facial myokymia, including hemifacial spasm and spastic parietic hemifacial contracture, tics, and Tourettism (5, 6, 7). These symptoms can gradually lead to disability in daily activities and consequently, to feelings of indignity.

In everyday life, the concept of dignity is equated with self-respect. Being treated with dignity means being treated with respect and considered worthy of others' respect. Losing dignity means feeling that one's value as a person has been irreparably diminished (8). Dignity is promoted when the patient becomes an active participant, when their feelings and thoughts are respected, when the patient's family is involved and listened to, when the patient feels free to provide critical feedback, when healthcare staff can address the patient's shortcomings, and when efforts are made to improve the aesthetic environment. Dignity is not promoted when healthcare staff overpower or dominate patients, when they focus solely on the patient's diagnosis rather than the person, or when healthcare staff and/or family members attempt to impose their own values (9).

There are many ways in which patients' dignity can be compromised in healthcare settings, including rudeness, indifference, dismissal, neglect, intrusive-

ness, objectification, restriction, labeling, contempt, discrimination, aversion, deprivation, and assault. Situations such as patient care, maintaining privacy, physical examinations, patient introductions, cases where the nurse and patient are not of the same gender, mixed wards, or neglecting to cover the patient's body can all contribute to this (10, 11).

The Act on the Protection of Patients' Rights in the Republic of Croatia stipulates that during examinations, treatments, and especially during the provision of personal care, patients have the right to conditions that ensure privacy. The protection of patients' rights is based on the principles of humanity and accessibility. The principle of humanity is realized by ensuring respect for the patient as a human being, safeguarding their physical and mental integrity, and protecting their personality, including respect for their privacy, worldview, and moral and religious beliefs. According to this law, patients' rights include the right to co-decision, the right to information, the right to accept or refuse specific diagnostic or therapeutic procedures, the right to access medical documentation, the right to confidentiality, the right to maintain personal contacts, the right to voluntarily leave a healthcare facility and the right to privacy (12).

For the perception of dignity, it is crucial that the patient-nurse collaboration is seen as well-functioning and characterized by trust. The behavior of nurses and respect for patient autonomy are critical aspects of care that significantly contribute to preserving dignity (13).

Multiple sclerosis is a progressive disease, with physical and cognitive limitations becoming increasingly pronounced over time. In the early years following diagnosis, patients are often more mobile, less dependent on others' assistance, and still actively adapting to their new life situation. During this period, they tend to have higher levels of hope, self-confidence, and a greater need for affirmation of personal dignity, which may result in higher expectations of healthcare providers and greater sensitivity to their approach and behavior. Conversely, with longer disease duration (5 years or more), many patients experience a decline in functional status, are more frequently exposed to hospital treatment or continuous care, and face physical dependence on others. As a result, their expectations regarding dignity may decrease, possibly due to adaptation to the reality of the disease, emotional resignation, or loss of faith in the healthcare system. Additionally, long-term ex-

perience with various forms of healthcare may lead to deeper insight into systemic shortcomings, which can contribute to lower satisfaction levels (14, 15).

Given the complexity of multiple sclerosis symptoms, it is important to understand how different methods of therapy administration may affect patients' subjective perception of dignity in daily care. Today, there are various therapeutic options for treating multiple sclerosis, differing in frequency of administration (some medications are indicated for use at intervals longer than 2 weeks, eliminating the need for daily administration) and method of administration (e.g., oral tablets do not require hospital visits, which may impact patients' satisfaction with dignity compared to medications administered via injections or infusions in a hospital setting). These factors can significantly shape the patient's experience, including their sense of autonomy, support, and respect in interactions with healthcare professionals. This study aims to contribute to a better understanding of how medical aspects of treatment can have broader psychosocial implications for individuals living with multiple sclerosis. Based on this, the research objective, problem, and hypotheses have been formulated.

Aim

The aim of this study is to examine the expectations and satisfaction of individuals with multiple sclerosis regarding the respect for their dignity in daily healthcare. In line with the main objective, three research problems have been formulated with corresponding hypotheses:

1. **Problem:** To investigate whether there are differences in expectations and satisfaction with dignity in daily care between participants who have had multiple sclerosis for less than 5 years and those who have had the disease for 5 years or more. **Hypothesis 1:** Participants who have had multiple sclerosis for 5 years or more report lower satisfaction and lower expectations regarding respect for dignity in daily care compared to those who have had the disease for less than 5 years.
2. **Problem:** To examine differences in expectations and satisfaction with dignity in daily care based on the method of therapy administration. **Hypothesis 2:** Participants receiving oral therapy report higher expectations and greater satisfaction regarding respect for dignity in daily care compared to those receiving therapy via injections or infusions.
3. **Problem:** To investigate whether there are differences in expectations and satisfaction with dignity in daily care between participants receiving therapy at intervals shorter than 2 weeks and those receiving therapy at intervals longer than 2 weeks. **Hypothesis 3:** Participants receiving therapy at intervals longer than 2 weeks report higher expectations and greater satisfaction regarding respect for dignity in daily care compared to those receiving therapy at intervals shorter than 2 weeks.

Methods

Participants

A cross-sectional study was conducted on a sample of 150 participants at the Neurology Clinic of the University Hospital Centre Zagreb over a period of 3 months. The inclusion criterion for completing the questionnaire was a confirmed diagnosis of multiple sclerosis for all participants who were receiving treatment at the Neurology Clinic at the time of the study. The study included 32 men (21.3%) and 118 women (78.7%). The age range varied from 18 to 67 years, with 84 participants (56%) aged between 18 and 39 years, 59 participants (39.3%) aged between 40 and 59 years, and 7 participants (4.7%) older than 60 years.

Regarding disease duration, participants were divided into two groups: 64 participants (42.7%) had been diagnosed with multiple sclerosis for less than 5 years, while 86 participants (57.3%) had the disease for 5 or more years. This division is based on relevant clinical and psychosocial changes typically occurring during disease progression, as well as findings from previous studies indicating that patients'

expectations and perceptions of care quality and dignity in treatment change over time (14, 16).

Based on the method of therapy administration, participants were divided into four groups: 46 participants (30.7%) were not receiving any therapy, 29 participants (19.3%) were receiving therapy in the form of tablets/capsules, 39 participants (26%) were receiving therapy via injections, and 26 participants (24%) were receiving therapy via infusions.

Regarding the frequency of therapy, participants were divided into two groups: 53 participants (51%) received therapy at intervals shorter than 2 weeks, and 51 participants (49%) received therapy at intervals longer than 2 weeks.

Instrument

For the purposes of this study, the publicly available Inpatient Dignity Scale (IPDS) was used (17). The questionnaire contains a total of 21 statements and measures two main dimensions: A) patients' expectations regarding dignity and B) satisfaction with dignity. Each of these dimensions is covered by four subscales: (1) respect for the individual as a human being, (2) respect for personal feelings and time, (3) respect for privacy and (4) respect for patient autonomy.

Participants were tasked with assessing their expectations regarding various aspects of care in a hospital setting and their level of satisfaction with the current state. Based on personal experience, participants rated each statement on a scale from 1 to 5 (Likert scale), first indicating their expectations and then their satisfaction with the conditions related to the specific aspect of care. To measure expectations, a Likert scale ranging from 1 (no expectations) to 5 (high expectations) was used, while satisfaction was measured using a Likert scale ranging from 1 (very dissatisfied) to 5 (very satisfied). Examples include: "Respects me as a human being," "Maintains eye contact during conversation," and similar statements.

In a sample of 363 participants in Singapore, the scale's authors established satisfactory reliability, with Cronbach's alpha coefficients for the satisfaction dimension ranging from 0.72 (privacy subscale) to 0.90 (respect for the individual subscale). For the expectations dimension, alpha reliability coefficients were also satisfactory, ranging from 0.72 (privacy subscale) to 0.88 (respect for the individual subscale) (17). In our sample, satisfactory reliability was

confirmed, ranging from 0.79 for *the Respect for Privacy* subscale to 0.89 for *the Respect for the Individual as a Human Being* subscale.

All participants signed an informed consent form before completing the questionnaire and were free to withdraw from the study at any time. The completion of the questionnaire was anonymous, and participants' personal information was not used in the study. Participant data were used solely for research purposes.

Ethics

This study received approval from the Ethics Committee of the University Hospital Centre Zagreb, Class: 8.1-22/55-2, Number: 02/013 AG.

Statistics

Statistical data analysis was conducted using the SPSS v.24 software (Statistical Package for the Social Sciences). Descriptive analysis was used to summarize the results. For comparing the means of two groups, a t-test was employed for quantitative variables, while analysis of variance (ANOVA) was used to compare more than two groups. Prior to applying the t-test and ANOVA, the assumptions for conducting these tests were verified.

For the t-test, the normality of variable distributions between groups was assessed using the Kolmogorov-Smirnov test, where p-values greater than 0.05 indicate no significant deviation from a normal distribution. For all tested variables, p-values were >0.05, confirming that the normality assumption was met. Homogeneity of variances was tested using Levene's test, where p-values greater than 0.05 indicate equal variances between groups. For all variables except one, Levene's test was not significant. A significant Levene's test was found for the variable *Respect for the Individual as a Human Being* (expectation) ($F(3, 146) = 5.05; p = 0.002$), indicating a violation of the homogeneity of variance assumption. Due to this violation, the Kruskal-Wallis test, an appropriate non-parametric test, was used to compare multiple independent groups for this variable. The Kruskal-Wallis test was chosen as it allows for the comparison of medians across three independent groups without assuming normal distribution or homogeneity of variances. The interpretation of the results includes, in addition to textual explanations, tabular presentations.

Results

In accordance with the first research problem, differences in expectations and satisfaction with dignity in daily care were examined between participants who have had multiple sclerosis (MS) for less than five years and those who have had MS for five years or more (Table 1).

The results of the independent samples t-test showed no statistically significant differences between the two groups in most of the examined dimensions, including overall satisfaction with dignity ($M_1 = 4.63$, $SD_1 = 0.56$; $M_2 = 4.56$, $SD_2 = 0.59$; $t = 0.71$; $p = 0.476$) and overall expectations ($M_1 = 3.96$, $SD_1 = 0.86$; $M_2 = 3.89$, $SD_2 = 1.00$; $t = 0.44$; $p = 0.663$).

The only dimension where a statistically significant difference was found relates to satisfaction with respect for autonomy, where participants who have had multiple sclerosis for less than five years report-

ed significantly higher satisfaction ($M = 4.70$, $SD = 0.59$) compared to those who have had the disease for five years or more ($M = 4.44$, $SD = 0.88$; $t = 2.17$; $p = 0.032$).

Other individual dimensions, both for satisfaction and expectations, did not show statistically significant differences between the groups ($p > 0.05$), although the mean values were generally slightly higher in the group with less than five years of disease duration.

Within the framework of the second research problem, differences in expectations and satisfaction with dignity in daily care were examined in relation to the mode of therapy administration among individuals with multiple sclerosis. Four groups of patients were compared: a) those not receiving therapy, b) those receiving oral tablets, c) those receiving injections and d) those receiving infusions. Data analysis was conducted using one-way analysis of variance (ANOVA). It was expected that participants receiving oral therapy would express higher expectations and greater satisfaction regarding respect for dignity in daily care compared to those receiving therapy via injections or infusions.

Table 1. Comparison of Patients by Disease Duration (t-test)

	Ill for less than 5 years (N=64)		Ill for more than 5 years (N=86)		t-test	
	M	SD	M	SD	t	p
Patient satisfaction regarding dignity	4.63	0.56	4.56	0.59	0.71	0.48
Patient expectations regarding dignity	3.97	0.87	3.92	1.01	0.35	0.73
Respect for a person as a human being (satisfaction)	4.71	0.52	4.63	0.64	0.8	0.43
Respect for a person as a human being (expectation)	4.33	0.89	4.18	1.08	0.93	0.35
Respect for personal feelings and time (satisfaction)	4.55	0.64	4.53	0.6	0.2	0.84
Respect for personal feelings and time (expectation)	3.5	1.14	3.46	1.2	0.22	0.83
Respect for autonomy (satisfaction)	4.7	0.59	4.44	0.88	*2.17	0.03
Respect for autonomy (expectations)	4.05	1.21	4.09	1.18	-0.23	0.82
Respect for privacy (satisfaction)	4.65	0.81	4.62	0.71	0.26	0.80
Respect for privacy (expectation)	4.01	1.1	4.06	1.18	-0.3	0.76
Overall score on the scale (satisfaction)	4.65	0.54	4.58	0.57	0.75	0.45
Overall score on the scale (expectation)	3.96	0.86	3.89	1	0.44	0.66

Note: A – MS diagnosed less than 5 years ago, B – MS diagnosed 5 or more years ago; * $p < 0.05$

The results indicate that no statistically significant differences were found among the groups in overall satisfaction with respect for dignity in daily care ($F = 0.069$; $p = 0.976$) or in overall expectations regarding respect for dignity in daily care ($F = 1.874$; $p = 0.137$). In addition to the absence of differences in overall satisfaction and expectations regarding dignity, no differences were found in individual dimensions: respect for the person as a human being, respect for privacy, respect for autonomy, or respect for personal feelings and time ($p > 0.05$).

The third research problem focused on examining differences in expectations and satisfaction with dignity in daily care between individuals receiving therapy for multiple sclerosis at intervals shorter than 2 weeks and those receiving it at intervals longer than 2 weeks. The analysis was conducted using an independent samples t-test, with results presented in Table 2.

The results indicate that no statistically significant differences were found between the two groups in overall satisfaction levels ($M1 = 3.97$, $SD1 = 0.88$; $M2 = 3.75$, $SD2 = 1.07$; $t = 1.15$; $p = 0.253$) or in overall expectations ($M1 = 4.58$, $SD1 = 0.53$; $M2 =$

4.62 , $SD2 = 0.61$; $t = -0.39$; $p = 0.699$). Although the mean values for expectations and satisfaction were slightly higher for most individual dimensions among participants receiving therapy at shorter intervals, these differences were not statistically significant ($p > 0.05$).

Discussion

The first objective of the study was to investigate whether there are differences in expectations and satisfaction with dignity in daily care between individuals with multiple sclerosis (MS) who have been diagnosed for less than 5 years and those who have been diagnosed for 5 years or more. It was hypothesized that the mode of therapy administration would be associated with levels of satisfaction and expectations regarding respect for dignity in care. Although the results for most dimensions were consistent

Table 2. Comparison of patients based on the frequency of therapy

	Intervals shorter than 2 weeks		Intervals greater than 2 weeks		t-test	
	M	SD	M	SD	t	p
Patient satisfaction regarding dignity	4.56	0.54	4.61	0.63	-0.39	0.697
Patient expectations regarding dignity	4	0.87	3.76	1.09	1,24	0.219
Respect for a person as a human being (satisfaction)	4.67	0.55	4.68	0.66	-0.06	0.954
Respect for a person as a human being (expectation)	4.32	0.88	4.01	1.23	1,49	0.139
Respect for personal feelings and time (satisfaction)	4.49	0.6	4.56	0.64	-0.58	0.566
Respect for personal feelings and time (expectation)	3.45	1.09	3.34	1.23	0.51	0.612
Respect for autonomy (satisfaction)	4.49	0.85	4.47	0.83	0.12	0.903
Respect for autonomy (expectations)	4.21	1.09	3.89	1.19	1.41	0.16
Respect for privacy (satisfaction)	4.11	1.13	3.87	1.21	1.06	0.29
Respect for privacy (expectation)	4.58	0.76	4.7	0.61	-0.89	0.376
Overall score on the scale (satisfaction)	3.97	0.88	3.75	1.07	1.15	0.253
Overall score on the scale (expectation)	4.58	0.53	4.62	0.61	-0.39	0.699

with expectations (lower mean values in the group with longer disease duration), a statistically significant difference was found only in the dimension of autonomy. A review of the professional literature in the field of nursing regarding dignity in MS patients reveals a limited number of studies, with most available studies based on small patient samples and qualitative designs. The results of our study, based on a sample of 150 participants, indicate that patients with less than 5 years since diagnosis report greater satisfaction in the domain of autonomy, specifically regarding their preserved independence, compared to those with a disease duration of 5 years or more. Given that multiple sclerosis is a progressive disease that can gradually lead to disability, these results are expected. The reason lies in the characteristic gradual progression of the disease over time. When autonomy is preserved, patients are more satisfied and consequently, their dignity in daily life is maintained. The results of our study pertain to patient dignity in hospital settings, specifically the behavior of medical staff toward patients, indicating that greater patient autonomy requires fewer interventions by nurses during their hospital stay, leading to higher patient satisfaction, preserved identity and dignity. This is supported by a study by Podolinska L. and Čap J. on the impact of multiple sclerosis on patient dignity, which involved 8 participants and used semi-structured interviews. Their findings suggest that MS can lead to reduced dignity and identity, but acceptance of the disease, resilience to its consequences and a sense of still being useful can help patients maintain their dignity (18). Our study presents results concerning patient dignity in hospital settings through the behavior of medical staff; however, other factors from the social environment, such as unemployment, which may threaten patients' dignity, should also be considered (19).

The second objective of the study was to examine differences in expectations and satisfaction with dignity in daily care based on the mode of therapy administration. Although it was expected that the mode of therapy administration would be associated with levels of satisfaction and expectations regarding respect for dignity in care, the analysis did not reveal statistically significant differences among the groups. The results of our study indicate no statistically significant differences in expectations and satisfaction among patients based on the mode of therapy administration, whether they are not receiving

any form of therapy or are receiving therapy in the form of tablets, injections, or infusions. These results are somewhat unexpected, as medications in the form of tablets and injections can be self-administered by patients at home, whereas infusions require administration in a day hospital, which demands additional effort from patients, particularly if they lack autonomy or are employed and requires extra time for hospital visits, as noted by other authors (4). The results may be influenced by legal regulations on patient rights protection in force in the Republic of Croatia. Patient dignity can be compromised in various situations during healthcare delivery in hospitals, as mentioned earlier. Nurses, during the provision of healthcare, also educate MS patients on the administration of medications at home. The approach and communication of nurses, as well as the mode of medication administration, can affect patients' self-esteem. Our results suggest that the frequency of therapy administration does not impact their dignity.

Additionally, it is possible that the perception of dignity is influenced by other factors, such as individual characteristics of participants, experiences with healthcare professionals, level of functionality or psychosocial support. Therefore, it is recommended to include additional variables in future research to more precisely determine the relationship between therapeutic approaches and the perception of dignity in care.

The third research problem aimed to investigate whether there are differences in expectations and satisfaction with dignity in daily care between participants receiving therapy at intervals shorter than 2 weeks and those receiving therapy at intervals longer than 2 weeks. Although it was expected that participants receiving therapy at shorter intervals would have higher expectations and greater satisfaction regarding respect for dignity in daily care compared to those receiving therapy at longer intervals, the analysis did not show statistically significant differences between the groups. It is possible that the frequency of therapy administration itself is not a decisive factor in shaping the perception of dignity in daily care, but rather that it is formed under the influence of other individual, organizational, and communication factors. Future research should consider the qualitative aspects of therapeutic encounters and experiences with care providers to gain a deeper understanding of the dynamics between therapeutic protocols and the perceived quality of care.

One limitation of this study is related to the sample size and its availability within a single institution, which may limit the generalizability of the results to the broader population of individuals with multiple sclerosis. Additionally, the use of a self-assessment questionnaire may be subject to the influence of the participants' current health status on their responses. It should also be noted that the assessment of dignity is based on perceptions during hospitalization, while experiences in outpatient or home settings were not included. This study did not include data on employment status, level of disability, or cognitive status of participants.

It is recommended that future research include a larger and more heterogeneous sample from different regions and healthcare institutions, as well as an expansion of methodology with qualitative approaches to further illuminate the personal experiences of patients. It would also be beneficial to consider longitudinal studies to track the development of expectations and satisfaction over time, in line with disease progression and changes in healthcare.

Conclusion

This study examined the expectations and satisfaction of individuals with multiple sclerosis regarding the respect for their dignity in daily healthcare. The dignity of MS patients was explored across four domains: respect for the person as a human being, personal feelings, autonomy, and privacy, in relation to disease duration, mode and frequency of therapy administration. The results indicate that the dignity of patients is preserved in terms of the behavior of medical staff in hospital settings.

The topic of patient dignity is significant and primarily linked to the clinical practice of nurses, yet it remains under-researched in the Republic of Croatia. It is recommended to conduct further studies on the dignity of individuals with multiple sclerosis in smaller hospitals and social environments.

The behavior of medical staff influences the preservation of patients' dignity and it is recommended for clinical practice to conduct research on interventions that contribute to and enhance the dignity of individuals with MS and other chronic diseases in the Republic of Croatia.

Author contributions

Conceptualization and methodology (AB, BM); data curation and formal analysis (AB, BM); investigation and project administration (AB); and writing – original draft and review & editing (KH). All authors have approved the final manuscript.

Conflict of interest

The authors declare no conflicts of interest.

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