Pielęgniarstwo
Neurologiczne i Neurochirurgiczne
THE JOURNAL OF NEUROLOGICAL AND NEUROSURGICAL NURSING

eISSN 2299-0321 ISSN 2084-8021 www.jnnn.wshe.pl **Original**

DOI: 10.15225/PNN.2015.4.1.3

The Degree of Illness Acceptance among Patients with Multiple Sclerosis

Poziom akceptacji choroby w stwardnieniu rozsianym

Lidia Pejas-Grzybek, Agnieszka Skorupska-Król

Department of Clinical Nursing, Institute of Nursing and Obstetrics
Faculty of Health Sciences, Collegium Medicum at Jagiellonian University, Cracow, Poland

Abstract

Introduction. Acceptance of chronic disease depends on patient's personal predisposition as well as on characteristics of the disease, such as the type and severity of symptoms, its consequences in the perspective of physical and psychosocial functioning and possibilities of treatment. In particular, it seems to be difficult to accept such a disease as multiple sclerosis, the beginning of which concerns mainly young people who are forced to re-evaluate their life and modify plans for the future so that the self-portrait would not become a source of frustration and a sense of a lower esteem.
Aim. The aim of the study was to assess the acceptance of the disease and to analyse the relationship of such acceptance with patients' functional status and with self-assessment of depression.
Material and Methods. The group of respondents consisted of 38 patients of the Department of Neurology in Cracow, who had been diagnosed with multiple sclerosis. In this work the method of diagnostic survey and the analysis of records were applied. Participants of the study were asked to complete such research tools as: the Beck Scale, Katz Scale, socio-demographic data inventory and the Acceptance of Illness Scale (AIS). The analysis covered their medical records and individual cards of medical orders. The obtained results were subject to statistical calculations.
Results. The score of a significant number of respondents — 13 (34.2%) on the AIS Scale was qualified to the highest score ranging from 32 to 40 points. Slightly more than 1/4 of the study group (10 patients, ie. 26.3%) obtained a score ranging from 23 to 31 points. The smallest group of respondents achieved the lowest score, as it was qualified for the range of 5–13 points (6 persons, ie. 15.8%). The AIS Scale average score for the whole group studied was 25.08 points. Between the acceptance of the disease, and the presence and severity of depression among respondents, there is a negative correlation (r=-0.29), however it is not statistically significant (p=0.08). The value of the correlation coefficient of the AIS and Katz Scales (r=0.15) results is not statistically significant either (p=0.37).
Conclusions. Acceptance of the disease in the group of people is average and similar to that encountered in other somatic diseases of chronic course. A better emotional condition seems to enhance greater acceptance of the disease.
(JNNN 2015;4(1):19–23)
Key Words: illness acceptance, chronic disease, multiple sclerosis

Streszczenie

Wstęp. Akceptacja choroby przewlekłej zależy od predyspozycji osobowościowych chorego i cech choroby, tj. rodzaj i nasilenie objawów, jej następstwa w perspektywie funkcjonowania fizycznego i psychospołecznego, możliwości leczenia. Szczególnie trudna wydaje się akceptacja takiej choroby, jaką jest stwardnienie rozsiane, której początek dotyczy najczęściej ludzi młodych, zmuszonych do tego, by przewartościować swoje życie i zmodyfikować plany na przyszłość tak, by autoportret własny nie stał się źródłem frustracji czy poczucia niższej wartości.
Cel. Celem przeprowadzonych badań była ocena akceptacji choroby oraz analiza związku takiej akceptacji ze stanem funkcjonalnym chorych i samooceną depresji.
Materiał i metody. Grupę badaną stanowiło 38 pacjentów Kliniki Neurologii w Krakowie, którzy otrzymali diagnozę stwardnienia rozsianego. W pracy wykorzystano metodę sondażu diagnostycznego i analizy dokumentacji. Uczestnicy badań zostali poproszeni o kompletowanie takich narzędzi badawczych, jak: Skala Becka, Skala Katza,

inwentarz danych socjodemograficznych i skala Akceptacji Choroby (AIS). Analiza obejmowała ich historie choroby oraz indywidualne karty zleceń lekarskich. Otrzymane wyniki poddano obliczeniom statystycznym.
Wyniki. Wynik skali AIS znacznej liczby ankietowanych, bo 13 osób (34,2%) został zakwalifikowany do najwyższego przedziału punktowego, czyli mieścił się między 32 a 40 punktów. Nieco ponad 1/4 badanej grupy (10 osób, tj. 26,3%) uzyskała wynik w przedziale między 23 a 31 punktów. Najmniej liczna grupa respondentów osiągnęła najniższy wynik, bo zakwalifikowany do przedziału 5–13 punktów (6 osób, tj. 15,8%). Średni wynik skali AIS dla całej badanej populacji wynosił 25,08 punkta. Pomiędzy akceptacją choroby, a obecnością i nasileniem depresji wśród badanych istnieje ujemna korelacja (r=-0,29), jednak nie jest ona istotna statystycznie (p=0,08). Wartość współczynnika korelacji wyników Skali AIS i Katza (r=0,15) również nie jest istotna statystycznie (p=0,37).
Wnioski. Akceptacja choroby w badanej grupie osób jest przeciętna i podobna do tej spotykanej w innych chorobach somatycznych o przewlekłym przebiegu. Wydaje się, że lepszy stan emocjonalny sprzyja większej akceptacji choroby. **(PNN 2015;4(1):19–23)**
Słowa kluczowe: akceptacja choroby, choroba przewlekła, stwardnienie rozsiane

Introduction

Even Hippocrates — the father of medicine, said that "it is more important to know what type of person has a disease than what disease this person suffers from". In other words, more important is one's attitude to the disease and to oneself than the disease itself once it occurs [1].

Particular meaning and importance is attributed to the aforementioned statement when there occurs a chronic disease and the related bio-psycho-social balance disorders become an extremely stressful event. In the light of Lazarus and Folkman's concept of stress [2], the patients who have a sense of control over the course of the disease, cooperate in the field of therapeutic proceedings, notice their effects, see the effectiveness of their own activities and better adjust to the new situation. If, however, a stressful event is defined by a chronic disease, such as multiple sclerosis — with incompletely recognized etiology (as it is the case in autoimmune diseases), of variable and difficult to predict dynamics, and treatment is not fully satisfactory, then the patient does not have a sense of control over it, which results in difficulties in adapting to it [2]. The way to the acceptance a chronic disease is usually multi-stage, and its main stages include: denial, fear and isolation, anger and irritation as well as bargaining, depression and acceptance. Not in every patient there occur all of the aforementioned stages, sometimes some of them might be experienced more than once. Kurowska and Lach add that people who can accept their illness, are more likely to take the challenges of struggle for recovery and they also experience fewer negative emotions [3].

The studies aimed at the assessment of:
1. the level of illness acceptance,
2. the relationship between the illness acceptance and:
— the presence and severity of depression;
— the level of independence regarding daily activities.

Material and Methods

The study group consisted of 38 patients of the Department of Neurology in Cracow, diagnosed with multiple sclerosis and remained under the care of the ward or its patient unit.

The following inclusion criteria were adopted for the research:
1. Conscious consent to participate in the study.
2. At least two-year duration of the disease.
3. At least two relapses of the disease.

In the studies the diagnostic survey method was applied, and using a survey technique the respondents were asked to complete such research tools as the Beck Depression Scale, Scale Katz, Acceptance of Illness Scale (AIS).

The AIS Scale contains eight statements describing negative consequences of poor health condition, which come down to recognizing the limitations imposed by the disease, lack of self-sufficiency, a sense of depending on others as well as decreased self-esteem. Illness acceptance is manifested in the decreased intensity of negative reactions and emotions associated with it [4]. Also, our sociodemographic inventory was used. For the purpose of obtaining data regarding the course of the disease, the method of documentation analysis was applied, in this case the records of the disease as well as individual cards of doctor's orders were subject to verification. The data obtained were subject to statistical analysis. In addition to descriptive statistics, r-Pearson correlation coefficient was applied. In the calculations performed, the significance level of $p<0.05$ was adopted.

Results

The group of respondents consisted mainly of women (73.7%, 28 patients), the average age of the entire group was 36 years. The age of most respondents ranged from 20 to 29 years (34.2%, 13 patients), and only 5 patients (13.2%) were over 50. Nearly 37% (14 patients) of respondents had higher education. Almost

70% of patients included in the group lived in the city. As many as 52.3% (20 respondents) were economically inactive. The majority of the patients were married (68.4%, 28 respondents). Most of them, 24 patients (63.2%) lived with their families, and only 2 respondents (2.3%) lived alone. In their self-assessment, 20 respondents (52.6%) defined their socio-economic condition as average and only one person (2.6%) responded that it was poor.

Duration of the disease in more than half (21;55.3%) of the respondents did not exceed 5 years. Six patients (15.8%) had suffered from the disease for longer than 10 years. Most, as many as 23 respondents (60.5%), experienced not more than three relapses of the disease. As many as 73.7% of all respondents (28 patients) were hospitalized due to the disease not more than three times. During the periods of symptom exacerbation, most respondents — as many as 73.7% (28 patients) were taking Metyleprednizolon. As many as 25 patients (65.8%) were not subject to the treatment which would prevent progression of the disease, and 9 patients (23.7%) underwent immunomodulatory therapy. In the case of 60.5% of patients diversfied symptomatic treatment was applied.

The analysis of the results according to the Acceptance of Illness Scale

All conclusions from the AIS Scale express certain difficulties and limitations caused by the process of the disease. The total score from the scale ranges from 8 to 40 points. The higher it is, the greater acceptance of illness and smaller psychological discomfort associated with the disease. In order to analyse of the results obtained, they were categorized (as shown below), and the first of numerical ranges established for the purpose of statistical calculations was extended (from number 5), so that the intervals were equal (Table 1).

The data indicate that the result of the AIS Scale obtained by a significant number of respondents, as many as 13 patients (34.2%), was classified to the highest point range, which means it ranged from 32 to 40 points. Slightly more than 1/4 of the study group (10 persons, ie. 26.3%) obtained a score ranging from 23 to 31 points. The least numerous group of respondents achieved the lowest score, classified for the range of 5–13 points (6 patients).

Table1. Acceptance of the illness in the studied group according to the AIS Scale

Point range made for AIS results	Number of patients (N)	Percentage (%)	$\bar{x}$
5–13	6	15.8	25.1
14–22	9	23.7	
23–31	10	26.3	
32–40	13	34.2	
Overall	38	100	

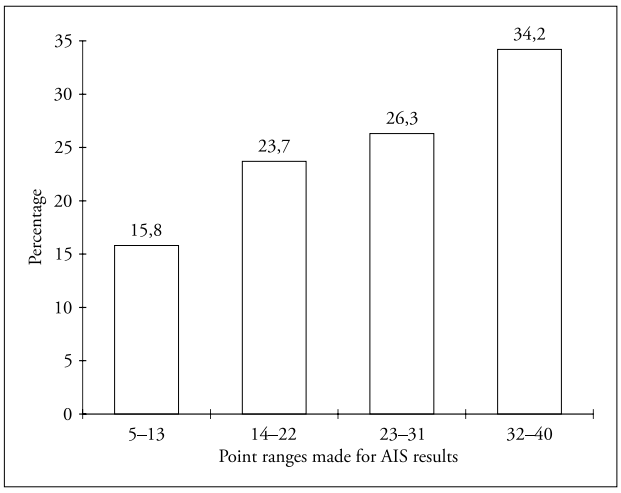

Figure 1. Graphical interpretation of the data from Table 1

The average result of the AIS Scale for the entire study group was 25.08 points, whereas minimum and maximum value obtained by the respondents was respectively 8 and 40 points.

In the subsequent stages of the analysis attempts were made to determine whether there is a statistically significant relationship between acceptance of the illness and other indicators of its progress, in other words, between a subjective feeling of depression and self-assessment of physical fitness in terms of everyday activities. By responding to this issue, r-Pearson correlation coefficient was calculated (Table 2).

Table 2. The value of the r-Pearson correlation coefficient for the variables studied (such as self-assessment of the illness acceptance, depression, and functional performance)

Variables		Acceptance of illness
Severity of depression (on the Beck Scale)	r	-0.29
	p	0.08
Independence (on theKatz Scale)	r	0.15
	p	0.37

p — level of statistical significance; r — value of the correlation coefficient

For the needs of this study it should be noted that the absence of depression among respondents was proved by the results obtained in the Beck Scale for about 1/3 of the group (36.8%), the others indicated the presence of depression: light (23.7%), medium (23.7%), deep (7.9%) and very deep (7.9%). In addition, 84.2% (32 patients) of respondents assessed their functional independence as full, and 10.5% (4 patients) considered themselves as not independent in terms of daily functioning.

Accurate data on this subject were published in the previous report regarding the spread of the phenomenon of depression in MS.

Analysis of the data included in Table 2 shows that between acceptance of the illness and the presence and severity of depression among the respondents, there is a negative correlation (r=-0.29), however it is not statistically significant (p=0.08). The value of the correlation coefficient of the results obtained by the AIS and Katz Scale (r=0.15) is not statistically significant (p=0.37) either.

Discussion

Multiple sclerosis is a disease that usually starts at young age, most often between 20 and 40 years of age, and its prognosis is negative. With its duration, patient mobility deteriorates, which in turn contributes to the adverse psychological and social consequences, such as lower self-esteem, helplessness and resignation, difficulties in carrying out one's duties arising from previous social roles (related to both family and work). The probability of such a perspective in life, additionally strengthened by the reduced possibilities of access to effective therapies, make it difficult to fully accept the situation although it is possible under certain conditions. Sęk and Niedzielski claim that the acceptance of chronic disease is determined by its specificity and individuality of the patient. Personality traits, essential for such acceptance include: hope, optimism, determination, belief in success and persistence. Disease characteristics required for its psychosocial adaptation include: symptoms, possibilities of effective treatment, complications and prognosis [5].

The research chronic disease acceptance was carried among 38 patients who were treated in the Department of Neurology in Cracow because of their diagnosis in multiple sclerosis. All of them were informed about the purpose and they agreed to take part in the study.

The data presented indicate that just over a third of respondents (34.2%) strongly accept their illness, as its result has been qualified to the highest point range, which was between 32 and 40 points. Nearly 1/4 of the group (10 persons) received a total score of the AIS Scale, which should be interpreted as the average (range between 23 and 31 points). The smallest group of respondents (6 patients) obtained the lowest score, as it was qualified for the range of 5–13 points. To compare the results obtained, Lach and Kurowska's studies [3] can be cited, where the authors made an attempt to assess the degree of disease acceptance among the patients diagnosed with type 2 diabetes. The average acceptance referred to more than half of the respondents (54.5%) whereas in the self-assessment of 28.6% of respondents the acceptance of diabetes was prevailing. The average score for the AIS Scale for study group diagnosed with MS was 25.08 points. Comparing it to the average results obtained in other disease units, one can conclude that it does not substantially differ from that received by: Bilińska and Sitek who were examining patients with myasthenia gravis (25.9 points) [6], Kurowska and Lach [3] examining patients with type 2 diabetes (25.2 points), March et al. [5] studying patients with chronic kidney disease and diabetic kidney disease — subject to hemodialysis (22.1 points), and finally Niedzielski et al. [5] examining patients with various somatic diseases of chronic course, such as asthma and coronary heart disease (24 points). In contrast to the aforementioned results, the result obtained by Amplified-Birch et al., who were examining patients with schizophrenia, seems to be significantly lower (18 points) [7]. The emerged difference may be due to the social image of a psychotic illness, such as schizophrenia, which still appears to be negative, characterised by resentment and fear. Lack of understanding of the essence of psychosis as well as the psychotic patient stereotype result in the situation where the patients themselves due to the so-called secondary constraints (which are not directly related to the image of the disease but to the reaction to it by people who are significant to the patient as well as by the wider social environment) do not accept it.

The statistical analysis was not only an attempt to assess the level of illness acceptance among patients with a diagnosis of MS, but it also was to indicate whether other dependent variables (whose level was assessed, and which included severity of depression and functional efficiency) are correlated with the results of the AIS Scale. Relevant calculations in this field allow us to conclude that neither the emotional state nor the functional efficiency are significantly associated with the level of the MS acceptance in the group of respondents. In both cases, the level of statistical significance (p) is greater than 0.05. Interpreting these calculations one can only add that the correlation of the results obtained by the Beck Scale and those from the AIS Scale (p=0.08) was closer to statistical significance and the coefficient of this correlation was negative (r=-0.29), which appears to indicate that at higher r values and at $p<0.05$ better self-assessment of the emotional state accompanies greater acceptance of the disease. Bilińska and Sitek [6] made an attempt to identify those factors which are significantly associated with the acceptance of chronic neuromuscular disease, such as myasthenia gravis. The cited studies indicate that the average score for the AIS Scale negatively correlated with the severity of depression (r=-0.5),with anxiety as a feature (r=-0.39) and performance status (r=-0.4). Therefore, less severe anxiety (as a feature), positive emotional state, and the good functioning in everyday life promoted the acceptance of

myasthenia. Peinter [5] adds that acceptance of the illness can be an element which activates the patient, but also physical (and other) fitness promotes the growth of illness acceptance.

Seeking acceptance determinants in a chronic somatic disease other than neurological, it is worth recalling relevant results obtained with the respondents diagnosed with diabetes or kidney disease. Kurowska and Lach [3] have proved that in the case of patients with type 2 diabetes, the more they accept their disease, the shorter its duration, have better financial conditions, and during the moments of stress they more often tend to focus on the task, and therefore have a greater incentive to solve problems. It is obvious that financial conditions are important even due to the fact that they allow one to use to a greater extend and more frequently different medical services, which are not provided by the NHF, and therefore the limitations resulting from the chronic disease process may be less troublesome and may progress more slowly.

Kossakowska while studying strategies for coping with stress among patients with multiple sclerosis and with healthy individuals, comes to an interesting conclusion. The author noted that the most statistically significant difference in terms of chosen strategy between the two groups concerned the acceptance (p=0.0001). Respondents diagnosed with MS more often chose such a strategy in a stressful situation, which in their opinion was associated with their chronic disease. The author explains that patients diagnosed with multiple sclerosis are forced to accept their disease, which is an unavoidable situation. This acceptance forced upon in a way by a chronic, progressive and incurable nature of the disease allows them to exist in the reality emerged [2].

Conclusions

The acceptance level of illness among patients with multiple sclerosis varies, and its score average for the entire group should be interpreted as the average and similar to that associated with other chronic diseases of somatic background.

Experiencing positive emotions promotes both greater acceptance of the illness as well as life situation related to it.

Implications for Nursing Practice

The more unpredictable the dynamics in the rise of a chronic disease symptoms is, the more difficult it is to accept it, and its consequences gradually reduce former activity of the patient. Multiple sclerosis due to the long-term and most frequently reoccurring course will, in a way, force the patient to psychosocial adjustment of both the disease as well as its consequences.

The nurse as a participant in the process of diagnosis, long-term therapy and rehabilitation supports the patient in activities which are supposed to make it easy to accept the course of the illness acceptance, and not being able to eliminate both the disease and the stress associated with it, the nurse provides emotional and social knowledge (such as the ability to deal with difficult situations) allowing the patient to accept functional limitations which have emerged.

References

[1] Wojciechowska J., *Sobie Moc czyli rehabilitacja wielowymiarowa w stwardnieniu rozsianym*. Wyd. II, Tarnów 2004.
[2] Kossakowska M. Strategie radzenia sobie z chorobą przewlekłą w stwardnieniu rozsianym. *Postępy Psychiatrii i Neurologii*. 2008;17(1):15–21.
[3] Kurowska K., Lach B. Akceptacja choroby i sposoby radzenia sobie ze stresem u chorych na cukrzycę typu 2. *Diabetologia Praktyczna*. 2011;3(12):113–119.
[4] Jurczyński Z. *Narzędzia pomiaru w promocji i psychologii zdrowia*. Pracownia Testów Psychologicznych Polskiego Towarzystwa Psychologicznego, Warszawa 2001.
[5] Marzec A., Andruszkiewicz A., Banaszkiewicz M. Poczucie koherencji, akceptacja choroby, a funkcjonowanie w chorobie przewlekłej u osób chorych na chorobę nerek i chorych na cukrzycę, hemodializowanych — doniesienie wstępne. *Pielęgniarstwo XXI wieku*. 2011;2(35):51–56.
[6] Bilińska M., Sitek E. Jakość życia i akceptacja choroby w miastenii. *Postępy Psychiatrii i Neurologii*. 2007;16(2): 139–143.
[7] Badura-Brzoza K., Piegza M., Błachut M., Ścisło P., Leksowaska A., Gorczyca P. Ocena wybranych czynników psychicznych i socjodemograficznych na jakość życia pacjentów ze schizofrenią. *Psychiatria Polska*. 2012;6:975–984.

Corresponding Author:
Agnieszka Skorupska-Król
Zakład Pielęgniarstwa Klinicznego
Instytut Pielęgniarstwa i Położnictwa, Wydział Nauk o Zdrowiu
Collegium Medicum Uniwersytetu Jagiellońskiego
ul. Kopernika 25, 31-501 Kraków, Poland
e-mail: agnieszka.skorupska@uj.edu.pl

Conflict of Interest: None
Funding: None
Author Contributions: Lidia Pejas-Grzybek[A, B, C, F], Agnieszka Skorupska-Król[A, C, E, F, G, H]
(A — Concept and design of research, B — Collection and/or compilation of data, C — Analysis and interpretation of data, E — Writing an article, F — Search of the literature, G — Critical article analysis, H — Approval of the final version of the article)
Received: 14.10.2014
Accepted: 08.12.2014