

Self-Help Groups and Social Support of Patients with Multiple Sclerosis

L. Majernikova (Ludmila Majernikova), D. Magurova (Dagmar Magurova), H. Galdunova (Helena Galdunova)

Original Article

University of Presov in Presov, Faculty of Health Care,
Department of Nursing, Slovakia

E-mail address:

majernikova@unipo.sk

Reprint address:

Ludmila Majernikova
University of Presov in Presov
Faculty of Health Care
Department of Nursing
Partizanska 1
08001 Presov
Slovakia

Source: Clinical Social Work and Health Intervention
Pages: 28 – 34

Volume: 10

Issue: 1

Cited references: 17

Reviewers:

Michael Costello
University of Scranton School of Education, USA
Roberto Cauda
University Catholica Clinica, Gemeli, Rome, Italia

Key words:

Social Support. Social Intervention Quality of Life. Self-help Organization.

Publisher:

International Society of Applied Preventive Medicine i-gap

CSWHI 2019; 10(1): 28 – 34; DOI 10.22359/cswhi_10_1_04 © 2019 Clinical Social Work and Health Intervention

Abstract:

Objective: The goal of the study was to compare the quality of life of patients with multiple sclerosis (MS) in Eastern Slovakia Region from the point of view of support MS organizations.

Design: comparative study, cross-sectional study.

Methods and participants: The sample of research consisted of 121 patients with multiple sclerosis (53 respondents who attended the self-help organization and 68 who did not attend the organization). We used to evaluate the standardized questionnaire WHOQOL-BREF.

The results indicate that social intervention have a positive impact on the quality of life of physical, mental and social health.

Conclusion: Clinical observation of the results of studies present that social support provided to clients with chronic disease can be very useful.

Introduction

Social support is a set of various support activities that come from supporting resources from the client environment. These include family, relatives, and friends, but also professionals at different jobs (such as a doctor, nurse, therapist, social worker and psychologist). The essence of social support lies in the awareness that other people are available to us and are willing to provide assistance if needed. Achievable social support means a form of assistance that is readily available in the immediate vicinity of a particular person, both on an official and unofficial level. In relation to this plane, we can talk about social support as a personal resource; in this sense the social support includes all the resources available for the individual within his / her individual social network. In general, we can say that perceived social support, that is, the kind of social intervention that the individual really contemplates is a reflection of social relations in the environment to which the individual belongs (Dimunova, 2017).

The high incidence of chronic illnesses in the Slovak Republic stimulates a comprehensive solution of the situation of these patients. As part of the overall approach, it is indispensable to address the issue of social support and support for these clients as well. Social support and good social relationships make a significant contribution to health, and their undeniable protective significance has also been demonstrated in the context of chronic diseases such as MS to which we pay attention in our study (Rakova, Bednarek, 2015).

Characteristics of the population and methodology

The sample consisted of 121 patients with multiple sclerosis (MS) comprised of 71 women and 50 men. The first comparative sample of respondents, who did not do social group self-help support interventions (NS) consisted of patients from Hospital Sv. Jakub n.o., Bardejov, Hospital Vranov nad Toplou consisted of 68 respondents. The second comparative research sample visited a self-help group (SS), and consisted of 53 patients diagnosed with MS who are registered members of the MS organizations in Presov, Vranov nad Toplou and Kosice.

Table 1: Characteristic of respondents

	NS n (68)	%	SS n (53)	%
Gender				
Male	34	50	16	30
Female	34	50	37	70
Eduaction				
Highschool without graduation	13	19	9	17
High school with graduation	45	66	36	68
University	10	15	8	15
Age (M ± SD)	45.1 ± 12.73		47,0 ± 13.2	
Duration off disease (M± SD)	13.4 ± 8.11		14.2 ± 7.96	

n – number, M – mean, SD – standard deviation

Both compared groups of respondents mostly had prevalently a high school education with graduation. The average duration of disease in patients SH was 14.2 ± 7.96 and NSH 13.4 ± 8.11 (Table 1). We used the standardized questionnaire from the World Health Organization WHO-QOL-BREF (short version) (Dragomirecka, Bartonova, 2006). The statistical analysis was performed using the statistical software package STATISTICA 14. Proportion comparisons were carried out with the Student's t-distribution. A value of $p < 0.05$ was set to indicate statistical significance for all comparisons. Correlation analysis was used in order to explore the statistical significance of relationships between each domain of the quality of life and the social support. Parametric statistics Pearson correlation coefficients were used in study.

Results

In general physical health, we noted significant differences in energy for life ($p < .001$) and satisfaction with sleep ($p < .001$). In other domains, we did not notice significant differences in the compared groups. In psychological health, we found significant differences better scores for patients visiting the club. Significant differences were seen in feeling of life meaningful ($p < .001$), enjoyment of life ($p < .001$), negative emotions and able to concentrate ($p < .05$). Significant differences were found in the social

and environmental aspects of the quality of life according to membership of MS organizations. The results showed better rating in respondents with social support in the spheres of satisfaction with sexual life ($p < .001$), satisfaction with self ($p < .01$), satisfaction with friends support ($p < .001$) and financial satisfaction ($p < .001$) (see Table 2). Statistically significant differences between respondents were discovered in the quality of life (QoL) in three domains of the WHOQOL BREF questionnaire. The social supported patients had statistically significance higher QoL in physical ($p = 0.0310$), psychological ($p = 0.0077$) and social ($p = 0.0000$) domains of QoL than not supported patients (see Table 2, Figure 1).

Figure 1 Results of WHOQOL-BREF - domains of QoL

Parametric statistics, Pearson correlation coefficients were used, where we found positive correlation between social support and domains of QoL. Our research showed significant differences in three domains of quality of life between the patients according to their membership in supporting organizations ($p \leq 0.05$ for physical, $p \leq 0.01$ for psychical and social domain of QoL). The dependence in physical, psychical and social domains was founded too (see Table 3). The results showed that the duration of SM was negatively.

Table 2: Analysis of the WHOQOL-Bref

Domain		SS n (53) M (SD)	NS n (68) M (SD)	p level
General physical Health	Ability to get around	3.33 (0.94)	2.98 (1.08)	0.514
	Energy for life	3.19 (0.62)	2.39 (1.11)	0.000***
	General health Satisfaction	3.25 (0.85)	3.49 (0.90)	0.200
	Discomfort, pain	3.32 (1.21)	3.33 (0.78)	0.390
	Accept bodily appearance	3.38 (0.98)	3.18 (1.11)	0.382
	Satisfaction with sleep	3.28 (0.88)	2.49 (0.79)	0.000***
Psycholo-gical Health	Feel life meaningful	2.69 (0.54)	2.09 (0.73)	0.000***
	Enjoyment of life	2.69 (0.54)	2.09 (0.73)	0.000***
	Negative emotions	3.24 (0.88)	2.72 (0.97)	0.016*
	Feel safe in daily life	2.63 (0.94)	2.09 (0.88)	0.053
	Able to concentrate	3.19 (0.48)	2.31(0.98)	0.000***
Social relations	Personal relations satisfaction	2.55 (0.61)	2.68 (0.73)	0.249
	Satisfaction with sex	3.93 1.12)	2.95 (0.93)	0.000***
	Satisfaction with self	3.12 (0.73)	2.83 (0.76)	0.007**
	Satisfaction with friends support	2.68 (0.42)	1.98 (0.54)	0.000***
Environ-ment Health	Satisfaction with health service	3.48 (0.45)	2.98 (0.64)	0.044*
	Financial satisfaction	3.33 (1.02)	2.98 (0.79)	0.040**
	Satisfaction with condition of place of living	3.22 (1.01)	3.30 (0.98)	0.290
	Opportunity for leisure activities	3.22 (0.98)	3.63 (0.89)	0.562
	Information satisfaction	2.12 (0.69)	2.27 (0.58)	0.235
WHO QOL BREF Domain Health	Physical	12.48 1.98)	11.49 2.05)	0.0310*
	Psychological	11.39 (2.75)	10.38 2.55)	0.0077**
	Social	11.40 (2.98)	9.57 (2.99)	0.0000***
	Environmental	12.48 (1.98)	11.49 (2.05)	0.0310*

*** significant at the 0.001 level, ** significant at the 0.01 level, * significant at the 0.05 level

Table 3: Pearson correlation coefficients for each domain of the quality of life and social support

Domains	Physical domain	Psychical domain	Social domain	Environ. domain	Social support	During MS
Physical		0.583**	0.277*	0.011	0.276*	0.004
Psychical	0.583**		0.794**	0.258	0.561**	0.189
Social	0.277*	0.794**		0.215	0.741**	0.124
Environment	0.011	0.258	0.215		0.251	0.208
Social support	0.276*	0.561**	0.741**	0.251		0.238
During SM	0.004	.189	0.124	0.208	0.238	

** Correlation is significant at the 0.01 level, * Correlation is significant at the 0.05 level

Discussion

Social support is recognized as a determinant of health, which acts upstream of traditional risk factors to affect the health and well-being of individuals. Social support is based on the perception that interpersonal relationships are able to fulfill the following functions: emotional support (caring, love, and empathy); instrumental support (concrete ways people assist each other such as providing financial assistance); social companionship (spending time with others); guidance (finding solutions to a problem); appraisal (Majernikova, Obrocnikova, 2019). Although there have been studies on the relationship between social support and QoL in patients with chronic progressive degenerative neurological diseases (Schwartz and Frohner, 2005; Nishida *et al.*, 2012), research investigating this association in patients with neuropathy is scarce. The relationship between social support and severity of disease has also not been well established.

In our study respondents' results positively correlated with social support - the psychological domain ($p < .01$), the social domain ($p < .001$) and the physical domain ($p < .05$). From the point of view of duration of the disease, we did not find any significant correlation of relationships. Respondents with a better perception of physical health showed a positive correlation in other domains in quality of life other than environmental.

Numerous epidemiological studies have reported that poor social support is associated with negative treatment response to dysthymia (Oxman *et al.*, 2001); seasonality of mood disorder (Michalak *et al.*, 2003); the presence of depression comorbid in several medical illnesses, such as multiple sclerosis (Mohr *et al.*, 2004); cancer (Manel *et al.*, 1999, Wong *et al.*, 2013, Salonen *et*

al., 2010); rheumatoid arthritis (Revenson *et al.*, 2015). In contrast to low social support, high levels appear to buffer or protect against the full impact of mental and physical illness. The relationship between good social support and superior mental and physical health has been observed in diverse populations including college students, unemployed workers, new mothers, widows, and parents of children with serious medical illnesses (Johnson *et al.*, 1997, Christianson *et al.*, 2013, Kang *et al.*, 2010).

Conclusion

Based on the theoretical analysis of available literature, studies and our results, we suggest the following intervention recommendations needed for practice, especially for health staff.

1. As regards health care, attention should be paid to the quality of life through modern and recommended measuring instruments whose results need to be analyzed and on that basis to apply changes in nursing practice.
2. Health staff should engage in self-help groups and clubs because they often miss high-quality feedback to monitor the area of knowledge and skill management of the patient and her/his family as well as the quality of life in the social sphere.
3. Further reason for greater involvement of health staff into self-help groups is to improve continuous health care for chronically ill.
4. It is essential that other professionals from different fields of medicine are also involved in the self-help movement who by their knowledge and experience improve their club activity.
5. Availability of specialist services, from different areas according to character of the organization which can change

the attitudes of the sick and their family members (psychologist, social worker, etc.) is important.

6. Provide assistance in setting up self-help groups in locations where it is needed & desirable.
7. Helping to increase the cooperation of self-help groups and organizations in Slovakia, in this way it is possible to achieve mainly the exploitation of different experiences in the area of club activity, to increase their mutual support and co-responsibility.
8. In larger measure establish international contacts with other clubs and self-help groups aimed at helping the sick.
9. Support professional guidance online counseling, online membership through expert guidance of such counselors; contributions to discussions on websites by nurses who have sufficient professional and practical experience.
10. Part of the conferences should be “patient seminars” which would solve the problems of the sick and their families at a professional level.

Ethical requirements - participation in the study was voluntary and anonymous. Each person was informed about the objective of the survey and the way of completing the questionnaires. Then, informed consent for participation in the study was signed by each [ersspn. The survey procedure was in accordance with the Declaration of Helsinki.

References

1. CHRISTIANSON HF, WEIS JM, FOUAD NA. (2013) *Cognitive Adaptation Theory and Quality of Life in Late-Stage Cancer Patients*. Journal of Psychosocial Oncology. 2013;31(3):266–281.
2. DIMUNOVA L (2017) *Integrated Health Care Centers*. In: *New Trends and Challenges social policy at present*. Brno: Tribun EU, 2017. pp. 96 - 99.
3. DRAGOMIRECKA E, BARTONOVA J (2006) *Handbook for Czech users of questionnaires quality of life of the World Health Organization*. 1. ed. Praha: 20.
4. JOHNSON D R, LUBIN H, ROSENHECK R et al. (1997) *The impact of the Homecoming reception on the development of posttraumatic stress disorder*. The west haven homecoming stress scale (WHHSS) J Trauma Stress. 1997;10:259–77.
5. KANG H S et al. (2010) *Development, implementation and evaluation of a new self-help programs for mothers of hemophilic children in Korea: A pilot study*. Haemophilia. 2010;16 (1):130–135.
6. MAJERNIKOVA L, JAKABOVICOVA A, OBROCNIKOVA A (2008) *The role of nursing in self-help clubs and groups*. MOLISA. 2008;(1):134–136.
7. MAJERNIKOVA L, OBROCNIKOVA A (2008) *The influence of the self-help group on quality life of the patient and his family*. 2019. Presov, PU in Presov. 120p.
8. MANNE S L, PAPE S J, TAYLOR K L, DOUGHERTY J (1999). *Spouse support, coping, and mood among individuals with cancer*. Ann Behav Med. 1999;21:111–21.
9. MICHALAK E E, WILKINSON C, HOOD K et al. (2003) *Seasonality, negative life events, and social support in a community sample*. Br J Psychiatry. 2003;182:434–8.
10. MOHR D C, CLASSEN C, BARRERA JR M (2004) *The relationship between social Med*. 2004;34:533–541.
11. NISHIDA T, ANDO E, SAKAKIBARA H (2012) *Social support associated with quality of life in home care patients with intractable neurological disease in Japan*. Nurs Res Pract 2012:402032.
12. OXMAN T E, HULL J G (2001) *Social support and treatment response in older depressed primary care patients*. J Gerontol B Psychol Sci Soc Sci. 2001;(56):35–45.

13. RAKOVA J, BEDNAREK A (2015) *Position of a social worker in healthcare devices. New trends in current health care: nursing, public health, economy, health*. Bratislava: Samosato, 2015. pp. 46-54.
14. REVENSON T A, SCHIAFFINO K M, MAJEROVITZ S D, GIBOFSKY A (2015) *Social support as a double-edged sword: The relation of positive and problematic support to depression among rheumatoid arthritis patients*. Soc Sci Med. 2015;33:807–13.
15. SALONEN P et al. (2010) *Quality of Life. Changes in quality of life in patients with breast cancer*. Journal of Clinical Nursing, 2010 (20):255-266.
16. SCHWARTZ C, FROHNER R (2005) *Contribution of demographic, medical, and social support variables in predicting the mental health dimension of quality of life among people with multiple sclerosis*. Health Soc Work 2005 (30):203–212.
17. SHERBOURNE C D, STEWART A L (1991) *The MOS social support survey*. Soc Sci Med 32:705–714.