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ACCESSING SATISFACTION WITH DIETARY RECOMMENDATIONS AMONG PATIENTS WITH MULTIPLE SCLEROSIS IN UKRAINE: A CROSS-SECTIONAL STUDY

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Background. Nutrition knowledge is a potential tool for improving disease management in multiple sclerosis (MS). Understanding how patients perceive and utilize dietary advice is crucial for optimizing support strategies to improve MS disease course management.

Aim. To evaluate patient satisfaction with dietary advice, explore dietary awareness and the need for tailored educational materials.

Materials and methods. A total of 52 patients diagnosed with multiple sclerosis (MS) participated in this single-center survey-based cross-sectional study. Data were collected through structured online questionnaires from MS patients receiving treatment at Kyiv City Clinical Hospital №4 in Ukraine between November 2024 to January 2025, and descriptive statistics were calculated.

Results. A total of 59 patients were invited to participate in the survey, with 7 declining to participate. The median age was 36 (IQR: 29-42). The group included 38 (65,4%) inpatient and 14 (34,6%) outpatient participants, with 65,4% being female. Patients were categorized as having relapsing-remitting (86.5%), primary progressive (9.6%), secondary progressive (3.9%) forms of MS. A majority (70.6%) considered nutrition recommendations important, while 49% initiated the primary dialogue about nutrition with physicians, and 67.4% sought information online. Satisfaction with online resources averaged 3.7/5 (n=30), compared to 3.6/5 (n=23) for information provided by physicians.

Conclusion. This study indicates moderate satisfaction with dietary information from online and physicians-provided sources, underscoring a necessity for improvement. Patients with MS value nutrition in disease management and express interest in receiving evidence-based guidance, highlighting the need for better educational materials.

Keywords: nutritional guidance, dietary habits, multiple sclerosis, disease management, survey-based study

Background. Multiple sclerosis (MS) is a chronic autoimmune neurological disease affecting the central nervous system, often leading to early-onset disability in young adults. Although the precise origins of MS remain unclear, scientific evidence suggests a combination of genetic and environmental factors contributes to its development and progression [1].

Recent studies found that higher Mediterranean diet adherence may slow down disease disability, promoting a better quality of life in adults with MS [2, 3]. Moreover, dietary choices of individuals with MS may be associated with improved quality of life, reduced disability, and alleviated symptoms such as fatigue and depression [4].

The decision to adhere to a particular type of diet after being diagnosed with MS is based both on medical advice and independent research. Assessing patients' perception, understanding, and the quality of the advice they receive can play a key role in complementary therapy and impact treatment outcomes and quality of life. In a non-interventional, cross-sectional study involving individuals with MS, neurologists received the highest patient satisfaction ratings for information quality, with 66.6% of patients rating their information 'excellent' while online information was rated as “sufficient” by only 25.8% of the participants [5].

For individuals with MS, the internet serves as the primary source of dietary information, followed by books [6]. However, online resources for MS nutrition are often characterized by inconsistencies, unreliability, and insufficient quality control, potentially exposing individuals to misleading or harmful advice [7, 13].

Major problems with information retrieval for patients with MS looking for dietary advice online were the inconsistencies and challenges in assessing its credibility, leading to considerable uncertainty [8]. Focus group discussions revealed that participants lacked clarity or felt uncertain about the components of a healthy diet in general, regardless of its potential impact on MS [8].

A study conducted in Germany revealed a significant gap in MS-specific nutrition knowledge among people with MS. Participants in this study demonstrated moderate levels of satisfaction with their understanding of MS-related nutrition information, with a mean satisfaction score of 3.56 out of 5 [9]. In a qualitative study conducted in Sweden, the findings suggest a need for a more diverse development of healthcare services to meet diverse needs in the population with greater acknowledgement of the person's lived experience [10].

Given the potential for dietary modifications to improve metabolic health and clinical outcomes in individuals with MS, there is a need for comprehensive patient education on healthy eating [3]. Enhanced adherence to a Mediterranean Diet (MD) was independently associated with decreased rates of overweight/obesity and abdominal obesity in patients with MS. Furthermore, greater adherence to the MD was associated with a lower incidence of advanced disease disability, higher levels of physical activity, improved quality of life, reduced depressive symptoms, and higher levels of certain blood biochemical parameters, indicative of improved iron status and reduced malnutrition [3]. By contrast, inadequate nutritional knowledge was associated with a higher frequency of adherence to Fast Food & Convenience Food Dietary Patterns [11].

It is also important to consider socio-economic factors when evaluating dietary patterns, habits, and recommendations, as they influence patients' decision-making. In study about international differences in multiple sclerosis health outcomes, there may be other factors that influence on patients' literacy and vary between regions, including differences in access to and quality of healthcare services, which impact the determination of disability in MS [12].

MS is a chronic condition, that's why patient's knowledge and nutrition literacy is an impactful factor for disease management, underlining the importance of patients and health professionals sharing complementary knowledge [13]. Given the correlation between disease duration and the severity of cognitive impairment, it is essential to enhance patient awareness of the role of nutrition and a healthy lifestyle at the earliest stages of diagnosis [14].

Considering the potential importance of diet and its possible impact on disease progression in patients with multiple sclerosis, this study aimed to objectively measure patient-reported experiences and perceptions regarding the dietary advice they received.

MATERIALS AND METHODS

Design and Setting

A single-center, non-interventional descriptive cross-sectional study was conducted to assess and analyze the satisfaction of patients diagnosed with MS regarding the quality of dietary advice received. The study included a total of 52 patients undergoing inpatient treatment (n=38) and outpatient care (n=14) from November 2024 to January 2025 at two departments of Kyiv City Clinical Hospital №4.

A quantitative research approach was employed to evaluate patient satisfaction with dietary counseling, explore access to dietary recommendations, and assess potential gaps in nutritional guidance provided to individuals with MS.

Recruitment and data collection

Participants were recruited based on established diagnosis of MS (ICD 10 code G35). The sampling process in this study included both purposeful and random sampling from the MS department database. The random sampling process was a tool to select participants to narrow the total population from the total n=120. While the criterion for the purposeful sampling was having patients with all types of disease modifying therapy, including naive patients, with the aim to have all segments represented in the study.

A total of 59 patients were invited to participate in a survey administered via an online structured questionnaire, developed independently based on the research objectives and validated by national and international experts. The questionnaire was distributed through the SurveyMonkey platform, and 7 patients declined participation. The final study cohort consisted of 52 participants. The collected data encompassed demographic details, primary MS symptoms, disease progression type, disease-modifying treatment measures, dietary and nutritional changes following diagnosis, and sources of dietary recommendations.

Participants met the inclusion criteria if they were adults (age > 18 years), with a medical diagnosis of MS within the previous 6 months, had no diagnosed autoimmune diseases other than MS, living in Ukraine, and spoke Ukrainian as primary language.

A QR-code was shown to patients with a link to the survey questionnaires n=47, 5 patients received a call and email with the link. All patients were informed about the purpose of the study, their voluntary participation, and their right to withdraw at any time without consequences. No financial compensation was provided for participation.

Each survey took approximately between 10 and 15 minutes to complete. Some patients asked the researchers for clarification, and all confusion regarding questions was resolved. Strict confidentiality measures were observed throughout the study to protect participant privacy. All collected data was anonymized and securely stored.

Analysis

The quantitative data obtained from the survey was analyzed using descriptive statistical methods. The findings were presented in the form of diagrams, charts, and tables, allowing for an objective assessment of patient satisfaction with dietary advice. Responses were categorized to identify trends in dietary counseling accessibility, the perceived quality of nutritional guidance, and patient adherence to dietary recommendations.

RESULTS

The study encompassed a cohort of 52 patients diagnosed with Multiple Sclerosis (MS), consisting of 34.6% (n=18) men and 65.4% (n=34) women, with ages ranging from 20 to 68 years (Table 1).

The majority of participants were diagnosed with relapsing-remitting MS, accounting for 86.5% (n=45) of the sample, followed by 9.6% (n=5) with primary-progressive MS and 3.9% (n=2) with secondary-progressive MS. Half of the participants (50%, n=26) reported being on disease-modifying therapies (DMTs). The most commonly used DMTs included Dimethyl fumarate (33.3%, n=6),

Table 1

Demographic Characteristics of Respondents

Variable	Number
Total number of respondents, n(%)	52(100,00)
Age, years, median	36(20-68)
Age 20-30 years, n (%)	15(28,85)
Age 30-40 years, n (%)	19(36,54)
Age 40-50 years, n (%)	9(17,31)
Age 50-60 years, n (%)	7(13,46)
Age 60-70 years, n (%)	2(3,85)
Sex, n (%) Male	18(34,6)
Female	34(65,4)

Glatiramer acetate (27.8%, n=5), Beta-interferon (22.2%, n=4), and Teriflunomide (11.1%, n=2), reflecting the diversity of treatment regimens within the cohort.

A significant proportion of patients (70.6%, n=36) acknowledged the important role of nutrition in MS management. However, only 49% (n=25) had discussed nutrition with their healthcare providers, and just 10.6% (n=5) received useful nutritional resources from their clinicians. The average satisfaction with dietary recommendations was moderate, with a score of 3.6 out of 5. Although 43.5% (n=10) of participants were fully satisfied, 17.4% (n=4) expressed complete dissatisfaction, highlighting notable gaps in dietary guidance.

A large number of patients (67.35%, n=33) sought dietary information online, consulting various sources. The most frequently referenced were Ukrainian-language specialized associations (19.5%, n=9), followed by English-language associations (17%, n=8), Facebook (10.6%, n=5), and YouTube (12.8%, n=6). Despite these efforts, only 29.63% of participants found comprehensive answers to their questions, while 60.6% (n=20) received partial information. Notably, 11.11% of respondents, all of whom relied solely on Ukrainian-language resources, reported being unable to find any relevant information. The overall quality of the online resources was rated at 3.7 out of 5, indicating that the reliability and comprehensiveness of available digital resources for MS patients could be significantly improved.

Regarding dietary behavior, 44% (n=23) of participants did not adhere to a specific diet, while 25.5% (n=13) made dietary changes, most commonly eliminating sugary drinks, pork, and fried foods. These findings suggest that while some patients actively modify their diets, many remain uncertain or unconvinced about the role of dietary interventions in MS management.

When stratified by gender, non-adherence to dietary recommendations was observed in 44.1% of women (n=15) and 55.5% of men (n=10) (P=0.641, P-value < 0.05 was considered statistically significant). Furthermore, no statistically significant difference was found between men and women in their perception of the importance of nutrition. 64.7% of women (n=22) reported considering nutrition an important topic, compared to 72.2% of men (n=13) (P=0.673, P-value < 0.05 was considered statistically significant).

Among the cohort of patients diagnosed with relapsing-remitting multiple sclerosis (RRMS) (n=45), dietary habits varied, with 25 individuals (55.5%) not adhering to any specific dietary regimen, while 20 patients (44.5%) reported following a particular diet. In contrast, among individuals with progressive forms of multiple sclerosis (including both primary and secondary progressive MS) (n=7), the majority (n=5, 71.4%) did not follow a specific diet, whereas only 2 patients (28.6%) adhered to dietary modifications (Figure 1).

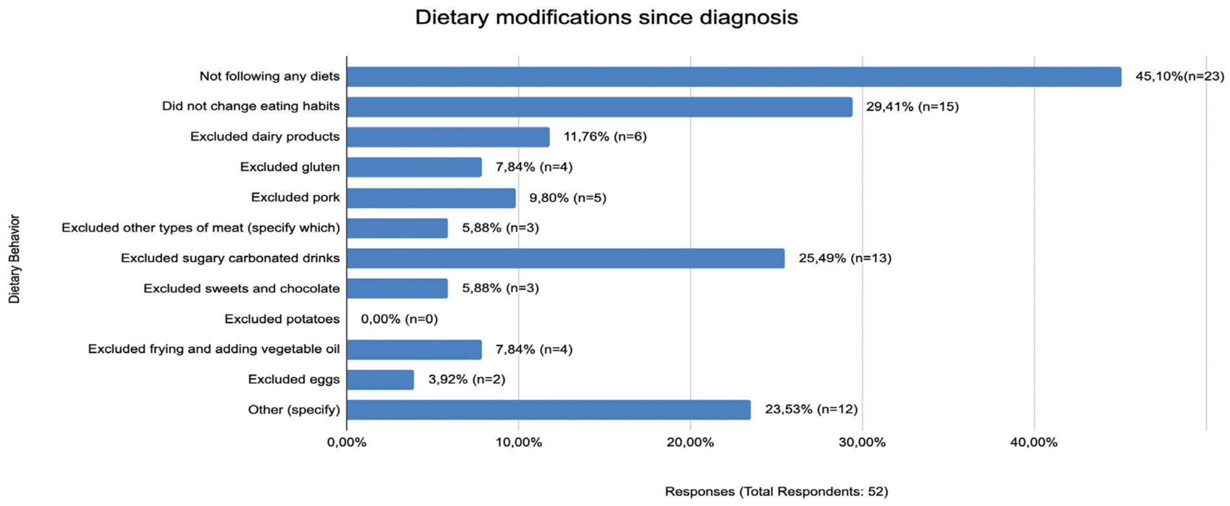

Fig. 1. Dietary modifications since diagnosis

Among the patients who did not adhere to a specific dietary regimen (n=30), 17 individuals (56.7%) were receiving disease-modifying therapy, whereas 13 patients (43.3%) were not undergoing any preventive treatment. Conversely, among those who followed a specific diet (n=22), only 10 patients (45.5%) were on preventive therapy, while the majority (n=12, 54.5%) were not receiving such treatment.

Supplementation was common, with 51%(n=24) of participants reporting the use of nutritional supplements. Among those, vitamin D was the most widely used (87,5%; n=21), followed by omega-3 fatty acids (45,8%; n=11), vitamin B (33,3%; n=8), and magnesium (20,8%; n=5). These findings suggest a growing awareness among patients of the potential benefits of supplements in managing MS symptoms, despite the limited formal guidance available.

These results underscore the pressing need for evidence-based, personalized dietary counseling and the development of reliable nutritional resources to support MS patients in managing their condition effectively. Strengthening collaboration between healthcare providers and patients, along with the creation of trustworthy educational materials, could address existing gaps in dietary management for individuals with MS.

DISCUSSION

The present study highlights key findings regarding patients' beliefs about the role of dietary habits and nutritional counseling among patients diagnosed with multiple sclerosis. Our results found moderate satisfaction with dietary information from online and physicians-provided sources, underscoring a necessity for improvement in both directions.

A considerable proportion of participants acknowledged the importance of nutrition in MS management, yet only a fraction had access to adequate dietary guidance from healthcare providers. Less than half of responders had discussed nutrition with their healthcare providers. Which is consistent with previous research where health professionals downplaying or not addressing the importance of following national dietary guidelines [15]. However, the percentage of those who have actually changed their dietary habits is significantly lower despite considering nutrition an important tool for influencing the course of the disease, which may indicate the controversial nature of the available data on the optimal dietary approach.

Many patients sought information from online sources, with varying degrees of satisfaction regarding the quality and reliability of the resources available. Our participants reported the difficulty judging the credibility of the vast amount of online information for MS, including Ukrainian-language resources. Therefore, the potential improvement of evidence-based Ukrainian-language literature could help enhance compliance by bridging the gap between understanding the importance of proper nutrition and adhering to a balanced diet.

Additionally, among dietary supplements, patients use vitamin D and Omega-3 supplements as part of their doctor's prescriptions. However, not all respondents take these supplements due to socioeconomic reasons or because they do not perceive any benefit.

The choice of a quantitative analysis method helps to clarify the current level of patient satisfaction with dietary recommendations and gather data on their experiences. However, complementing this study with qualitative analysis is necessary to fully explore the key challenges faced by patients diagnosed with multiple sclerosis. Including both inpatient and outpatient populations, as well as patients receiving different types of disease-modifying therapy, strengthens the applicability of the findings across various care settings. However, other potential limitations should also be considered. The sample may have been skewed by the exclusion of people without digital access due to the convenience sampling method used on social media. Furthermore, the study's representativeness was limited by the fact that the sample was drawn from a single center, whereas the situation in other regions of Ukraine may differ.

CONCLUSIONS

This is the first quantitative study to assess dietary satisfaction in people recently diagnosed with MS in Ukraine. The use of survey-based methodology enabled probing to explore nutritional experiences after receiving MS diagnosis.

According to the study's findings, MS patients in Ukraine have a difficult time getting trustworthy dietary advice because of the dearth of structured advice from medical professionals and the abundance of faulty internet information, which leaves patients with little support in managing their nutritional needs. Even allocating time within the consultation structure to explain the importance of a balanced diet could serve as a valuable piece of advice, as it may overall improve patients' quality of life and help prevent complications or the onset of other diseases. By addressing these problems with specialized, evidence-based resources and better healthcare training, MS patients' dietary management and general well-being could be greatly improved.

Professional guidance gaps could be filled by creating dietary guidelines tailored to MS and including dietitians in care teams. The confusion brought on by contradictory internet information would be lessened with the provision of centralised, evidence-based resources. Future programs ought to concentrate on training medical professionals to deliver more individualised and useful nutritional recommendations. These initiatives might be strengthened even more by longitudinal studies looking at how customised therapies affect patient outcomes.

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ОЦІНКА ЗАДОВОЛЕНОСТІ РЕКОМЕНДАЦІЯМИ ПО ХАРЧУВАННЮ СЕРЕД ПАЦІЄНТІВ З РОЗСІЯНИМ СКЛЕРОЗОМ В УКРАЇНІ: ПОПЕРЕЧНЕ ДОСЛІДЖЕННЯ

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Актуальність. Актуальність теми зумовлюється тим, що харчування є важливим комплементарним інструментом в лікувальному плані, який потенційно може покращити контроль за перебігом та активністю розсіяного склерозу (РС). Розуміння того, як пацієнти сприймають і використовують поради щодо дієти, має вирішальне значення для оптимізації стратегій супровідного лікування при РС.

Ціль: оцінка задоволеності пацієнтів дієтичними порадами, дослідження обізнаності щодо оптимальної дієти при РС та визначення потреби в спеціальних освітніх матеріалах.

Матеріали та методи. Загалом 52 пацієнти з діагнозом розсіяний склероз (РС) взяли участь в одноцентровому поперечному дослідженні з використанням дескриптивної статистики. Дані були зібрані за допомогою структурованої онлайн-анкети від пацієнтів з РС, які проходили лікування в Київській міській клінічній лікарні №4 в Україні в період з листопада 2024 року по січень 2025 року.

Результати. Всього до опитування було запрошено 59 пацієнтів, 7 відмовилися від участі. Середній вік становив 36 років (IQR: 29-42). До групи увійшло 38 (65,4%) стаціонарних і 14 (34,6%) амбулаторних пацієнтів, з них 65,4% жінок. Пацієнти були розділені на рецидивно-ремітуючу (86,5%), первинно прогресуючу (9,6%), вторинно прогресуючу (3,9%) форми РС. Більшість (70,6%) вважали рекомендації щодо харчування важливими, тоді як 49% самостійно ініціювали первинний діалог про харчування з лікарями, а 67,4% шукали інформацію в Інтернеті. Задоволеність онлайн-ресурсами становила в середньому 3,7/5 (n=30), порівняно з 3,6/5 (n=23) для інформації, наданої лікарями.

Висновки. Це дослідження вказує на помірну задоволеність інформацією про дієту з Інтернету та джерел, наданих лікарями, що підкреслює необхідність покращення. Пацієнти з РС оцінюють харчування в лікуванні захворювання як важливе та висловлюють зацікавленість в отриманні науково обґрунтованих рекомендацій, підкреслюючи потребу в кращих освітніх матеріалах.

Ключові слова: поради з харчування, харчові звички, розсіяний склероз, перебіг та активність захворювання, опитування