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Clinical and Sociodemographic Variables and the Level of Social Support in People with Multiple Sclerosis

Zmienne kliniczne i socjodemograficzne a poziom wsparcia społecznego u osób ze stwardnieniem rozsianym

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Abstract

Introduction. Multiple sclerosis (MS) is a chronic progressive demyelinating disease of the central nervous system which leads to permanent disability. Social support is a resource that is particularly important in the situation of chronic illness.

Aim. The aim of the study was to determine the relationship between clinical and sociodemographic variables and the level of social support in people with multiple sclerosis.

Material and Methods. 137 people diagnosed with MS participated in the study. Extended Disability Status Scale (EDSS), Guy's Neurological Disability Scale (GNDS) and Berlin Social Support Scales were used in the study.

Results. Perceived social support is not related to clinical variables such as disability or disease symptoms. However, the relationship between the need for support and disability and some symptoms (i.a. cognitive impairment, mood disorders and intestinal problems) was demonstrated. Women, people married, having children and in better financial condition felt greater social support. Women also need more support and more often seek it.

Conclusions. Perceived social support in people with multiple sclerosis is less associated with clinical variables, but more to variables such as gender, marital status or having children. Of the studied types of support, the need for support was most related to the features of the disease. People living with a disability or more severe symptoms need help in daily functioning as well as emotional support. This is also associated with the need for professional support from doctors, psychologists and nurses. (JNPN 2019;8(4):148–156)

Key Words: Multiple sclerosis, social support, disability

Streszczenie

Wstęp. Stwardnienie rozsiane (SM) jest przewlekłą, postępującą neurologiczną chorobą, która może prowadzić do znacznej niepełnosprawności. Istotnym zasobem w radzeniu sobie z SM i innymi chorobami przewlekłymi jest wsparcie społeczne.

Cel. Celem badań było określenie związku pomiędzy zmiennymi klinicznymi i socjodemograficznymi a wsparciem społecznym u osób z SM.

Materiał i metody. W badaniu wykorzystano Rozszerzoną Skalę Niewydolności Ruchowej (EDSS), Skalę Niepełnosprawności Neurologicznej Szpitala Guy (GNDS) oraz Berlińskie Skale Wsparcia Społecznego Grupy badaną stanowiło 137 osób ze zdiagnozowanym SM.

Wyniki. Spostrzegane wsparcie społeczne nie jest powiązane ze zmiennymi klinicznymi, takimi jak niepełnosprawność czy objawy choroby. Wykazano jednak związek między zapotrzebowaniem na wsparcie a niepełnosprawnością neurologiczną i niektórymi objawami (m.in. zaburzeniami poznawczymi, zaburzeniami nastroju i problemami jelitowymi). Kobiety, osoby pozostające w związku małżeńskim, mające dzieci i będące w lepszej sytuacji finansowej odczuwały większe wsparcie społeczne. Kobiety również potrzebują większego wsparcia i częściej go szukają.

Wnioski. Spostrzegane wsparcie społeczne u osób ze stwardnieniem rozsianym jest w mniejszym stopniu związane ze zmiennymi klinicznymi, a bardziej z socjodemograficznymi, takimi jak płeć, stan cywilny lub posiadanie dzieci. Spośród badanych rodzajów wsparcia społecznego zapotrzebowanie na wsparcie było najsilniej związane z cechami choroby. Osoby zmagające się z niepełnosprawnością i poważniejszymi objawami potrzebują pomocy w codziennym

funkcjonowaniu, a także wsparcia emocjonalnego. Jest to również związane z potrzebą profesjonalnego wsparcia ze strony lekarzy, psychologów i pielęgniarek. (PNN 2019;8(4):148–156)

Słowa kluczowe: stwardnienie rozsiane, wsparcie społeczne, niepełnosprawność

Introduction

Multiple sclerosis is a chronic, progressive, degenerative neurological disease. It is one of the most common neurological diseases in young adults and the leading cause of non-traumatic disability in young and middle-aged adults. Signs and symptoms of MS vary widely among patients and may include a variety of neurological signs and symptoms, such as: motor disturbances, difficulties with coordination and balance, visual problems, pain, bowel and bladder difficulties, sexual dysfunction, problems with speech and swallowing, fatigue, emotional and cognitive problems [1,2].

MS as a chronic disease that occurs in young people in the most productive period of their lives is associated with many psychosocial problems, such as changing their social roles and modification of life goals [3]. The social costs of MS are higher than those associated with strokes or Alzheimer's disease. It is associated with onset in early to middle adulthood, duration of the disease (It has a relatively small impact on life expectancy, so there is a need to treat the patient for many years), early loss of work capacity due to disability, wide range of symptoms, the need for care and assistance in carrying out daily activities, and the high cost of immunomodulatory therapies or interdisciplinary medical care [4,5]. Due to the increase of disability and the impact of the disease on daily functioning, most patients need social support from their environment.

Social support is an important resource that helps people cope with difficult situations. It is usually defined as help available to individuals in stressful situations [6]. Social support is the perception that one is cared for, has assistance available from other people, and that one is a part of a supportive social network. There are many classifications of social support. Researchers make a distinction between received and perceived support. The first one is retrospective and relates to the help that a person has received, while the second one is prospective and is related to the beliefs of the individual regarding people he or she can count on during times of need. Concepts of received and perceived social support are associated with the idea of the need for support, which is related to the individuals' conviction about whether they are doing better on their own or thanks to the help of others, and the concept of mobilization and seeking support [7].

Social support is a resource that is particularly important in the situation of chronic disease [8]. However, the disease itself can also affect the size of

social networks and the ability to use them. Many people with MS report a decrease in the number of social roles and contacts [9]. Other studies show that in 29% of people with MS social contacts are limited to their immediate surroundings [10]. The disease can also lead to breaking family bonds [11] and according to the results of the research, social support is one of the factors affecting HRQoL [12]. In addition, studies on other patient groups have shown that social support can be affected by the type of disease [13].

The aim of the study was to determine the relationship between clinical and sociodemographic variables and the level of social support in people with multiple sclerosis.

Materials and Methods

Characteristics of the Study Group

The study group consisted of 137 individuals diagnosed with multiple sclerosis — 73 women and 64 men aged between 18 and 73 ($M=46.47$; $SD=12.59$). The group was diverse in terms of level of education. Most of the respondents were on a pension or retired (63.5%). The study excluded patients with cognitive deficits hindering the understanding of psychological questionnaires, i.e. patients who obtained more than 3 points on the Cognitive Disorders subscale in the GNDS questionnaire. The average duration of MS of the studied sample was 14.61 years ($SD=8.31$). Mean age at diagnosis in the studied population was 33.94 years ($SD=10.65$). The characteristics of the subjects were presented in Table 1.

Table 1. Characteristics of the study group

Variable	N	%	
	1	2	3
Gender			
Woman	73		53.3
Man	64		46.7
Education			
Basic	2		1.5
Vocational	25		18.3
Secondary	58		42.3
Bachelor's degree	13		9.5
Master's degree	38		27.7
No data	1		0.7

Table 1. Continued

	1	2	3
Type of the disease			
Relapsing-remitting		43	31.4
Primary progressive		22	16.1
Secondary progressive		31	22.6
Progressive-relapsing		8	5.8
Unspecified		33	24.1
EDSS			
0.0–4.0		60	43.8
4.5–5.5		25	18.2
6.0–6.5		26	19.0
7.0–7.5		20	14.6
8.0–9.5		6	4.4
		M	SD
Age		46.47	12.59
Duration of disease		14.61	8.31
Motor impairment (EDSS)		4.57	2.10
Neurological disability (GNDS)		16.98	8.31

Research Methods

Three questionnaires were used in the study. The first was The Extended Disability Status Scale (EDSS) by Kurtzke which is the most commonly used scale for assessing level of disability in individuals affected by multiple sclerosis. The EDSS scale ranges from 0 to 10 in 0.5 unit increments. Higher scores on the scale indicate higher levels of disability [14]. The Guy's Neurological Disability Scale (GNDS) was used for the assessment disability and symptoms experienced by individuals with multiple sclerosis. It consists of 12 subscales regarding problems in various areas of functioning: cognitive, mood, vision, speech, swallowing, upper-limb function, lower-limb function, bladder function, bowel function, sexual function, fatigue, and others. In each subscale, disability is assessed on six levels of severity. Results on separate subscales are summed in order to describe the overall levels of disability of a patient. The higher the score, the greater the disability [15].

Berlin Social Support Scales (BSSS) by Schwarzer in Polish adaptation of Łuszczynska et al. [16] was used for the assessment cognitive and behavioral aspects of social support. The BSSS questionnaire consists of five subscales. The first three subscales were used in the study: perceived support (instrumental and emotional), need for support and support seeking. The respondent answers on a 4-point scale, in which 1 means definitely no and 4 means definitely yes. The higher the score, the greater the level of social support. Reliability and validity of the

Polish version of the scale are satisfactory. Cronbach coefficients were equal to 0.90 for perceived social support, 0.71 for the need for support and 0.80 for seeking support.

Research Procedure

The study was conducted in a single meeting with the patient, with no time limit; the duration was adjusted to the psychophysical capacity of the respondents. Patients were asked to consent to participate in the study before it began. All patients agreed to participate in the study, which was preceded by a short conversation on general topics aimed at reducing anxiety. The study consisted of the completion of a set of questionnaires, which were always presented to the respondents in the same order. Consent was granted by the Ethics Committee at the Institute of Psychology of the University of Gdańsk, Poland (No. 19/06/2015).

Results

Multiple sclerosis is a clinically heterogeneous condition. In the studied population, most participants had the relapsing-remitting form of MS (31.4%), then the primary progressive form (22.6%), followed by the secondary progressive form (16.1%). The mean level of motor disability measured by EDSS was equal to 4.57 (SD=2.10). The neurological disability was measured by GNDS scale. The most severe symptom in this group was fatigue (2.86), followed by problems with bladder function (2.64), lower limb function (2.16), and sexual functioning (2.08). Among the less frequent symptoms were 'other problems' (1.79), mood problems (1.47), upper limb disability (1.36), bowel function problems (1.07), and cognitive function problems (1.04). The least frequent problems concerned swallowing (0.36), speech (0.49), and vision (0.52). In the studied group, 62.04% had access to therapies which can modify the course of MS and 37.96% never used those types of treatment. Interferon beta was the most commonly used medication in the studied population (43.07%), followed by mitoxantrone (16.79%), and glatiramer acetate (7.30%). The characteristics of the subjects in terms of clinical features of MS has been presented in Table 1.

To determine differences in social support in patients with different types of multiple sclerosis an analysis of variance was performed. An analysis was done between patients suffering from three types of multiple sclerosis (relapsing-remitting, primary-progressive, and secondary-progressive). The analysis excluded a group of people with progressive-relapsing form because of the small size of this population (N=8) and a group of people with

unspecified form of multiple sclerosis. Results are shown in Table 2. The results showed no significant differences between the study groups in social support. This means that the type of the disease is not a variable that differentiates the level of social support.

The relation between social support and the duration of illness, age at the time of diagnosis, age of respondents and degree of disability measured by the EDSS and GNDS was determined with Pearson's linear correlation method, the relationship between social support and symptoms of MS, the level of education and the material status was conducted using the Spearman's-rank method, while the relationship between treatment, sex, professional activity, marital status and having children was assessed using the point-biserial correlation method. The results are shown in Table 3.

There was no relation between the duration of the disease, age at the time of diagnosis, motor impairment (EDSS) and neurological disability (GNDS) with the most types of support. There was only a correlation between the need for support and neurological disability and age at the time of diagnosis and support seeking. The older the person was at the time of diagnosis, the greater the support seeking and the greater the neurological disability, the greater the need for support.

Social support was only slightly related to the symptoms of multiple sclerosis. Statistically significant positive correlations were found between the need for support and severity of mood disorders, intestinal problems, other problems related to MS, problems in sexual functioning and cognitive impairment. This means that the greater the severity of the symptoms, the greater the need for support. Relationships between intestinal problems and support seeking have also been shown. The higher the severity of intestinal problems, the greater the support seeking.

The study showed that social support was related to gender. Women declare higher perceived support, including emotional support. Both the need for support and its seeking were also higher in women. This means that women with multiple sclerosis are more likely to feel that support is available to them, they need more support and more often seek it. The age of the respondents was not significantly associated with most types of support. Only a weak positive correlation of age with seeking support was observed, which means that the older the person, the more often he or she seeks support. There was no relationship between the level of education and professional activity and social support. However, a relationship between the material situation and

Table 2. Differences in the level of social support in patients with various types of multiple sclerosis (ANOVA)

Variable	Descriptive Statistics		Levene's Test		ANOVA		
	Type of the disease	M	SD	F	P	F	P
Perceived, emotional, support	Relapsing-remitting	13.35	2.73	3.59	0.032	0.14	0.866
	Secondary progressive	13.32	1.94				
	Primary progressive	13.06	2.03				
	Total	13.25	2.33				
Perceived, instrumental, support	Relapsing-remitting	13.79	2.97	1.96	0.146	0.05	0.953
	Secondary progressive	13.68	2.64				
	Primary progressive	13.90	1.87				
	Total	13.80	2.56				
Perceived, social, support	Relapsing-remitting	27.14	5.52	3.89	0.024	0.01	0.986
	Secondary progressive	27.00	4.41				
	Primary progressive	26.97	3.37				
	Total	27.05	4.62				
Need for support	Relapsing-remitting	11.70	2.96	0.05	0.952	0.03	0.971
	Secondary progressive	11.55	2.54				
	Primary progressive	11.58	2.43				
	Total	11.63	2.68				
Support seeking	Relapsing-remitting	15.00	2.73	1.37	0.258	0.55	0.578
	Secondary progressive	14.95	3.02				
	Primary progressive	14.26	3.79				
	Total	14.75	3.16				

Table 3. Relationship between social support and the severity of biomedical variables

Variable	Perceived support	Perceived emotional support	Perceived instrumental support	Need for support	Support seeking
Duration of illness	0.067	0.096	0.090	0.054	-0.020
Age at the time of diagnosis	0.060	0.123	0.102	-0.032	0.219*
Motor impairment (EDSS)	0.005	-0.024	0.028	0.090	0.030
Neurological disability (GNDS)	0.028	0.020	0.032	0.286**	0.078
Treatment which modifies the course of the illness (1 — yes, 2 — no)	0.033	0.012	0.045	0.090	0.087
Cognitive disorders	-0.056	-0.032	-0.093	0.195*	0.128
Mood disorders	-0.124	-0.117	-0.124	0.319**	-0.005
Impaired vision	0.103	0.080	0.130	0.140	-0.052
Impaired speech	-0.056	-0.030	-0.084	0.049	0.040
Impaired swallowing	-0.001	0.007	0.004	0.067	0.043
Upper-limb disability	0.031	0.042	0.031	0.053	-0.135
Lower-limb disability	-0.034	-0.055	0.011	0.091	0.008
Impaired bladder functions	0.057	0.098	0.016	0.119	0.084
Impaired intestinal functions	0.037	0.070	0.005	0.278**	0.229**
Sexual problems	0.116	0.085	0.153	0.217*	-0.047
Fatigue	-0.019	-0.034	-0.019	0.144	0.054
Other problems	0.082	0.042	0.118	0.266**	0.101
Gender (1 — woman, 2 — man)	-0.208*	-0.240**	-0.144	-0.208*	-0.175*
Age	0.136	0.087	0.160	0.062	0.213*
Education (1 — vocational school; 2 — high school; 3 — bachelor's degree; 4 — master's degree)	0.055	0.023	0.061	0.055	-0.059
Professional activity (1 — not working, 2 — working)	0.003	0.000	-0.003	-0.052	-0.139
Financial situation (1 — very heavy, 2 — heavy, 3 — average, 4 — good, 5 — very good)	0.209*	0.150	0.237**	-0.026	0.051
Marital status (1 — single or divorced, 2 — married)	0.323*	0.159	0.260**	-0.113	0.009
Children (1 — not having, 2 — having)	0.204*	0.145	0.224**	0.054	0.089

* $p < 0.05$; ** $p < 0.01$.

perceived support and perceived instrumental support was observed. A better financial situation was related to the higher perceived social support. Married people declared a higher level of social support, including instrumental support. People with children experienced a higher level of social support.

Discussion

Social support is an interpersonal external resource that plays an important role when the individual's personal resources are insufficient to cope with a difficult situation. Social support gives a sense of belonging and social bond, thanks to which an individual can receive positive emotions, advice and care. Many studies in different populations have shown that illness and

disability can be associated with social support, and the receiving of support can affect the course of the disease. Studies on multiple sclerosis patients showed that the highest level of social support facilitates daily functioning however deterioration of daily functioning was associated with a decrease in social support [8].

In this study the relationship between social support and clinical variables associated with the course of multiple sclerosis was analyzed. The study showed that the older the person was at the time of diagnosis, the greater the seeking for support. This can be explained by participating in social life. People who were older at the time of diagnosis could have created larger social networks before being diagnosed by participating in family (getting married, having children) and work life. The social life of people diagnosed at a young age may have been limited by the disease, some of them may not

get married, they may not have decided to have children, and therefore their social networks may have been limited. Therefore, it can be concluded that age at the time of diagnosis, by affecting the size of the support network, can also affect the support seeking as one of the ways to cope with the disease. Other studies have shown that people who have been sick for a long time have less contact with members of their social network [17]. However, the current study did not show any relationship between any kind of social support and the duration of the disease. It is most likely that other variables have a bigger influence on social support.

The study did not show a relationship between social support and motor impairment measured by the EDSS. The scale is too much focused on assessing mobility. In contrast, social support is an interpersonal resource and is influenced not only by the internal features of the individual or disease-related features, such as the degree of motor impairment, but above all by the functioning in society, including being professionally active, having families, children or a spouse. Other studies found that the duration of the disease and the ability to move independently were not associated with general social support. However, longer disease duration and a higher level of disability have been associated with greater material support [9].

Neurological disability consisting of MS symptoms was associated only with the need for support. The greater the neurological disability, the greater the need for support. It could be associated with a lower ability to cope. Researchers prove that the level of social support depends primarily on day-to-day problems that the individuals experience [18]. A person with a higher disability has problems with many daily activities — eating, personal hygiene, dressing, mobility, and therefore needs more help from other people. In other research disability was the strongest factor associated with social support. Lower levels of disability were strongly associated with higher level of social support [18]. People with a higher level of disability received less support from their partner and family [17]. Along with the loss of mobility, the level of received social support is decreasing [8]. It is associated with the sense of being unnecessary, helplessness and a decrease in self-esteem. The quality of life is also decreasing [19]. High functional disability has been found to be associated with low social support also in other chronic diseases [20].

The relationship between social support and symptoms of multiple sclerosis was also analyzed, as this relationship has been confirmed for other chronic diseases [21]. In patients with MS the symptoms of the disease are primarily related to the need for support. It was also shown in another research in which symptom severity was associated with a greater need for psychological support services [22]. In current study the greater the

severity of mood disorders, cognitive impairment, intestinal problems, sexual disorders and other problems associated with the course of multiple sclerosis, the greater the need for support. It has also been shown that the greater the intestinal problems, the greater support seeking.

The need for support is most strongly associated with mood disorders. The relationship between depression and social support in people with physical disabilities, including people with multiple sclerosis, has also been demonstrated in other studies [23–25]. Depression is associated with powerlessness, helplessness, a sense of being inferior and less competent. People with depression have low self-esteem and self-efficacy, therefore they need support more often than others. But there is also an inverse relationship, people who don't get support may feel depressed. Studies on the relationship between perceived social support and depression in people with MS have found that a higher level of perceived social support is associated with a lower severity of depressive symptoms [12,26].

The need for support and support seeking are associated with intestinal problems, including, how it can be supposed, fecal incontinence. Due to the fact that problems with fecal incontinence occur primarily in patients with higher levels of disability, they need help in personal hygiene. Also, problems in sexual functioning and other problems related to the course of MS, including pain symptoms are associated with a need for support. Cognitive impairment is also slightly associated with the need for support. People with cognitive impairment need help in planning, financial matters and decision-making, and therefore it is not surprising that people with cognitive impairment need more support from their environment.

The relationship between clinical variables associated with multiple sclerosis and social support is not clear. Some studies have shown that newly diagnosed patients without disability needed more emotional support, while those in a more advanced stage of the disease with a higher level of disability, needed more instrumental help [27]. The discrepancy in the results of many studies may be due to the fact that different types of support are analyzed in them, which are not always associated with the same biomedical variables. Another explanation for these discrepancies is the possibility that relationship between clinical variables and social support is disturbed by other variables, e.g. sociodemographic.

The relationship between social support and sociodemographic variables was also analyzed in this study. It was demonstrated that perceived social support, including emotional support, need for support and support seeking were related to the sex of respondents. Women felt greater social support, including emotional support, had a greater need for support and sought it

more often. It has been confirmed in other studies, in which it was shown that women received greater social support from the family and friends than men [25,28]. The use of support may be culturally conditioned [29]. Women give more support than men, but they also receive support more often. Women are more involved in close interpersonal relations, more often seek social support, use it more often and include it in their coping strategies. It is related to the female role, which is more focused on interpersonal relations than the male one [30]. However, in other studies on the group of people with multiple sclerosis, it was found that unmarried people and women are particularly vulnerable to reduced social support during illness, while men with MS report a higher level of perceived social support [31]. Other studies have shown that the level of social support varies according to gender and marital status. The surveyed men indicated a higher level of total social support as well as emotional, informational and material support compared to women. In addition, marriage has been shown to be more beneficial for men compared to women. Married men reported more positive social relationships than married women [9].

The current study showed that perceived social support and perceived instrumental support were most closely related to marital status. Married people experience greater social support, including instrumental support, compared to unmarried or divorced persons. Other studies have shown that people who lived alone were at increased risk of low levels of social support. Particularly low support is characteristic of women who live alone and have low incomes [9]. The current study also showed that a higher level of perceived social support and information support is characteristic for people with children compared to people who do not have children. These results indicate that the source of available social support, primarily informational, are the spouse and children.

The study also showed that perceived social support and informational support were related to the material situation of patients. People with better financial situations declared higher level of social support. Other studies have shown that higher income among women was associated with a higher level of perceived social support, while in the group of men, income was not significant for the level of social support [9]. The current study on a group of people with multiple sclerosis also showed that age is associated with support seeking. Older people more often sought support compared to younger people. However, other studies have shown that older age was associated with greater material support [9], while some researchers indicate that there was a gradual decrease in social support with patients age [25]. Some studies have shown that younger and newly diagnosed patients needed more emotional support, while those older, in

a more advanced stage of the disease, needed more instrumental help [27]. Despite obtaining significant results, the study is not free from limitations. The cross-sectional design of the study does not allow to draw causality or explore further the direction of association. In order to verify the presented relationships more accurately, more advanced qualitative longitudinal studies should be performed. Longitudinal research should explore whether the disability leads people to feel they are not supported enough or they feel more disabled because they are not supported.

Conclusions

Summarizing, perceived social support is a resource that is less affected by biomedical variables, but more by variables such as gender, marital status or having children. Whether a person will receive support is less related to the course of the disease and symptoms, and more to whether they are married or have children. Of the studied types of support, the need for support was most related to the features of the disease. Multiple sclerosis, like any chronic diseases, is associated with a greater need for support. Literature has already demonstrated that psychological treatment is efficacious in improving functional domains such as interpersonal relationships, social participation, etc. [32], which, in turn, have a strong relationship with social support [18]. This is particularly important because we know that social support is related to adjustment to the disease and quality of life.

Implications for Nursing Practice

People living with a disability or symptoms such as cognitive impairment, mood disorders or intestinal problems needs help in daily functioning as well as emotional support and a sense that there are people for whom they are important. This is also associated with the need for professional support from doctors, psychologists and nurses. Diagnosis of the social support should be an important element of working with a patient with multiple sclerosis. Providing support to a patient with MS the nurse should have knowledge about the disease and its course. It is important to be aware of the significance of psychological and invisible symptoms, such as mood and cognitive disorders. Special support, in addition to patients with visible physical disability, should be given to the patients with mood and cognitive disorders as well as those who do not receive emotional support from their families. Enhancement of social support has been recommended as an important part of the treatment for people with multiple sclerosis and

other neurological diseases, which can be a special task for neurological nurses.

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