

The most important psychological and psychosocial needs of Polish multiple sclerosis patients and their significant others

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Background: People with multiple sclerosis (MS) and their relatives often have multiple, complex needs which require support from a wide range of services. The aim of the study, the first of its kind in Poland, was to identify the most important needs of patients with MS and their significant others (SO).

Methods: A questionnaire developed from focus groups consisting of 20 needs-related statements was administered in seven MS centers to 573 MS patients and 220 SO. The mean age of the patients was 42.61 years old; the mean MS duration was 9.43 years. The respondents were asked to rate the needs statements according to their importance on an 11-point scale. The questionnaire was similar for the MS patients and their SO.

Results: The most important needs in the patient group were: to feel needed and efficient in life; to have easy access to professional rehabilitation; and to be sure that doctors are interested in my condition. The three most important needs in the SO group were: to know that relatives/friends feel needed and efficient in life; to have good living conditions; and to be sure that doctors are interested in my relative's/friend's condition. Correlation analysis revealed that in the patients group, there was a positive correlation between patient's age and the importance of factors such as the need for support and interest in their disease from the family doctor ($P < 0.004$), receiving educational materials from an MS clinic ($P < 0.011$), interest from the clinic in life issues of the patient ($P < 0.001$), and the need for access to self-rehabilitation ($P < 0.003$); while the need to continue working part-time was inversely correlated with age ($P < 0.009$).

Conclusion: The needs of the MS patients and SO were similar. The data validate the importance of interdisciplinary care for the MS population.

Keywords: multiple sclerosis, unmet needs, needs assessment, Poland

Introduction

Multiple sclerosis (MS) is a chronic and incurable neurological disorder. Patients with MS and their significant others (SO) struggle with a chronic and unpredictable disease and will benefit from various forms of psychological support. So far, the organization of this care has not been informed of the needs and expectations of the Polish patients and their SO.

The concept of a "need" has a multidimensional aspect, containing a comprehensive list of meanings and a broad formula of interpretation. In psychology, the concept of need is understood as an inseparable part of human nature, and it is explained as a strongly felt desire for what is needed for a normal existence, or for proper functioning. In sociology, need is understood as a state of absence, and addressing it is a necessary condition for existence and development. Murray's concept presupposes the existence

of a hierarchy in which some needs take precedence over others.¹ According to Maslow, a need is regarded as the force that determines human behavior, and deprivation in meeting the needs affects the current state of the individual and his or her perceptions of the future – if a person is dominated by a need, their whole philosophy of the future changes.²

In a study of care-related needs among 1,143 patients, the most important needs included the need for temporary patient care, family support, support from others living with MS, and advice for the family regarding the disease.³ In another study, the focus was more on the caregivers of people with MS, who reported needs related to patient care, practical activities, obtaining information on MS, and care preparation.⁴ In a study conducted by Wollin et al, it was confirmed that the caregivers expected more of a practical support rather than information on how they could be relieved.⁵ The researchers came to the important conclusion that care should be carefully planned and developed on the basis of identified needs. A systematic review of 24 studies of the needs of the caregivers of people with MS highlighted the need for further research in the area of the caregivers' needs and, in particular, the development of a tool for assessing the "load" of the caregiver.⁶

The questionnaire survey of patients and caregivers in Canada considered a conscious use of the services and assistance offered to those in need by doctors, physiotherapists, occupational therapists, and nurses, as well as adaptation of the living space to be important.⁷

Koopman et al's study lists the most important needs as physical, medical, psychological, and financial, along with those regarding living conditions, employment, leisure, and obtaining information.⁸ Another study, which analyzed data obtained from 353 patients and 240 caregivers defined the ten most important needs and found that in both groups the needs were similar.⁹

The results of the research regarding the needs of patients with longstanding MS and those severely affected by the disease are interesting.^{10–14}

Most studies assessing the needs of MS patients were based on questionnaires developed by the researchers and completed by the respondents themselves, utilizing needs identified by patients in pilot studies.

The aim of our study was to identify the most important psychological and psychosocial needs of people with MS and their SO, and to make doctors and persons involved in care aware of these needs through the analysis of a specially developed questionnaire.

Recognizing the psychological and psychosocial needs of Polish MS patients and their SO might help doctors improve the quality of communication and help in meeting patients' expectations.

The study covered a diverse selection of Polish regions, taking into account the differences in the organization of patient care. This paper presents the most important needs identified by people with MS and their SO.

Methods

A questionnaire survey among patients with MS and their SO was carried out between October 2015 and May 2016 in seven Polish MS centers: five clinical wards and outpatient MS clinics, an MS rehabilitation center, and a center for clinical trials related to MS (Table 1). The questionnaire was developed and the analysis of the data was carried out at the Department of Clinical Psychology and Psychoprophylaxis of the University of Szczecin in Szczecin.

The questionnaire was issued to 800 patients with MS selected from the databases. The questionnaire was also issued to 400 patients with MS randomly selected from the same databases, with a request that their SO complete the questionnaire as well. Participants in the study, ie, the patients and the SO, were separated for the questionnaire so communication between them could not affect the objectivity of data. Before being included in the research all MS patients had been assessed through Mini-Mental State Examination (MMSE) and Beck Depression Inventory (BDI). All patients

Table 1 Centers and number of MS patients and their significant others

City	Center	Number of patients	Number of significant others
Borne Sulinowo	Rehabilitation center	153	46
Białystok	University center	124	44
Rzeszów	University center	98	33
Szczecin	Clinical trial center	73	52
Końskie	Specialist hospital and MS outpatients clinic	72	22
Warszawa Międzyzylesie	Specialist hospital and MS outpatients clinic	27	17
Warszawa	Military Institute of Medicine and MS outpatients clinic	26	8
Total		573	222

Abbreviation: MS, multiple sclerosis.

with an MMSE score lower than 20 or displaying signs of major depression (BDI above 27 points) were excluded from the research. The assessment of needs was carried out in two stages: 1) the pilot study (drafting and verification of the questionnaire) and 2) the actual survey.

Ethics statement

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study was approved by the Regional Medical Ethics Committee of the Zachodniopomorska Medical Council in Szczecin (no 17/2015). Written informed consent was obtained from all individual participants included in the original clinical studies.

Developing the questionnaire

To select the questions for the needs questionnaire a focus group interview was carried out with 30 MS patients and 15 SO. The needs questionnaire was developed on the basis of data obtained from that group. The items describing the needs were then analyzed to verify their content validity. Twenty items describing the needs of patients and their SO in relation to treatment, health, living conditions, finances, employment, leisure, and obtaining information were specified. The wording used by the participants of the focus group study was preserved almost entirely in its original form. A pilot survey carried out with 20 patients and ten SO showed no need for adjustments. An interdisciplinary research team consisting of neurologists, psychologists, occupational therapists, and nurses found no reason to amend the items included in the questionnaire.

The contents of the items of the needs questionnaire were the same for the group of patients with MS and the group of SO. The respondents evaluated the importance of specific needs using an analog Likert scale from 0 (unimportant) to 10 (very important). A “not applicable” answer was also possible. Needs which were given values in the range of 7 to 10 were considered to be important or very important. Other patient data included demographic variables, information on housing and living conditions, employment status, year of diagnosis, the type of the course of MS, and the patient’s mobility level. Data obtained from the SO included demographics, relationship and degree of closeness to the patient, and employment status.

The contents of the questionnaire assessing the needs were similar in the group of patients with MS and the group of SO.

Cronbach’s alpha coefficient of the needs questionnaire was 0.87 for patients with MS and 0.85 for the SO. During a planned doctor’s appointment, each participant received full written information about the course of the study and its objectives, a consent form to participate in the study, which they signed, the questionnaire, and a stamped, addressed envelope. Participants who expressed a desire to receive the results were assured that the summary of the results would be communicated to them in due course.

Statistical analysis

The differences between the needs of the MS patients and the SO were compared using descriptive statistics for comparisons of means (Student’s *t*-test) and ratios (chi-square test). The data were analyzed using SPSS Statistica for Windows, Version 17.0, 2008 (SPSS Inc., Chicago, IL, USA).

Results

Of those who were given the questionnaire, 573 MS patients (67.4%) and 222 SO (55.5%) returned it. The respondents were demographically representative of the Polish population of MS patients.

The demographic data of the respondents are presented in Table 2. Data on the relationship of the SO with patients are presented in Table 3.

It was found that of the 20 assessed needs, the patients and the SO considered the same ten to be the most important, albeit in a slightly different order. The analysis of the needs evaluated as important and very important – that is rated 7 to 10 on the Likert scale (Table 4) – demonstrated that in both groups the most important need was “the need to feel needed and efficient in life despite the disease”. The second most important need for patients was “easy access to professional rehabilitation” and for the SO, “good living conditions”. The third most important need, the same in both groups, was “the need to ensure that doctors were interested in the health of the patient”.

Among the patients the most significant needs included “support from close friends and relatives” (position 4) and “a desire for the disease not to change their relationship with their SO” (position 6). “Needs related to the organization of treatment” were placed at positions 7, 9, and 10, and the “need for access to self-rehabilitation” in position 8.

For the SO, however, the group of needs related to medical care proved to be more important than for the patients – “interest in the disease shown by doctors” (3rd place), “regular control examination in MS clinic” (4th place), and “interest in the patient of the person from the MS clinic” (5th place).

Table 2 Demographic data of patients and their significant others

Variable	MS patient (N=573)	MS patient (%)	Significant others (N=222)	Significant others (%)
Female/male	351/222		134/88	
Sex (female to male ratio)	1.68		1.52	
Mean age (years)	42.61 (± 12.41)		59.41 (± 18.28)	
Late on onset (years)	9.43 (± 8.00)		10.28 (± 7.58)	
Education				
High school	214	28.04	77	34.69
Secondary	232	47.12	86	38.74
Vocational	94	15.18	27	12.16
Elementary	33	5.76	32	14.41
Employment				
Full-time	270	47.12	74	34.23
Part-time	46	8.01	30	13.51
Pension	212	47.08	110	49.55
Never worked	45	7.85	8	3.60
Marital status				
Married/partnership	390	68.06	111	50.00
Divorced	40	6.98	47	21.17
Widow/widower	17	2.97	46	20.72
Bachelorette/bachelor	126	21.90	18	8.11
Residence				
Rural area	211	37.02	83	37.39
City up to 10,000 inhabitants	70	11.7	20	7.66
City up to 100,000 inhabitants	147	25.74	46	22.07
City with over 100,000 inhabitants	145	25.53	73	32.88
MS course				
Relapsing-remitting	226	47.37	100	45.01
Progressive	173	22.32	44	19.83
Stable	174	30.32	78	35.16
Mobility				
Without assistance	382	68.25	129	58.11
With the use of a device	148	25.98	67	30.18
With the assistance of another person	43	5.77	26	11.71

Abbreviation: MS, multiple sclerosis.

The “needs related to rehabilitation” were considered as slightly less important by the SO and placed in positions 6 and 8. The “need for support” and “for MS not to change the relationship between the patient and their SO” were lower than in the group of patients, at positions 9 and 10.

The relative importance of the ten most important needs determined on the basis of the mean item scores on the

0–10 scale (Table 5) was compared to the ranking of needs based on the proportion of respondents who chose the needs as important (scores of 7 to 10) (Table 4). Among the patients with MS, the resulting order of the first five needs was the same for both techniques, and the resulting order of the five next ones, whose mean scores were very similar, differed only slightly. In the group of SO, the rankings of needs constructed according to their mean scores on the 0–10 scales and according to the proportion of respondents who chose 7–10 scores also differed only slightly.

In the group of needs which were placed between the 11th and the 20th position, positions 11 and 12 were occupied by a sense of “support from the family and from the family doctor”; these were given scores of 7 and above by 73% of the patients and, respectively, 76% and 71% of the SO. The need to “continue working full time” was in the 13th place for both surveyed groups (chosen by 67% of the patients

Table 3 Type of significant others

Significant others	n	Age	Number of years of care
Spouse	134	47.28 (± 18.27)	8.27 (± 4.43)
Parent/parents	41	66.21 (± 5.27)	18.89 (± 22.78)
Child	14	21.16 (± 6.78)	6.25 (± 11.12)
Outside family	33	42.11 (± 12.34)	9.34 (± 7.22)

Table 4 The most important (7–10 in Likert scale) psychological and psychosocial needs of polish MS patients and their significant others

Place	MS patient needs	%	Place	Significant other needs	%
1	To feel needed and efficient in life despite the disease	89.08	1	To feel needed and efficient in life despite the disease	86.04
2	To have easy access to professional rehabilitation	86.42	2	To have good living conditions	86.04
3	To be sure that the doctors are interested in my condition	82.50	3	To be sure that the doctors are interested in my condition	85.00
4	To have support and help with important personal affairs	82.22	4	To participate in the regular control examination in MS clinic	84.23
5	To have good living conditions	81.88	5	To be sure that MS clinic is interested in my health condition	83.41
6	To feel that the disease will not negatively influence my relationship with a child/children	80.85	6	To have easy access to professional rehabilitation	83.33
7	To have the possibility to talk to my neurologist	80.63	7	To have the possibility to talk to my neurologist	79.37
8	To have easy access to unassisted rehabilitation	80.46	8	To have easy access to unassisted rehabilitation	78.83
9	To be sure that MS clinic is interested in my health condition	80.07	9	To have support and help with important personal affairs	78.28
10	To participate in the regular control examination in MS clinic	78.33	10	To feel that the disease will not negatively influence my relationship with a child/children	77.03

Note: Shading: need was placed in the same position by both groups.

Abbreviation: MS, multiple sclerosis.

and 69% of the SO), and the “need to continue working part-time” in the 17th place for the patients (55%) and 15th for the SO (62%).

The lower-ranking needs related to “social life and support from friends” (64% and 53% of the patients and 62% and 58% of the SO chose those needs, respectively). Education needs “being given educational materials and participation

in education days” proved less important, chosen by, respectively, 56% and 51% of the patients and 61% and 53% of the SO. The “need for support regarding financial and tax advice” proved to be the relatively least important and was chosen by 50% of the patients and 58% of the SO.

Analysis of the ratings for the ten most important needs revealed no statistically significant differences between the

Table 5 The top ten needs according to MS patients and significant others

Place	MS patient needs	Likert scale 0–10	Place	Significant others needs	Likert scale 0–10
1	To feel needed and efficient in life despite the disease	9.01	1	To feel needed and efficient in life despite the disease	8.92
2	To have easy access to professional rehabilitation	8.82	2	To have good living conditions	8.68
3	To be sure that the doctors are interested in my condition	8.60	3	To be sure that the doctors are interested in my condition	8.65
4	To have support and help with important personal affairs	8.52	4	To be sure that MS clinic is interested in my health condition	8.63
5	To have good living conditions	8.47	5	To have easy access to professional rehabilitation	8.60
6	To have easy access to unassisted rehabilitation	8.34	6	To participate in the regular control examination in MS clinic	8.53
7	To be sure that MS clinic is interested in my health condition	8.33	7	To have support and help with important personal affairs	8.33
8	To have the possibility to talk to my neurologist	8.32	8	To have the possibility to talk to my neurologist	8.30
9	To participate in the regular control examination in MS clinic	8.28	9	To have easy access to unassisted rehabilitation	8.23
10	To feel that the disease will not negatively influence my relationship with a child/children	8.27	10	To feel that the disease will not negatively influence my relationship with a child/children	8.15

Notes: Answers in Likert scale from 0–10. Shading: need was placed in the same position by both groups.

Abbreviation: MS, multiple sclerosis.

surveyed groups. However, there were statistically significant differences in ratings of importance of the needs placed in positions 11–20. And, thus, the need expressed as “to be sure that the MS clinic is interested in my life, work, personal life and family problems” was rated as very important by 50.26% of the patients and by 57.40% of the SO ($P < 0.006$). While 49.82% of the MS patients ranked the “need for support in terms of financial counseling” in the last position, 57.80% of the SO considered it to be very important ($P < 0.036$). There was also a statistically significant difference in the ratings of “importance of part-time work” – 55.56% of the patients and 61.99% of the SO considered this need to be very important ($P < 0.012$).

Correlation analysis showed that in the patients group, the higher the patient’s age the more important were “the needs for support and interest in their disease from the family doctor” ($P < 0.004$), “receiving educational materials from an MS clinic” ($P < 0.011$), “interest from the clinic in life issues of the patient” ($P < 0.001$), and “the need for access to self-rehabilitation” ($P < 0.003$), while the need to “continue working part-time” was inversely correlated with age ($P < 0.009$). It was also shown that the longer the duration of MS, the less important were needs described as “doctor’s interest in the disease” ($P < 0.001$), “support and help from close friends and relatives” ($P < 0.005$), “participation in check-ups at an MS clinic” ($P < 0.005$), and “continuation of work” ($P < 0.002$).

Discussion

The literature contains research on the needs of patients with MS and their caregivers carried out in many countries.^{6,8,9,15–19} The present study is the first study of this kind carried out on the Polish population of MS patients and their SO.

The study of the needs of the Polish patients with MS and their SO was based on a needs questionnaire developed during a focus-group study. A similar methodology was used in the Koopman et al study.⁹ In contrast, previous studies focused either on the needs of patients or SO and often used different research tools. Our study used one tool for both groups, which allowed us to compare the most important needs identified by the patients with MS and by their SO. The results of this study demonstrated that the needs of MS patients and their caregivers are similar.

The study was carried out primarily with the idea that the results would improve patient support, especially social and psychological support, and improve communication with patients. The study confirmed that knowing the needs for psychological and psychosocial care is important for

patients with MS and is a key conclusion resulting from the study. Similar conclusions concerning the organization of the treatment of MS were obtained in a multicenter study in Italy.¹⁵

Both the Polish patients and their SO rated the feeling of being needed and efficient in life despite the disease as the most important need, which confirms the need for psychological support for patients in maintaining or developing this belief. Important information for those involved in patient care is the high ranking by both of the respondent groups of the needs associated with treatment and establishing contact with the doctor and the MS clinic. A higher ranking of these needs in the SO group expresses particular concerns about and expectations of the highest possible quality of care. These findings are similar to those resulting from other needs assessment studies.^{6,9}

The need for good housing, adapted to the patient’s condition, indicated as one of the most important needs by Aronson et al’s study,⁷ was placed by the Polish patients in 4th place but by their SO in the very high, 2nd position. This seems understandable, particularly among the non-working patients, in the context of them spending a large proportion of their time in the home environment.

With the aim of carrying out as detailed an examination of the importance of the participants’ needs as possible, the authors employed two methods to rank them. The first method was related to the evaluation of the frequency of rating the need as the most important (scores 7–10 on the scale), and the second consisted of the assessment of the mean scores for the individual needs rated on a scale of 0–10. The analysis demonstrated that the rankings of needs obtained using both these methods were quite similar.

The study was carried out in five clinical wards and outpatient MS clinics, a specialist rehabilitation center, and one center for clinical trials with patients. For these reasons, and because the study covered approximately 5% of the whole population of Polish MS patients, we believe that the results can be applied to the entire population of Polish MS patients.

The study results invite a consideration of who is actually supposed to meet the needs identified in the research, including the psychosocial needs, and whether all needs should be met, and how to satisfy everybody.²⁰ It seems clear that the needs related to the doctors at the MS clinic or to the family doctor should be considered by the doctors and, if possible, fulfilled. It also seems reasonable that associations of MS patients and community organizations should be involved in meeting some of the needs for support. Future research

should also include an assessment of the needs of patients by doctors and compare these assessments with the assessments by the MS patients themselves, which could help reduce the existing differences in meeting the needs, as it was already pointed out more than 10 years ago.²¹

The results of this study are very important for the MS researchers in Poland. The obtained list identified the most important needs and confirmed the predictions of the researchers about the relative importance of various needs among Polish MS patients. The dominance of the psychosocial needs among the most important needs emphasizes the requirement for an interdisciplinary approach to the treatment of MS, and for the presence of psychologists and psychotherapists in each of the specialist MS clinics, and the importance of health care units cooperating with patient associations. Polish services taking part in psychotherapy, psychological support, and palliative care should be acquainted with the most important psychological and psychosocial needs. Actions resulting from the knowledge about these needs should be an essential element of the multi-professional setting.

So far the Polish health care system has not taken into account the needs of MS patients and their SO. Practical significance of the results has been recognized by Polish MS experts and Polish MS society.

The results of the study have given Polish doctors entirely new knowledge concerning the needs of patients and their SO. Moreover, the results confirm that these needs are similar to the needs of MS patients recognized in other trials.

The authors' opinion is that the improvement in communication resulting from the outcomes of their study might contribute to the improvement in adherence, which was also pointed out by other authors.^{22,23}

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Author contributions

All authors contributed toward data analysis, drafting and revising the paper, and agree to be accountable for all aspects of the work.

Disclosure

The authors report no conflicts of interest in this work.

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