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The Impact of Ilness Acceptance on Quality of Life of Patients with Multiple Sclerosis — Preliminary Study

Wpływ akceptacji choroby na jakość życia pacjentów chorych na stwardnienie rozsiane — badania wstępne

Joanna Rosińczuk[1], **Katarzyna Rychła**[1], **Joanna Bronowicka**[2], **Aleksandra Kołtuniuk**[1]

[1]Department of Nervous System Diseases, Faculty of Health Sciences, Medical University in Wrocław, Poland
[2]Medical Emergency Centre with Paramedic Training School, Legnica, Poland

Abstract

Introduction. Multiple Sclerosis (MS) is a disease that often changes the life of a patient and his or her immediate family. The lack of aetiology, young age and the inability to control the dynamics of disease development and the lack of complete cure are factors impeding the acceptance of the disease.

Aim. Evaluation of the effect of disease acceptance on quality of life (QOL) of MS patients.

Material and Methods. The study was conducted among 128 people (93 women and 35 men) with MS using a shortened quality of life questionnaire of The World Health Organization (WHOQOL-BREF), as well as the Acceptance of Illness Scale (AIS) and the Author's Own Survey (AOS). The research project was approved by the Bioethics Committee of Wrocław Medical University (no. KB-444/2016). The research material was subjected to statistical analysis using the Statistica program version 13.1.

Results. Analysis of the research material revealed that only one in three respondents was satisfied or very satisfied with their health condition, the lowest respondents rated the quality of their lives in the somatic domain, every fourth respondent does not accept his or her own disease, the higher the level of disease acceptance, the higher the score obtained in the WHOQOL-BREF questionnaire.

Conclusions. The level of disease acceptance significantly affects QOL patients with MS. **(JNNN 2017;6(4):157–162)**

Key Words: multiple sclerosis, acceptance of illness, quality of life, nursing care

Streszczenie

Wstęp. Stwardnienie rozsiane (MS, Multiple Sclerosis) to choroba, która często powoduje zmianę dotychczasowego życia pacjenta i osób z jego najbliższego otoczenia. Brak etiologii, młody wiek zachorowania a także niemożność kontroli nad dynamika rozwoju choroby i brak możliwości całkowitego wyleczenia to czynniki utrudniające akceptację choroby.

Cel. Ocena wpływu akceptacji choroby na jakość życia pacjentów (QOL, Quality of Life) chorych na MS.

Materiał i metody. Badanie przeprowadzono wśród 128 osób (93 kobiety oraz 35 mężczyzn) chorujących na MS wykorzystując skrócony kwestionariusz jakości życia Światowej Organizacji Zdrowia (WHOQOL-BREF, World Health Organisation Quality of Life Scale Brief Version) służący do QOL, a także skalę akceptacji choroby (AIS, Acceptance of Illness Scale) oraz kwestionariusz własnego autorstwa (AOS, Author's Own Survey). Na przeprowadzenie badań uzyskano zgodę Komisji Bioetycznej przy Uniwersytecie Medycznym we Wrocławiu (nr KB-444/2016). Materiał badawczy poddano analizie statystycznej przy użyciu programu Statistica 13.1.

Wyniki. Analiza materiału badawczego wykazała, iż: tylko co trzeci ankietowany była zadowolony lub bardzo zadowolony ze stanu swojego zdrowia, najniżej respondenci ocenili jakość swojego życia w domenie somatycznej, co czwarty ankietowany nie akceptuje własnej choroby, im wyższy poziom akceptacji choroby tym wyższy wynik uzyskany w kwestionariuszu WHOQOL-BREF.

Wnioski. Poziom akceptacji choroby istotnie wpływa na QOL chorych na MS. **(PNN 2017;6(4):157–162)**

Słowa kluczowe: stwardnienie rozsiane, akceptacja choroby, jakość życia, opieka pielęgniarska

Introduction

Multiple sclerosis (MS) is an autoimmune disease of the central nervous system (CNS). This disorder has a demyelinating background caused by an inflammatory process that damages the myelin sheath and axons. The aetiology of MS is unknown, however, at the onset of illness is the time when lymphocytes and macrophages react to stimulate the autoimmune process. Immune cells interrupt the blood-brain barrier and their response is directed against nerve cells. The demyelination process does not directly damage whole neurons of white and grey matter, but rather damages myelin and leads to astrocytic scarring. Myelin sheaths produced in the CNS by oligodendrocytes are damaged or severely fragmented with their oedema. The chronic and progressive nature of the disease results in persistent activation of macrophages located in the CNS (microglia cells) [1].

There is a many aetiological concepts of MS, and among the most likely causes are environmental factors (infectious, physical, toxic) and genetic determinants (about 20–30%) [2,3]. In first line relatives, the risk of MS is almost 20 times higher [1,3]. The disease is most likely to occur before adolescence, but noticeable signs of MS are mostly seen in young adults, and the peak of the disease is estimated at about 30 years. Almost twice as many women are infected with MS than men [4].

Geographical distribution of patients with MS is also very characteristic. The highest incidence occurs in moderate climates: in North America (Canada, Northern USA), Northern Europe, South Australia. Significantly lower rates of disease occur in the tropics and in areas with equatorial climate [4,5]. Due to geographical location, Poland is one of the countries with high incidence of multiple sclerosis [6].

The number of MS patients in the world is estimated at over 2.300.000 cases, of which 600.000 are from Europe. In Poland, 43 464 people were registered in the National Health Fund (data as at 31.12.2016), but it cannot be conclusively estimated whether the number of people suffering from the disease, as the list specifies the diagnosis and the suspicion of MS [6].

The main symptoms of MS include: movement and balance disorders (loss of balance, difficulty in making precise movements, paresis, sphincter dysfunction (urinary incontinence, constipation), dysphagia, fatigue, visual disturbances (diplopia, nystagmus), muscle tone disorders (increased muscle tone), disorders in the reception of external stimuli (paraesthesia, neuralgia), speech disorders, sexual dysfunction (impotence, sexual dysfunction) and perception disorders and emotional disorders (feelings lability, lower mood, depression) [7].

The diagnosis of MS significantly affects the life of the patient and his family [8,9]. The lack of aetiology, young age, symptoms multiplicity, and the inability to control the progression of disease and the lack of complete cure are factors hindering the acceptance of disease. It is therefore necessary to establish new goals in the patient's life based on his current system of values and individual needs [10].

One of the most important factors improving the quality of life is adaptation to life with a disease and different life situation (acceptance) [11–15]. Acceptance of the disease means being reconciled to a changing situation such as a deterioration of efficiency [16] It is also characterized by a lower intensity of negative emotions [16–18]. Previous studies on the effect of disease acceptance on quality of life were mainly related to those suffering from chronic respiratory diseases (COPD) [12,13], cardiovascular system (hypertension) [19], diabetes [11], and patient after stroke [15]. However, the impact of disease acceptance on the quality of life of MS patients has not been studied so far.

The aim of the study was to evaluate the effect of the degree of disease acceptance on the quality of life of MS patients treated with immunomodulatory drugs.

Material and Methods

Patients' Characteristic

The study was conducted between February and April 2017 among 128 people with multiple sclerosis treated with 1-line immunomodulatory drugs.

Participation in the study was anonymous and voluntary. All participants gave written informed consent after thorough explanation of the procedures involved and they were informed of the possibility of renouncement at every stage of the study.

Qualification Criteria

Inclusion criteria were as follows: (1) confirmed diagnosis of MS based on medical records, (2) taking 1-line immunomodulatory drugs, and (3) age over 18. Exclusion criteria were: (1) participants without a confirmed diagnosis of MS, (2) participants with a confirmed diagnosis of MS but not taking 1-line immunomodulatory drugs, and (3) patients who, for mental reasons e.g. disorientation, were unable to fill out the survey form.

Formal Permissions

The study was conducted according to the Declarations of Helsinki and the guidelines for Good Clinical Practice.

The research project was approved by the Bioethics Committee of the Wrocław Medical University (no. KB-444/2016).

Research Tools

The diagnostic survey method was applied for the purposes of this study with the use of: (1) the author's own survey (AOS) and standardized questionnaires i.e. (2) Acceptance of Illness Scale (AIS) [20] and (3) Polish version of WHO Quality of Life-BREF questionnaire (WHOQOL-BREF) [21].

a. Author's Own Survey (AOS)

Author's questionnaire was a survey of own authorship, which included questions about socio-demographic data, i.e. age, sex and questions about the use of rehabilitation procedures.

b. Acceptance of Illness Scale (AIS)

This scale was developed in 1984 by Felton et al., and it was adapted to Polish conditions by Juczyński in 2001 [20,22]. The scale determines the degree of acceptance of disease by means of eight statements that describe the subjective attitude of patients to difficulties and limitations caused by illness. A total score is a measure of degree of illness acceptance, ranging from 8 to 40. Score of 8–18 indicates a lack of acceptance of disease, 19–29 — average level of acceptance, 30–40 acceptance of the health situation on a high level. Cronbach alfa for the Polish version is 0.85, and for the original version 0.82, while the test-retest reliability for the Polish version is 0.64 and for the original version 0.69 [20].

c. Polish version of the WHO Quality of Life Questionnaire (WHOQOL-BREF)

It was developed in Polish by a team of specialists from Poznań [21]. It covers four areas of life, including physical and mental states, social relationships, and the environment. The physical domain, also referred to as somatic, included factors such as: the presence of pain, the level of demand for treatment, the degree of satisfaction with rest and sleep, but also the complacency of daily productivity at work and in private life. The psychological domain takes into account the satisfaction of the patient with patient's own appearance, the patient's complacency of life and the frequency of feelings such as depression, anxiety, despair, depression and joy. The social domain takes into account relationships with other people and the support of close relatives to MS patient. The environmental domain includes the sense of security, housing conditions and financial condition of the patient, ability to pursue interests, accessibility to health care and communication. The tool also contains two questions that are analysed individually: the first concerns the self-assessment of the patient's quality of life, and the second individual perceptions of the patient's state of health.

Statistical Analysis

Statistical calculations were performed in Statistica software version 13.1 (StatSoft, Dell Inc., USA). Analysis of quantitative variables was performed by calculating mean, standard deviation and minimum and maximum. Analysis of qualitative variables was performed by calculating the number and percentage of occurrences of each value. Variable distribution normality was verified using the Shapiro-Wilk test. The Mann-Whitney U test was used for comparisons of independent variables between two groups, and the Kruskal-Wallis test was used for comparisons of independent variables between multiple groups. Correlation between two quantitative variables was analysed using Pearson's correlation coefficient (when both variables had a normal distribution) or Spearman (when at least one of them has no normal distribution). Correlation analysis are interpreted as follows: $|r| \geq 0.9$ — very strong correlation; $0.7 \leq |r| < 0.9$ — strong correlation; $0.5 \leq |r| < 0.7$ — moderately strong correlation; $0.3 \leq |r| < 0.5$ — weak correlation; $|r| \geq 0.3$ — very weak (negligible) correlation [23]. All analyses used a significance level p values of less than 0.05 were interpreted as statistically significant.

Results

The study involved a group of 128 people (93 women and 35 men) aged 18 to 65 years. The largest group was 31 to 40 years old (29%), who regularly used rehabilitation during the MS (60%).

Analysis of the study material showed that only 35.9% of respondents were satisfied or very satisfied with their health condition. However, 41.4% of the respondents were satisfied with the quality of their lives and 9.4% were very satisfied. The patients rated their quality of life in the somatic and environmental domains. Detailed data on the participants' characteristics are presented in Table 1.

Table 1. Result of WHOQOL-BREF questionnaire including domain allocation

WHOQOL-BREF domains	Min	Max	Mean	SD
Physical	5.14	20.0	12.69	3.13
Psychological	6.0	19.33	13.17	3.13
Social	5.33	20.0	13.33	3.37
Environmental	6.0	19.0	12.77	2.86

Analysis of the data from the AIS questionnaire showed that the average group score was 24.83 (SD=9.41). Among the surveyed population, 26.5% do not accept their own disease, 37.5% have an average level of disease acceptance, and 36% accept their own disease.

The medium strong and strong correlations between the results of the AIS questionnaire and the domains of the WHOQOL-BREF questionnaire were demonstrated (Table 2 and Figures 1–4). This means that the higher the degree of disease acceptance, the higher the patients' quality of life in each domain.

Table 2. Person's correlation coefficient between domains of WHOQOL-BREF questionnaire and AIS questionnaire

WHOQOL-BREF domains	AIS	
	r	p
Physical	0.75	<0.05
Psychological	0.67	<0.05
Social	0.66	<0.05
Environmental	0.66	<0.05

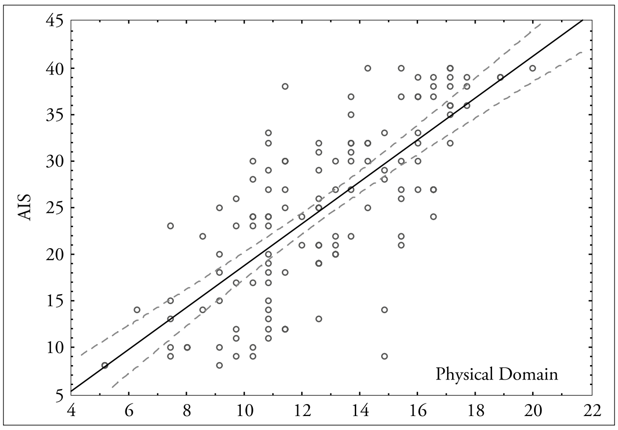

Figure 1. Correlation between the results of the AIS questionnaire and physical domain of WHOQOL-BREF questionnaire

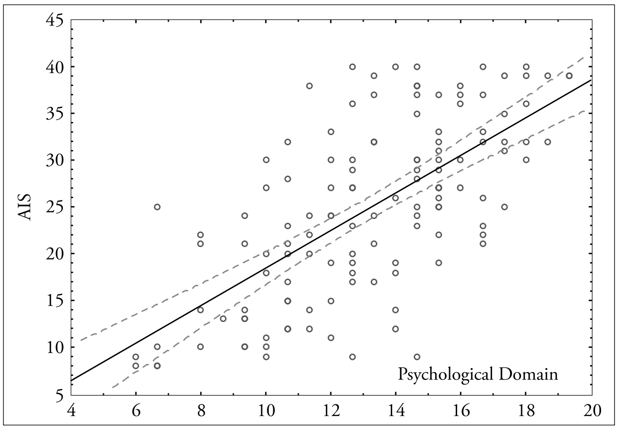

Figure 2. Correlation between the results of the AIS questionnaire and psychological domain of WHOQOL-BREF questionnaire

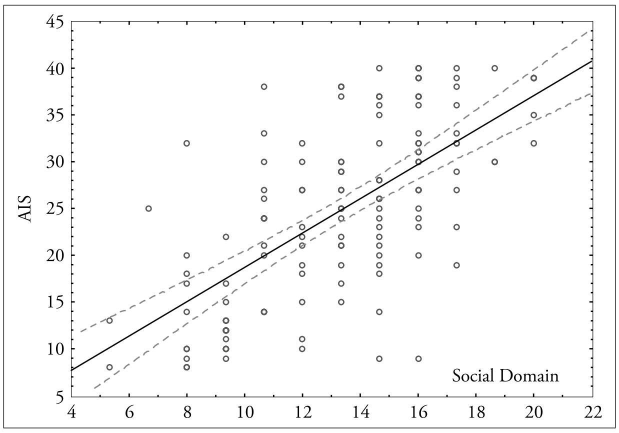

Figure 3. Correlation between the results of the AIS questionnaire and social domain of WHOQOL-BREF questionnaire

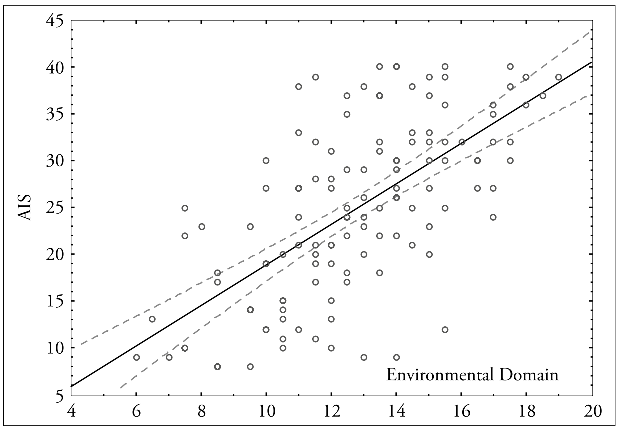

Figure 4. Correlation between the results of the AIS questionnaire and environmental domain of WHOQOL-BREF questionnaire

It has also been determined that people using rehabilitation have a lower degree of disease acceptance (p<0.005, r=-2.29) and lower quality of life in the physical domain of the WHOQOL-BREF questionnaire (p=0.02, r=-2.29).

Discussion

MS is a chronic, progressive and incurable disease of the CNS affecting most young adults [4]. Due to the multiplicity of symptoms, progressive nature and lack of cure, this disease is a serious medical and social problem. Study by Lorencowicz et al. [24] demonstrated that mong MS patients, only 38.5% of respondents are satisfied or very satisfied with the quality of their lives. Similar results were also obtained in the own study. However, the percentage of people positively evaluating their state of health in Lorencowicz et al. [24] was significantly lower than the results obtained in this study.

Numerous studies [9,24–28] have indicated that multiple sclerosis significantly reduces the quality of life of patients, as demonstrated in the own study. Our own study confirmed that the patients with MS had the lowest quality of life in the somatic domain, assessing the degree of efficiency and independent functioning [24–27]. This is related to the occurrence of certain groups of symptoms from the movement system in these patients (loss of balance, apraxia, paresis), which limit the ability of moving and significantly hinder an independent functioning.

Therefore, assessment of quality of life and its determinants should be a permanent feature of the therapeutic process, to be able to capture important elements that may further affect the deterioration of the quality of life.

Predictors of disease acceptance are psychological reconciliation and adaptation to potential limitations, leading to the integration of changed psychophysical condition with the old way of life [29]. Our own studies have shown that the mean score for the whole group of MS patients was 24.83, which coincides with the results obtained by Pejas-Grzybek et al. [30]. In Król et al. study [31], it appears that acceptance of disease in MS patients has a strong positive relationship with subjective physical efficiency assessment and moderate positive association with subjective mental efficiency assessment, that found confirmation in the results of own study, where the acceptance of the disease positively correlated with the quality of life in the somatic and mental domains. Evaluation of disease acceptance among MS patients should be an integral part of the therapeutic process, because the patient's reconciliation with the disease allows to reduce the negative feelings [17,18] and fear [32], as well as more effective control of the course of the disease [12] and thus improve the quality of life [11,13–15].

Implication for Nursing Practice

Nurses working with MS patients should provide them with information support (associated with, e.g., way of medication administration, possible side effects of treatment) and emotional issues. With support, MS patients have the opportunity to reconcile more easily themselves with their own limitations as a result of disease and to better adapt to their new life situation.

Conclusions

1. The level of acceptance of the disease significantly affects the quality of life of MS patients.
2. Evaluation of the acceptance level of the disease in MS patients should be an integral part of the therapeutic process.

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Corresponding Author:
Joanna Rosińczuk
Department of Nervous System Diseases
The Faculty of Health Sciences
Wrocław Medical University
Bartla Street 5, 51-618 Wrocław, Poland
e-mail: joanna.rosinczuk@umed.wroc.pl

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Author Contributions: Joanna Rosińczuk[A, G, H], Katarzyna Rychła[B–D], Joanna Bronowicka[G, H], Aleksandra Kołtuniuk[E–G] (A — Concept and design of research, B — Collection and/or compilation of data, C — Analysis and interpretation of data, D — Statistical analysis, E — Writing an article, F — Search of the literature, G — Critical article analysis, H — Approval of the final version of the article)
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