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ORIGINAL PAPER

SELF-HELP GROUP AND THE QUALITY OF LIFE OF PATIENTS WITH MULTIPLE SCLEROSIS – PILOT STUDY

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Abstract

Aim: The goal of the pilot study was to compare the quality of life of patients with multiple sclerosis in the Presov region with or without the support of a self-help group. *Design*: The character of this pilot study on patients with MS was related to the use of self-help groups and their impact on the assessment of the quality of life of the respondents, with the help of a questionnaire (WHOQOL-BREF). *Methods:* The research was carried out in the Prešov region with the help of the standardized WHOQOL-BREF questionnaire. Ninety-one patients with MS participated in the pilot study (46 respondents attended a self-help group and 35 did not). *Results:* The groups, when compared, aided by the statistically evaluated WHOQOL-BREF domains, were found to show significant differences in their evaluation of quality of life in three domains: domain one: physical health; domain two: surviving; domain three: social relations. Better scores were achieved in these domains by those who attended a group. In the physical sphere, we noticed significant differences in sleep quality, and sexual satisfaction ($p < 0.001$), while in social and economic areas, there were significant differences in satisfaction with personal relationships ($p < 0.001$), and economic circumstances ($p < 0.01$), self-contentment ($p < 0.01$), and coping with negative feelings ($p < 0.05$). *Conclusion:* Patients with multiple sclerosis can live normal lives provided they are supported by their families, friends, health care professionals, and self-help groups.

Key words: multiple sclerosis, quality of life, health care, self-help group.

Introduction

Multiple sclerosis (MS) is a heterogenous nosological unit with a variable clinical presentation, characterized by a whole spectrum of defects in individual physical functions and various degrees of disability. Patients need a personalized approach to solving their various interdisciplinary problems (for example urination, depression, anxiety, cognitive dysfunction, chronic exhaustion), in addition to assistance in coping with everyday tasks. In this context, the evaluation of a patient‘s quality of life gains particular importance (Kantorová, Kurča, Michalik, 2012). A complete cure for this disease is not possible at present. Recently, the phenomenon of quality of life has taken centre stage in many disciplines. The concept of quality of life mainly involves questions about physical and spiritual health, and certainly has a multidimensional character, and relates to multiple aspects of our lives (physical, sexual, rational, emotional, religious, economic, work, family, and social).

Undeniably, the subjective character of the evaluation of quality of life of the individual patient is a major factor resulting from the unique character of each subject and his or her ability to adapt to life’s circumstances, while a patient´s surroundings also play an important role (Švehlíková, Heretik, 2008). The subjective feedback given by patients enables health care professionals to improve cooperation with them and thereby improve their adherence to treatment, adjusted to their own genuine requirements. Another view of this progressive disease and quality of life of patients affected by it is provided by their partners and nurses. These evaluations are often very different to the evaluations given by the patients themselves, due to the well-known tendency of nurses to evaluate quality of life with greater negativity and consequently as worse than patients might themselves report (Hloch et al., 2011; Kantorová, Kurča, Michalik, 2012). Quality of life as influenced by self-help groups is measured only sporadically; nor is this question adressed in the field of nursing. A self-help group is a small voluntary organisation made up of individuals with

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similar health, social or everyday concerns (Bútora, 1991). Self-help groups are founded on the assumption that an affected person can best be helped by people who are experiencing or have experienced similar situations (Mohapl, 1992). The health sciences are beginning to have an important place in self-help organisations in this country. The World Health Organisation suggests that the strategy, ´Health for everyone by 2000´ will continue with ´Strategy for health for everyone in the 21st century´, and recommends that health care providers get involved in self-help groups and organisations. The aim of nursing is to help a client/patient satisfy his or her needs. The nurse, therefore, has the responsibility of finding appropriate means to support self-care physically, socially, spiritually, and psychologically. According to the circumstances of each client, the nurse considers whether or not a self-help group would be effective (Majerníková, Jakabovičová, Obročníková, 2008). Nursing care should be oriented to the use of opportunities for different forms of social support (Gurková, 2011).

The therapeutic potential of groups has been known since ancient times. From the dawn of mankind, various members of tribes or peoples participated in treating their own kind. The types of help were various, for example ceremonial, dance, ritual singing, sacrificial and others. The sick did not carry the burden of disease alone, but their peers took an interest in them and tried to help. This pulling together or solidarity, was not only triggered by illness in the past, but by any individual crisis (difficult birth, injury, possession by evil spirits) or, indeed, any situation affecting the group (hunger, drought, natural disaster and others), and is also characteristic of modern group therapy led by professionals and lay self-help groups. In the 20th century institutionalized and centralized mutual assistance groups emerged, which generally changed into organisations representing the interests of certain professions. Among the pioneers of social work in medicine was an American doctor named Pratt, who introduced group sittings to patients with tuberculosis. The goal of these sittings was to disengage the patient from unproductive introspection and self-pity. Pratt motivated other doctors to organise similar sittings for people with problems such as high blood pressure, diabetes mellitus, mothers with undernourished children, and anywhere there was a need for cooperation and social support. The Bierers are credited with establishing the first club in the field of psychotherapy in 1938 in Great Britain. It was a club for “spiritually ill”. Today, a large number of diverse clubs and self-help groups exist which help people overcome barriers and live normal lives. Among these are individual clubs, or clubs and groups associated with national or international organisations (Mohapl, 1992).

Aim

The aim of the pilot study was to determine and compare the level of self-evaluated quality of life in patients with MS who did or did not visit self-help organisations for patients with MS, in terms of physical, psychological, spiritual, and socio-economic domains.

Methods

Design

The study had the character of a pilot study of patients with MS focusing on support from self-help groups, and its effect on the evaluation of quality of life of the respondents with the aid of the WHOQOL-BREF questionnaire.

Sample

Ninety-one patients with MS participated in our study. The first comparative sample of respondents who did not visit self-help groups (NSH) consisted of 35 patients (11 men, 24 women) from the Physio-rehabilitation department and neurology clinic NsP St. Jacob n.o., Bardejov. The second comparative research sample attended a self-help group (SH), and consisted of 46 patients (19 men, 27 women) diagnosed with MS who are registered members of the MS club in Presov. Respondents included in the study fulfilled the following criteria: being above the age of majority, having chronic MS for more than one year, consenting to participation in the study.

Data collection

The study was carried out between January and March 2014 using the standardized WHOQOL-BREF (short version) questionnaire from the World Health Organisation, comprising 26 items of the Likert type. The questionnaire covers two individual items; evaluation of general quality of life (general satisfaction with quality of life and health), and four quality of life domains:

- *Area of health* – including daily activity, determines the need for medical assistance, adequate sleep, capacity to work, general mobility of the individual.
- *Psychological aspects* – determines level of concentration, positive emotions, negative emotions, physical appearence, spirituality, self-evaluation.
- *Social relations* – personal relationships, sexual activity, social support.

- *Surrounding factors* – financial resources, living conditions, transportation, access to services, safety, free-time activity (Dragomirecká, Bartoňová, 2006).

The range in individual items is 1–5, whereby a higher score indicates better quality of life. The score in the domains ranges between 4 and 20, whereby a higher score again indicates better quality of life. The results of the questionnaires were evaluated individually and also with the domain scores, which represent approximate average score totals for corresponding items, involving transformation to the 4–20 scale in accordance with the methodolgy of Dragomirecká a Bartoňová (2006). The questionnaire was supplemented with demographic and other basic information about the respondents – age, sex, duration of disease, level of education. The questionnaire was anonymous.

Data analysis

In order to statistically process our data, SPSS 15.0 software was used. To statistically compare the monitored groups, we used a t-test and F-test, which determined the normality of the layout of the files. The statistically determined results were evaluated at a level of relevancy 5%.

Results

Both groups of respondents were mostly secondary school-educated. The average duration of disease in patients SH was 11.1 ± 7.17 and NSH 10.8 ± 6.72. See Table 1 for further characteristics of the respondents.

With respect to evaluation of quality of life, individual groups of patients gave distinct evaluations in individual areas: physical, psychological, social and spiritual.

Most common physical problems in patients with MS

Manifestations of MS persistently deepen and everyday activities become limited, which reflects on patients´ perception of quality of life. In the physical domain of quality of life, we noticed significant differences between the monitored groups of respondents, particularly in the areas of sleep and sexual satisfaction. The overall level of quality of life was evaluated more positively by respondents who did not visit self-help groups. With the help of statistical analysis, we determined differences in problem areas with sleep and sexuality at a level of $p < 0.001$, whereby better scores were reported by respondents SH (see Table 2).

Socio-economic area in the lives of respondents

Social functioning is a significant component of quality of life. The results of comparisons regarding social and economic problems are presented in Table 3. Satisfaction with social situation was expressed predominantly by respondents who attended self-help groups. Significant differences in opinion were noted in the areas of satisfaction with personal relationships ($p < 0.001$) and satisfaction with economic circumstances ($p < 0.01$) favouring patients who attended a group.

Table 1 Characteristics of respondents

	SH		**NSH**	
	n	**%**	**n**	**%**
Gender				
Male	19	41	11	31
Female	27	59	24	69
Education				
Secondary school (not completed)	11	24	8	23
Secondary school (completed)	25	54	21	60
University	10	22	6	17
Age (Mean ± SD)	42.2 ± 11.26		44.4 ± 11.98	
Duration of disease (Mean ± SD)	11.1 ± 7.17		10.8 ± 6.72	

n – number, SH – respondents from self-help group, NSS – respondents, who didn´t attend self-help group, SD – standard deviation

Psychological and spiritual areas in life of respondents

Statistically significant differences in psychological and spiritual realms were recorded; namely in the areas of pleasure from life, evaluation of quality of life, and concentration and vigilance at a level of $p < 0.001$, self-satisfaction at a level of $p < 0.01$, and overcoming negative feelings, after statistical analysis, at a level of $p < 0.05$, in favour of patients who attended a self-help group (see Table 4).

On the basis of the presented statistical comparisons, we can find significant differences in the monitored groups of respondents in individual areas of quality of life as a result of participation in a self-help group.

Table 2 Comparison of quality of life in physical areas

Evaluation in areas	SH Mean	SD	NSH Mean	SD	p
Total quality of life	3.15	0.85	3.31	0.88	0.85
Pain	3.36	1.31	3.31	0.88	0.39
Movement	3.40	0.94	2.94	1.18	0.054
Sleep	3.39	0.93	2.53	0.76	0.000***
Possibility of realized everyday tasks	3.38	0.96	3.17	1.21	0.373
Total satisfaction with health	3.15	0.85	3.47	0.90	0.100
Sexual satisfaction	3.83	1.02	2.83	0.76	0.000***

*p < 0.05; **p < 0.01; ***p < 0.001, SD – standard deviation, SH – respondents from self-help group, NSS – respondents, who didn´t attend the self-help group

Table 3 Comparison of quality of life in social and economic areas

Evaluation in areas	SH Mean	SD	NSH Mean	SD	p
Satisfaction with personal relationships	2.58	0.39	2.01	0.6	0.000***
Support of family and friends	2.45	0.61	2.28	0.73	0.261
Accessibility and availability to information	2.02	0.67	2.25	0.55	0.103
Hobbies	3.15	0.94	3.53	0.99	0.083
Satisfaction with economic circumstances	3.36	1.24	2.63	0.79	0.003**

*p < 0.05; **p < 0.01; ***p < 0.001 SH – respondents from self-help group, NSS – respondents, who didn´t attend the self-help group, SD – standard deviation

Table 4 Comparison of quality of life in psychical and spiritual areas

Evaluation in areas	SH Mean	SD	NSH Mean	SD	p
´I Enjoy my life´	3.25	0.49	2.25	1.06	0.000***
Managing of my life	2.81	0.68	2.13	1.07	0.000***
Concentration and attention	3.06	0.86	2.07	1.03	0.000***
Satisfaction with myself	3.22	0.74	2.72	0.89	0.007**
Acceptance of appearance	2.56	0.96	2.17	0.81	0.053
Overcoming negative feelings – depression, helplessness, despair	3.36	0.84	2.82	0.95	0.016*

*p < 0.05; **p < 0.01; ***p < 0.001 SH – respondents from self-help group, NSS – respondents who didn´t attend the self-help group, SD – standard deviation

Evaluation of the domains of the WHOQOL-BREFF questionnaire

Overall quality of life, satisfaction with health, and general domains of the WHOQOL-BREFF were evaluated by respondents as being, on average, worse than the popular norm (see Table 5). The NSH group of patients had the lowest scores in domain three, Social relations (9.48) and domain two, Perception (10.32). The SH group of respondents achieved higher scores in individual domains but similarly gave negative assessments in the area of domain two, Perception (11.41).

On comparing groups with the help of statistically evaluated WHOQOL-BREFF domains, we discovered significant differences in the evaluation of quality of life in three domains: domain one: physical health; domain two: perception; and domain three: social relationships (see Table 6); whereby higher scores were achieved by SH respondents.

Discussion

Quality of life, as a dynamically changing state, affects a complex of clinical, personal, and social factors. Its support is becoming an aim of therapeutic and nursing interventions in which the use of a holistic, comprehensive approach – perceiving the patient as a unique bio-psycho-social and spiritual being – is used, thereby balancing subjective with objective criteria.

The concept of quality of life should be multidimensional, meaning that it should include subjective comfort as an emotional component, satisfaction as a cognitive component, social functioning as a productive component, and the meaning of life as a spiritual component (Ondrejka, Adamicová, 2001).

On a visual-analogue scale (for comparison of various diseases from the standpoint of effect on quality of life), MS is considered to be similar to rheumatoid arthritis or angina pectoris, with a medium value of 0.56 from a total score of 1.0

(Hloch et al., 2011; Kobelt, Texier-Richard, Lindgren, 2009). With MS, as with other chronic degenerative diseases, there are changes in quality of life. The means of evaluating quality of life in patients with MS in countries with high incidence and prevalence of the disease are comparable. Patients claim mobility problems to be the most important parameter. Limited individual mobility has the greatest correlation to decreased quality of life.

Table 5 Average scores of items and WHOQOL-BREFF domains in patients with MS (n = 91) against general population

	Patients SH		**Patients NSH**		**Population standards***	
	Mean	**SD**	**Mean**	**SD**	**Mean**	**SD**
Quality of life	**3.15**	**0.85**	**3.31**	**0.88**	**3.82**	**0.72**
Satisfaction with health	3.15	0.85	3.47	0.90	3.68	0.85
Domain 1: Physical health	**12.38**	**2.05**	**11.51**	**1.99**	**15.55**	**2.55**
Pain and discomfort	3.36	1.31	3.31	0.88	4.03	1.05
Dependence on medication	2.48	1.00	2.58	1.02	4.16	0.95
Energy and fatigue	2.34	0.89	2.44	0.98	3.62	0.93
Mobility	3.40	0.94	2.94	1.18	4.27	0.84
Sleep and rest	3.39	0.93	2.53	0.76	3.61	0.99
Everyday tasks	3.38	0.96	3.17	1.21	3.76	0.78
Working efficiency	3.01	0.77	2.96	1.03	3.76	0.80
Domain two: Perception	**11.41**	**2.75**	**10.32**	**2.55**	**14.78**	**2.43**
Pleasure in life	3.25	0.49	2.25	1.06	3.83	0.90
Meaning of life	2.81	0.68	2.13	1.07	3.86	0.85
Concentration	3.06	0.86	2.07	1.03	3.55	0.88
Body image	2.56	0.96	2.17	0.81	3.90	0.82
Self esteem	3.22	0.74	2.72	0.89	3.57	0.76
Negative feelings	3.36	0.84	2.82	0.95	3.47	0.95
Domain three: Social relationships	**11.81**	**3.02**	**9.48**	**2.74**	**14.98**	**2.89**
Physical safety and security	2.89	0.95	2.87	0.97	3.24	0.79
Personal relations	2.58	0.39	2.01	0.60	3.75	0.91
Sexual satisfaction	3.83	1.02	2.83	0.76	3.64	1.07
Practical social support	2.45	0.61	2.28	0.73	3.85	0.80
Domain four: Environment	**11.86**	**2.32**	**11.93**	**2.89**	**13.30**	**2.08**
Home environment economic	3.06	0.56	3.3	0.66	2.85	0.92
circumstances	3.36	1.24	2.63	0.79	2.87	1.08
Information and skills	2.02	0.67	2.25	0.55	3.87	0.77
Recreation and leisure	3.15	0.94	3.53	0.99	3.33	1.00
Physical environment	3.38	0.74	3.48	0.78	3.54	0.86
Access to health and social care	2.88	0.56	2.98	0.77	3.70	0.79
Transport	2.98	0.85	2.98	0.96	3.19	1.07

n – number, SH – respondents from self-help group, NSS – respondents, who didn´t attend the self-help group, SD – standard deviation, population standards* by Dragomirecká, Bartoňová, 2006

Table 6 Differences in domains of monitored groups

Evaluation in areas	**SH**		**NSH**		
	Mean	**SD**	**Mean**	**SD**	**p**
Domain one: Physical health	12.38	2.05	11.51	1.99	0.0420*
Domain two: Perception	11.41	2.75	10.32	2.55	0.0382*
Domain three: Social relationships	11.81	3.02	9.48	2.74	0.000***
Domain four: Environment	11.86	2.32	11.93	2.89	0.785

SH – respondents from self-help group, NSS – respondents, who didn´t attend the self-help group, SD – standard deviation

Respondents in the pilot study reported positive evaluations in overcoming problems related to the physical domain (see table 2). The average scale of evaluation in almost all assessments of the physical domain exceeded level three. In the other domains for evaluating quality of life (psychological, social, spiritual), the average numerical values are at the level 2–2.5. In our study, we focused on comparing quality of life in patients with MS who used the support of self-help groups with regard to groups of probands without this support. The philosophy of self-help groups does not come from dissatisfaction with official health care, but relates to the development of deeply rooted humanistic traditions of health-related self-help. It is therefore very much desired that health providers better understand problems in the field they work in, and also take account of self-help groups. In this way, health providers better understand the needs of the individually ill as well as their immediate social surroundings. The continuity of patient care, satisfaction and monitoring of their needs outside the medical environment is also important. It is essential that they be assisted by the application of knowledge, skills and treatment at home.

These days, clubs and self-help groups are combining into national coalitions, federations, and associations which have the aim of solving problems in given groups nationally, and, in some cases, internationally (Majerníková, Jakabovičová, Obročníková, 2006). In our contribution, we present results from two groups of respondents: those who utilized the services of groups for patients with MS with those who, for various reasons, did not. The results of the pilot study indicate a better quality of life for patients supported by self-help groups in a significant number of evaluated areas.

In their study, Kang et al. (2010) show the impact of support from self-help groups for mothers of children with the lifelong condition hemophilia. The main goal of the programme was to reduce stress iand depression in the mothers, and also to help properly ensure health care for the sick children at home. The pilot study indicated that the actions of support groups had a positive affect in terms of providing knowledge for the mothers, which thereby caused significant change in the occurence of symptoms of depression and quality of life levels of respondents. However, while the authors consider this programme to be effective, further studies are necessary to prove this beyond doubt. Another parallel study (Beneth et al., 2010) focused on patients post-laryngectomy and was specifically focused on monitoring changes in lifestyle connected to loss of voice, awareness of body, and general resocialization. Analysis of the results proved that the support of professionals, family, friends, and health care providers was important for the successful transition of this stressful period. An important role was also played by Internet-based support groups which contributed to improvements in communication and integration in life. Research by Timko et al. (2013) ascertained the effect of self-help groups on social anxiety in patients. Results were compared at intervals of six, 12, and 24 months post-treatment. They found positive effects among participants, but not a higher frequency of participation at meetings.

Limitation of Study

A limit of the study is the choice of sample patients in selected localities of the Presov region. Given that this was a pilot study, we are planning to undertake a study of multiple self-help groups for patients with MS and also to involve patients with MS from outside these organisations in many different localities in Slovakia.

Conclusion

People are social beings. We know who we are only in the company of others. Usually, in times of difficulty, we look for support from our fellow men, from people who have experienced or are experiencing similar situations, or are at least able to understand our difficulties. A person can be shaped by certain groups, for example in the area of their actions, thoughts, or feelings. Self-help groups use this shaping power. Their main goal is to help sick people, human beings in destitution, and their immediate social environment. The aim of this study was to show that it is desirable for health care to focus on the community, including self-help groups. These groups need professional help to thereby improve the quality of life of people with certain disabilities or diseases and their families.

Ethical aspects and conflict of interest

The authors are not aware of any conflict of interest and have complied with ethical standards of research. The institutions where research was conducted have consented to the use of the questionnaire. Participants were informed of the purpose of the research and only those who signed an informed consent form were included in the research sample.

Author contribution

Study conception and study design (AE, LM, MK), data analysis and interpretation (AE, LM, AH, MK), manuscript draft (LM, AH), critical revisions of the manuscript (LM, AH), final approval of the manuscript (LM, AE).

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