PUBLIC HEALTH

ASSESING THE QUALITY OF LIFE IN INDIVIDUALS WITH MULTIPLE SCLEROSIS

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Abstract

Multiple sclerosis (MS) is linked with a wide range of physical, psychological, and societal challenges that significantly impact the quality of life (QoL) of those affected by the disease. This comprehensive study delved into the multifaceted aspects of MS, aiming to unravel the intricate relationships between disability, self-efficacy, acceptance of illness, and various dimensions of QoL. Material and methods: The study, encompassing 778 participants from diverse backgrounds, highlighted the nuanced experiences of individuals with MS, emphasizing the importance of understanding the unique challenges faced by different age groups and disease subtypes. The findings revealed profound connections between MS-related symptoms and psychological well-being, underscoring the necessity for tailored interventions. Notably, self-efficacy and acceptance of illness emerged as pivotal factors influencing QoL, providing crucial insights for healthcare providers and policymakers. Furthermore, this study underscored the importance of a holistic approach to MS management, integrating biomedical and psychosocial perspectives. The study's outcomes offer valuable direction for future research endeavors, advocating for longitudinal studies to capture the dynamic nature of QoL challenges, exploring patient perspectives through qualitative methods, and investigating the impact of socioeconomic factors on QoL outcomes. Additionally, the potential of telemedicine and digital interventions in providing continuous support and evidence-based counseling for individuals with chronic conditions is highlighted. By addressing these critical areas, future research endeavors can contribute to a more compassionate and empowering framework, enhancing the lives of those affected by MS and their families.

ЈАВНО ЗДРАВЈЕ

ПРОЦЕНКА НА КВАЛИТЕТОТ НА ЖИВОТОТ КАЈ ЛИЦАТА СО МУЛТИПНА СКЛЕРОЗА

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Извадок

Мултипната склероза (МС) претставува комплексна мрежа на физички, психолошки и општествени предизвици кои значително влијаат врз квалитетот на животот на оние погодени од болеста. Ова сеопфатно истражување навлегува во повеќеслојните аспекти на МС, со цел да ги разоткрие сложените односи помеѓу попреченоста, самоефикасноста, прифаќањето на болеста и различните димензии на квалитетот на животот. Студијата, која опфаќа 778 учесници од различно потекло, ги истакна нијансираните искуства на лицата со МС, нагласувајќи ја важноста од разбирање на уникатните предизвици со кои се соочуваат различни возрасни групи и подтипови на болести. Наодите открија длабоки врски помеѓу симптомите поврзани со МС и психолошката благосостојба, нагласувајќи ја потребата за приспособени интервенции, како и поврзаност на квалитетот на животот со полот и видот на МС. Имено, само-ефикасноста и прифаќањето на болеста се појавија како клучни фактори кои влијаат врз квалитетот на животот, обезбедувајќи клучни сознанија за здравствените професионалци. Ова истражување ја нагласува важноста на холистичкиот пристап кон менаџирањето на МС, интегрирајќи ги биомедицинските и психосоцијалните перспективи. Резултатите од истражувањето нудат вредни насоки за идните истражувачки напори, застапувајќи за лонгитудинални студии за да се долови динамичната природа на предизвиците на квалитетот на животот, истражување на перспективите на пациентите преку квалитативни методи и истражување на влијанието на социо-економските фактори врз резултатите од квалитетот на животот. Се истакнува потенцијалот на телемедицината и дигиталните интервенции за обезбедување континуирана поддршка и советување засновано на докази за лица со хронични состојби.

Introduction

MS is one of the most mysterious and disabling autoimmune diseases of the central nervous system affecting millions of people globally. This disease presents complex patho-physiological mysteries including immune system dysregulation that leads to demyelination and axonal damages resulting into diverse signs and symptoms such as muscle weakness and sensory disturbances, cognitive deficiencies and clinical manifestations, however, lies a profound and often overlooked aspect of the disease: the quality of Life (QoL).[1]

Quality of life (QoL) refers to the complete health of an individual as it extends beyond physical health incorporating mental health, social connections, and satisfaction with life. Every day is a challenge for people with MS whether apparent or not. Some visible problems include difficulties in movement and walking as well as chronic pains and exhaustion that greatly affect patients' daily functioning. However, some of the hidden challenges are more powerful and pose serious problems. They include psychological traumas of living with sickness, uncertainty regarding future disease evolution, and the sense of alienation associated with disability.[2]

Apart from restricting capacity for daily activities, these physical disabilities manifest themselves in impaired mobility and dexterity resulting into loss of independence and freedom. Impairment of cognitive skills such as minor memory lapses up to severe executive dysfunctions may lead to patients' reduced confidence and hinder their interaction with others. Moreover, such emotional disorders as depression and anxiety, observed in MS patients, produce chronic turmoil that has far-reaching effects on an individual's life including her/his interpersonal relations and overall sense of wellbeing.[3]

The inner battles are not the only determinants of quality of life in MS patients; moreover, society plays a critical part in what constitutes normality. The problems endured by people with MS usually become aggravated when coupled with stigmatization, inaccessibility of support systems and poor knowledge of the condition. Thus, the need arises for a sensitive analysis of the quality of life of persons with multiple sclerosis.[4]

This study aimed to obtain a thorough knowledge of the determinants of QoL in MS by meticulously analyzing the complex causal relationship among disease-specific factors, mental health, societal support, and the availability to medical care. The aim of this study was not only to bring to light problems encountered. In addition, it attempted to find ways that can be used in helping and providing support for MS patients. It will help in formulating an appropriate care strategy by knowing the particular areas in which people's lives are adversely affected. Furthermore, increasing awareness on the unseen disabilities that come

with MS could help create an understanding nation, which is sympathetic enough to help people living with this unrelenting illness.[5]

It is believed that multiple sclerosis involves an interaction between genetic factors and environmental factors, resulting in an immune inflammatory response within the central nervous system. Although consistent immunological abnormalities have been reported, not all components of the immune response in tissue damage and the extent to which these changes are a cause or consequence of myelin are yet to be fully understood. There is strong evidence for the genetic component of multiple sclerosis, while the influence of the environment is conditioned by variations in the incidence and prevalence of the disease across geographic regions. [6,7]

Currently, there is no cure for multiple sclerosis, but there is a wide range of treatment options that improve long-term outcomes for patients. Without treatment, the condition of patients gradually worsens over time. The goal of therapy in multiple sclerosis is to reduce relapses and improve and maintain functionality throughout a patient's life.[8]

Although neurological rehabilitation does not improve the underlying damage that continues to progress, it has a positive impact on many symptoms, disability, and many aspects of QoL. The neurological rehabilitation process should be continuous throughout the entire evolution of the disease, carried out in specialized centers, as well as in the community.

The aim of this study was to provide invaluable contributions to the medical profession in the development of better specificity and individualization for improving the quality of life of multiple sclerosis patients. The main goal of our study was to identify the gender-specific and subtype-specific variations in QoL of MS patients in order to create more precise interventions for promoting better health and QoL.

Materials and methods

Instrument and procedures

Expanded Disability Status Scale (EDSS) - Evaluation of neurological impairment in disabled multiple sclerosis subjects. This scale quantifies impairments in eight functional systems: Pathway: Pyramidal pathways - cortical tracts of cerebral motor cortex associated with large pyramidal neurons; cortico-spinal pathway - projection of the motor cortex into the cerebral column as T5-L2 - anterior horn cells. The segment of EDSS scale related to motor function was used in this study. Scores for the scale vary between 0 and 10, where score of 0 indicates a normal neurological examination, and score of 10 indicates death.

MSQOL-SF and MSQOL-29. - MSQOL survey was used to measure the standard of living of the study group. This is a multi-faceted instrument addressing general as well as specific issues regarding people with MS. This includes 18 items in

the generic dimension and touches on issues affecting people with MS involving their cognitive function, daily living, and social interactions among others. The MSQOL instrument encompasses twelve subscales that explore areas such as physical aspect, physical limitations, emotional health, pain, fatigue, social relations, cognitive and general health.

Patients were given separate sections of the scale for motor activity and handicap. Participants were informed about the general component of the MSQOL questionnaire plus different subscales. The survey was done respecting participant's feeling, comfort and anonymity. Respondents were asked to give their responses whenever they were willing to, under no pressure. We made our detailed analysis of their neurological status and quality of life based on the responses received.

This study was conducted worldwide by using an internet questionnaire, necessitated by the COVID-19 pandemic, which limited tradiational data collection methods. Respondents from diverse continents, including Europe, Asia, and Africa (with a smaller representation), actively participated, with the majority of respondents from North America, specifically the United States and Canada.

Table 1. Age of participants

Age	Participants	%
10 - 20 years	74	9
20 - 30 years	230	30
30 - 40 years	270	35
40 - 50 years	151	19
50 - 60 years	43	5
60 - 70 years	7	1
70 - 80 years	1	1

Results

In our study, 778 respondents provided data on the age of onset of multiple sclerosis. The youngest participant was 10 years old, while the oldest was 80 years. On average, MS onset occurred at 33 years (SD = 10.84). The majority of respondents
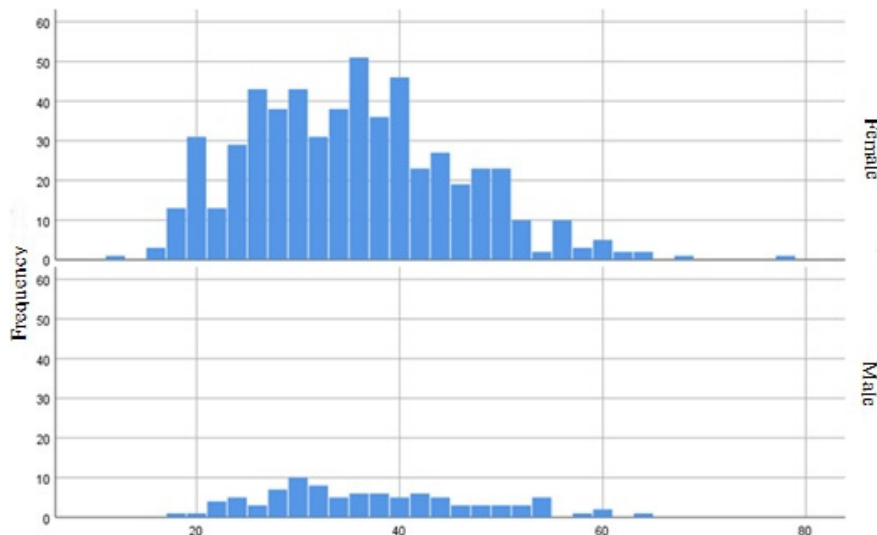
Fig. 1. Age of diagnosis of multiple sclerosis in men and women.

were aged between 30 and 40 years.

Figure 2 presents the correlation of the age of participants with the time of diagnosis of multiple sclerosis in men and women included in the study. The most common age of onset of multiple sclerosis was between 20 and 50 years among participants at the international level, while fewer participants were affected by the disease at around 70 years of age. In men, the mean age of developing multiple sclerosis was 36.73 years, while in women it was 34.84 years, with a standard deviation about 10 years for both genders.

Table 2. EDSS scale for the level of disability in participants.

No.	Level of disability	f	%
0.0	Normal neurological examination, without disability in any functional system, ambulatory patient without assistance from another person.	72	10
1,0	No disability, minimal signs of impairment in one functional system.	77	10
1,5	Without disability, minimal signs of impairment in more than one functional system.	68	9
2,0	Minimal disability in one functional system.	24	3
2,5	Mild disability in one functional system or minimal disability in two functional systems.	50	6
3,0	Moderate disability in one functional system or mild disability in three or four functional systems, without walking impairment.	22	3
3,5	Moderate disability in one functional system or more than one minimal disability in various functional systems, without walking impairment	31	4
4,0	Significant disability, independent for up to 12 hours a day. Able to walk up to 500 meters without assistance.	46	6
4,5	Significant disability, but independent for most of the day. Capable of working full-time, but with limitations in everyday activities or requiring minimal assistance from others. The person is able to walk without an assistive device for up to 300 meters.	39	5
5,0	Significant disability that impairs daily activities and ability to work. Able to walk without an assistive device for up to 200 meters.	50	6
5,5	Significant disability that excludes independent activities of daily living. The person is able to walk up to 100 meters without an assistive device	49	6

		f	%
6,0	Significant disability that excludes independent activities of daily living. The person is able to walk up to 100 meters without an assistive device.	112	14
6,5	The person requires two mobility aids (cane, crutches, walker) to walk up to 20 meters without resting	38	5
7,0	The person is unable to walk more than 5 meters even with an assistive device. He/she is limited to a wheelchair but can operate it independently. The person spends 12 hours a day in a wheelchair.	31	4
7,5	The person is unable to take more than a few steps and is confined to a wheelchair, requiring assistance with transfers. He/she can independently operate the wheelchair but cannot operate a standard wheelchair (only motorized).	20	2
8,0	The person is bedridden and the wheelchair is operated with the assistance of another person. The person retains only a few self-care functions. Generally, there is effective use of the upper extremities.	24	3
8,5	The person is essentially confined to bed for most of the day. He/she has minimal use of his/her upper extremities and retain minimal independence in self-care.	9	1
9,0	The person is bedridden. He/she can communicate and eat.	8	1
9,5	The person is bedridden and entirely dependent on another person. He/she cannot effectively communicate or eat/swallow.	7	1
10,0	Death due to multiple sclerosis during the study.		

Table 2 illustrates the level of disability in 778 participants. Based on the results obtained, the largest number of participants had a disability level of 6.0, i.e. 112 participants, and the smallest number of participants had a disability level of 9.5, i.e., 7 participants, excluding the death case at level 10.0 (SD = 27.06).

The scale regarding disability level showed the mobility, everyday activities, use of assistive devices, and need for personal assistance and care for the participants. The scale itself with a level of 4.5 indicates that participants are completely independent and have a low level of disability. This study included 429 participants up to level 4.5 of the scale, i.e., these participants had a higher level of independence with a percentage of 55%.

The scale from 5.0 to 10.0 indicates a significant level of disability of participants, who require the use of assistive devices, assistance in daily activities, or the need for a personal assistant or caregiver. A total of 349 participants or 45% in our study responded to be at this level. SD between these divisions was 40.

Table 3. QoL among survey participants

	f	%
Terrible	26	3
Very dissatisfied	185	24
Neither satisfied nor dissatisfied	214	28
Satisfied	306	40
Enthusiastically satisfied	41	5

Table number 3 provides a detailed analysis of the descriptive method for assessing the quality of life among participants with multiple sclerosis. According to the data obtained, the majority of participants reported being satisfied with their quality of life, which corresponded to the numerical representation of the quality of life (7.8), while a small percentage of participants reported feeling terrible about their quality of life (3%), which

corresponded to the numerical representation of the quality of life (1.2). The standard deviation of the population sample was 106.59944, and the variance was 11363.44.

Table 4. T-test for mean QoL score between men and women

QoL	N	Mean	SD	Std. error mean
Men	100	5,54	2,129	213
Women	590	6,29	2,125	088

A t-test was employed to assess whether the mean quality of life score differed between men and women. The results presented in Table 4 indicate a lower mean score for men, with a significance level of p = 0.001, suggesting a significant difference in overall quality of life between the two genders.

Table 5. Mean score of quality of life among participants depending on the type of multiple sclerosis.

QoL	Sum of squares	df	Mean square	F	P
Between 2 groups	172,477	2	86,239	19,904	0,000
With 2 groups	2842,306	656	4,333		
Total	3014,783	658			

We employed an ANOVA test to examine whether mean scores in participants with different types of multiple sclerosis were similar or varied. The results revealed significant differences among participant groups (p = 0.000). As illustrated in the box plot, individuals with relapsing-remitting multiple sclerosis and clinically isolated syndrome exhibited a higher quality of life scores in comparison to those with primary progressive and secondary progressive types of multiple sclerosis.
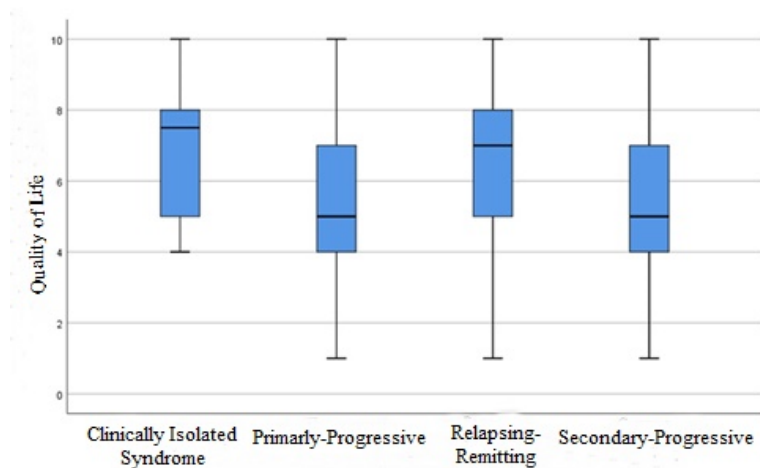
Fig. 2. Box plot for the mean score of quality of life among participants compared to the type of multiple sclerosis.

Discussion

MS is an intricate neurological disease which presents itself in varied forms, manifesting by several facets of problems and symptoms affecting different people in diverse ways. This study included a total of 778 participants, all representing different stories of lives with MS. This paper acknowledges the inherent variation in participants such as that they could have varying degrees of their symptoms and may also give very diverse responses to some questions. Participants frequently experience discomfort or unease when talking about some symptoms as a result of the heterogeneous character of MS. This particularly refers to probing questions that are highly intimate and touchy regarding the routine daily activities and wellness. As such, participants responses show changes in different questions, which signifies the complex nature of their experiences.

The diverse responses given by participants is a sign of the complexities of living with multiple sclerosis. Some participants are willing to disclose their problems but others could find it difficult and reveal less information. We are aware of these nuances as researchers, and hence, our data consist of more than numbers, but a mix of respondents' physical and emotional wellbeing. When evaluating the results, respondents' disparities should be tackled cautiously and taking into account their feelings. The fact that some of these differences have been observed does not undermine the validity of our findings. Instead, it adds to the knowledge of how multiple sclerosis is experienced differently by different individuals.

Multiple sclerosis tends to have a greater impact on quality of life than on its duration, and the expected lifespan of patients only decreases slightly. However, the probability of death among multiple sclerosis patients is more than four times higher than that of the general population.[9]

One study investigated the relationship between disability status, as measured by the Expanded Disability Status Scale (EDSS), and health-related quality of life (HRQOL) in MS patients. Surveys were sent to 7305 MS patients, with 3157 participating. Patients were categorized into three groups based on disability status. Interestingly, the study found a non-linear relationship between disability status and HRQOL. Specifically, the differences in HRQOL between different disability groups were not consistently proportional to the increase in EDSS score, challenging the assumption of the EDSS being interval scaled. This suggests that absolute EDSS scores might not be the most suitable outcome variable in MS studies.[10]

In one systematic review, a comprehensive analysis of clinical, sociodemographic, and psychosocial factors affecting QoL in adults with multiple sclerosis was undertaken. The study encompassed various risk factors such as disability, fatigue, depression, cognitive impairment, and unemployment, while identifying protective factors such as higher self-esteem, self-efficacy, resilience, and social support. Additionally, the review explored a range of psychological interventions including mindfulness, cognitive behavioral therapy, self-help groups, and self-management, all of which exhibited

positive effects on different aspects of QoL.[11]

In one research, the aim was to assess the level of adaptation to multiple sclerosis and health-related quality of life (HRQoL) in 137 patients. Various factors such as motor impairment, neurological disability, adaptation to illness, and HRQoL were analyzed. Correlations were discovered between motor impairment, neurological disability, adaptation to illness, and HRQoL. Lower-limb disability, fatigue, and mood disorders showed strong correlations with adaptation. Additionally, all symptoms, including lower-limb disability, fatigue, other MS-related problems, and mood disorders, were found to impact HRQoL significantly.

Comparatively, our study outcomes are in agreement with the findings presented in the previous research, emphasizing the significant impact of factors like lower-limb disability, fatigue, and mood disorders on adaptation to MS and HRQoL. In both studies, the importance of these specific symptoms on the overall well-being of individuals with MS has been highlighted. Additionally, while our study explored differences in HRQoL among different types of MS, the previously mentioned study delved into the relationships between adaptation, disability, and HRQoL, enriching the collective understanding of MS-related challenges and their effects on patients' lives.[12]

The combined insights from both studies emphasize the multidimensional nature of MS and showed the importance of tailored interventions that address specific symptoms, adaptation challenges, and varying types of MS, ultimately contributing to a comprehensive approach to enhancing the overall quality of life of individuals living with this condition.

One study described the unique challenges faced by pediatric-onset multiple sclerosis (POMS) patients, emphasizing the importance of a comprehensive disease management to optimize the quality of life of these individuals. Our study focused on adults with MS, while the mentioned study concentrated on POMS cases, particularly during adolescence. The shared emphasis was on holistic management, including disease-modifying therapies, nutritional considerations, exercise, and behavioral interventions.[13]

Our study, examining adults with MS, is an addition to the POMS study by extending the understanding of QoL challenges across different age groups affected by multiple sclerosis. While the focus in the POMS study was on younger patients, our study provided valuable insights into the experiences and QoL concerns of adults. By integrating these perspectives, a comprehensive understanding of the lifelong impact of MS on QoL emerges.

Considering the age factor in our participants, ranging across various stages of adulthood, the integration of findings illuminates the diverse experiences and challenges faced by individuals at different life stages. This comprehensive perspective enriches the understanding of QoL issues in the broader context of multiple sclerosis, guiding the development of tailored interventions and support systems that can help the unique needs of individuals across different age groups and disease onset stages.

Conclusion

Overall, this study has shed light on some crucial issues that determine the quality of life of people suffering from multiple sclerosis. We have found strong relationships of disability, fatigue, self-efficacy, as well of acceptance of illness with some aspects of the QoL. Findings have demonstrated interrelationships between biomedical and psychological factors, highlighting the necessity for an integrated approach to management of MS.

It is important that health care providers and policy makers understand how these factors affect QoL so as to develop tailored interventions for addressing multiple problems that MS patients face. Thus, by understanding that self-efficacy and acceptance of illness are crucial factors in boosting psychological well-being, interventions can fit the needs of people with MS, leading to a better quality of life.

Building on the insights gained from this study, future research in the field of MS should explore nuanced areas to further enhance our understanding and refine interventions:

- Longitudinal studies: Carry out longitudinal studies in order to monitor changes in the QoL and its key predictor factors through time, presenting a more complete picture of fluctuating nature of challenges associated with multiple sclerosis.

- Interventional research: Evaluation of the efficacy of tailored interventions like cognitive-behavioral therapy, mindfulness programs and peer support networks in enhancing self-efficacy, acceptance and overall QoL of individuals with multiple sclerosis.

- Incorporating patient perspectives: Employ exploratory/qualitative methods like interviewing and focus groups to understand the experiences of people living with MS.

- Exploring socioeconomic factors: Investigating how socio-economic factors such as access to healthcare, job opportunities, and social relations affect the QoL of people with MS will provide a broader perspective for interventions approach.

- Telemedicine and digital interventions: Investigate the effectiveness of telemedicine programs and digital health solutions offering continuous support, self-management of symptoms, and evidence based counseling or psychological treatment of chronic conditions.

Thus, the potential areas for future research may extend in order to provide better help to those suffering from MS so that we achieve a more open, encouraging and inspiring framework that supports such persons and their families.

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