

An Investigation on the Relationship between the Quality of Life and Stress Coping Strategies in the Families of Patients with Multiple Sclerosis (Case study: the members of Ahvaz Ms. Society, Iran, 2008)

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Abstract: Multiple sclerosis (MS), a chronic disease in nervous system, is the second source, preceded by traumatic events, of paralysis among the young people. The number of these communities amounts, annually, to 7,000 in Iran. This study is designed to find out the quality of life and methods of stress coping for the care givers of patients with multiple sclerosis. The study is descriptive in design. Among the members of the families giving care to MS people who are members of Ahvaz Ms. Society, 200 were studied via using three anonymous questionnaires. 108 men and 90 women, as qualified, were selected. The quality of life of these families, based on physical, psychological, social, and economic aspects, was rated as average; especially the life quality of the men in terms of psychological qualities outdid the women's. With respect to all the aspects studied, the care givers' quality of life was significantly related to their education. The majority of the women and men used fair and good strategies to cope with stress, respectively. The significance of social support and the development of educational programs for the care giving families of patients with MS, especially in those families with a low level of knowledge, is explained by a higher quality of life for the care givers with a higher education and those who have made use of appropriate coping strategies.

Keywords: quality of life, coping strategies, multiple sclerosis

1. Introduction

Given the prevalence of chronic diseases among different socio – cultural, economic, and age groups, health authorities are always largely concerned with such diseases. The number of people, based on some research, with these diseases exceeds 167,000,000 by 2050 and their health bills have been annually. Estimated as \$ 797 billion; However, the research findings indicate that some 44- percent decrease will be obtained in the costs of hospitalization and care giving practices if they are given home care.

In multiple sclerosis, a chronic disease, the myelin sheath of nervous cells in the brain and

spinal cord is damaged multifocal. Developed in the thirties and forties, the disease prevalence for women is relatively 2.5 times more than men. With an annual prevalence ranging from 1.5 to 11 million, the illness is the second source, following traumatic events, of paralysis among young adults.

Its clinical symptoms include optical neuritis. Strabismus, imbalance, vertigo, faintness, kinetic – sensory disturbances of the organs, genito-urinary disorders including neurogenic bladder, in voluntary urine, and impotence, constipation, sleep disorders, and depression. As reported by Iran's MS society, every year the number of people with MS is

rising by 7.000. According to the latest figures made by the society, also, the number of the individuals suffering from MS has reached 40.000 in 2006. Individual lives are directly and indirectly affected by chronic illnesses which will compromise both the patient's life and her caregivers' lives.

These caregivers face serious problems concerning the emotional challenges and stress, coping with new duties, the health care issues, and the loss of quality of life. Among the most essential objectives in health care settings is the preservation and promotion of patients' life quality. Furthermore, the intervention efforts by health care providers is directly associated with any improvement in the quality of patients' life. Assessment of chronic diseases, improved relation between patient and doctor, assessing the effectiveness and relative advantage of different health care practices, evaluation of health care services, research, healthcare policies, economic measurements and resource distribution are the areas for which quality measurement of the individual lives is likely to be useful. Some studies point out that issues like stress, fear of an ambiguous future, social disintegration, occupational economic drawbacks, and isolation are the major determinants of care givers' quality of life. The patient's life as well as her caregiver's and family members' lives may be qualitatively affected by stress and its coping methods.

Given the importance of the level of life quality and the utilization of efficient and appropriate coping methods on the part of care givers in MS patients, this study, therefore, is intended to explore the quality of life of MS patients' family members and to find out the methods and strategies they use in order to cope with stress.

2. Materials

In this descriptive – correlative study, the families of MS patients, the members of MS

Society in Rehabilitation Faculty, Jundi Shapoor University of Medical Sciences, Ahvaz, Iran, were assessed in terms of quality of life based on physical, psychological, social, and economical parameters as well as stress coping methods, both with excitement and problem orientations. The number of the members is 500, out of which 200 were selected based on a random-gradual sampling method once they expressed their consent to participate in the study.

The selection was done by a sample volume formulation. In order for caregivers to be included in the study,

they have to hold the least education qualifications as of reading and writing, the age group of 20-60, no prior exposure to chronic diseases, living with MS patients in the same dwelling place and giving care to the patients as well as no involvement in similar studies.

The data on these care givers were collected and recorded by means of predesigned questionnaires which included demographic data such as age, gender, ethnicity, employment, the kinship ties with the patient, education, family's monthly income, the age of the inception of MS and the term of the illness, Ferel and Grant's Questionnaire for the standards of life quality of the individuals giving care to those with chronic illnesses.

The number of items on quality assessment of life based on socio-economic, psychological, and physical factors was 9, 5, and 16, respectively. This questionnaire was validated by Fotookian (2004) in Iran. The last section is attributed to Jalouis's stress coping methods including 25 and 15 items on problem – and excitement – oriented coping strategies. The first validation of the questionnaire was done in Iran by Zohari.

Following the approval of the study by the research committee in Islamic Azad University of Medicine, Tehran Branch and the coordination with Ahvaz MS society, attempts were made to collect and record the data. The participation was voluntary and the

questionnaire was designed in an anonymous style. Also the respondents were assured of confidentiality of their input information. To analyze the data, descriptive - inferential statistics, χ^2 - square test, Kendall - Spearman correlation coefficient, and a SPSS. V14 software was used. The level of significance (p) was less than 0.05 ($P < 0.05$).

3. Results and discussion

To assign the family members to the predefined age groups, 13 (7.3%) were in the group of below 20, 51 (28.8%) between 21 and 30, 61 (34.5%) between 31 and 40, and 52 (29.4%) were above 40 years old. In terms of gender distribution, 108 male (54.5%) and 90 female (45.5%) participants were identified as qualified. In terms of the kinship ties among the caregivers and patients, 98 husbands and wives (51%), 18 fathers (9.4%), 19 mothers (9.9%) 18 brothers (9.4%), 22 sisters (11.5%), 8 sons (4.2%) and 9 daughters were identified. In terms of the caregivers' employment, 109 (56.8%) were working, 26 (13.5%) were jobless, 5 (2.6%) were retired, and 52 (27.1%) were housewives.

In terms of ethnicity, 21 (10.7%) were Lors, 44 (22.3%) were Arabs, 7 (3.6%) were Turks, 73 (37.1%) were Fars, 35 (17.8%) were Bakhtiaris, and 17 (8.6%) had a different ethnicity. The education of the caregivers was as following: 6 illiterate (3%), 99 (50.3%) with a diploma or lower, 43 (21.8%) had a two - year college degree, 39 (19.8%) with a bachelor degree, and finally 10 (5.1%) had a M.A or Ph.D. degree. With respect to the term of disease, 58 cases (29.9%) had a less than 2-year affliction, 81 cases (41.8%) with term duration of 2-6 years, 31 cases (16%) 6-10 years, and 24 cases (12.4%) were suffering for more than ten years.

Based on the age of inception, it was reported that 32 cases (18.4%) were below 20, 49 cases (28.2%) between 20 and 25, 36 cases (20.7%) 25-30, and 57 cases (32.8%) were above 30. in

terms of the families; monthly income, 49 had a monthly income (25.7%) with a range of 300-350, and 95 (49.7%) had earned more than 300.000 toomans per month. An average quality of life was observed for most of the families involved in the study.

Gender was not significantly related to the overall quality of life although the men had experienced a higher quality of life. There was a significant negative correlation between the age of the caregivers and their quality of life; thereby, the young people had a higher quality of life ($p = .004$, $r = .263$). The couples, with the highest percentage of frequency, had an average - good quality of life. However, this advantage was not statistically significant. The overall quality of life was not significantly related to such items as employment, family's monthly income, ethnic group, and the term of. There was a significant correlation among the caregivers' overall quality of life, their education, and the inception age ($p = .017$ and $r = .113$), in which a better quality of life is possible for those with a higher education and an older age of inception.

The people with an average quality of life (49.5%) undid physically the others. The difference between men and women, on physical grounds, in terms of quality of life, was not significant.

There was a significant negative correlation between the caregivers' quality of life and their age ($p = .005$ and $r = .187$).

As such, the physical quality and life quality of the young people was higher. Among the family members under study, the couples had the highest frequency of fair - good quality of life, though the difference is not statistically significant ($p = .066$).

The physical aspect and quality of life were not significantly related to the families' monthly income, ethnic groups, and the age of inception and the term of the disease.

There was a significant correlation between the care givers' education and their quality of life

as well as their physical qualities. ($p = .048$ and $r = .121$) As such, the educated caregivers experienced a higher quality of life and a better physical aspect. Compared with other groups, 62.5% of the families with an average quality of life outdid psychologically.

On psychological grounds, the men experienced a significantly higher quality of life compared with the women ($p = .005$ and $r = .145$).

There was no significant relationship among the psychological aspect, quality of life, employment, family's monthly income, ethnic group, and the term of the disease. However, a significant correlation was found among the psychological aspect, quality of life the age of inception ($p = .045$ and $r = .145$), and education ($p = .039$ and $r = .121$).

Nevertheless, a negative correlation was found between the psychological aspect and quality of life ($p = .006$ and $r = .141$).

The quality of life of many families (50%) was, in social terms, average and the higher quality of men's lives, compared with the women's, was not significant.

There was a significantly negative correlation between the age and the social aspect of the caregivers' quality of life ($p = .006$ and $r = .222$).

In this case, the young caregivers had a better social life and a higher quality of life while the social quality of life and the education of the care givers were significantly correlated ($p = .003$ and $r = .224$).

It means that educated people have a higher quality of life and a better social world.

This social aspect of the quality of life is not significantly related to employment, family's monthly income, ethnic group, the kinship ties of the caregivers, the age of inception, and the term of the disease.

A large number of the families (66.9%) employed appropriate strategies to cope with stress. For many women (59.6%) those strategies

were average, but for many men they were good ($p = .021$ and $r = .230$). In other words, the men more frequently used stress coping methods. The use of appropriate stress coping strategies among the couples was significantly less than that of the other kins ($p = .006$ and $r = .186$).

There was not significant correlation among such parameters as age, education, employment, ethnic group, the age of inception, and the term of the disease as well as the caregivers' use of stress coping strategies. The findings indicate that most of the families (58.5%) have used appropriate excitement – oriented strategies. The majority of the women (56.3%) and the men (60.6%) have used average and good excitement – oriented approaches to coping with stress, respectively ($p = .029$ and $r = .141$).

No significant correlation was found among the parameters including age, employment, ethnic group, education, the age of inception, the term of the disease, and the caregivers' excitement – oriented approaches to coping with stress.

As stated earlier, the majority of the families (78%) used appropriate problem – oriented practices to cope with stress. A significant correlation was found between the problem – oriented methods of stress coping used by the families of the patients with multiple sclerosis and their education ($p = .049$ and $r = .149$).

Thus subjects with higher education more often used good problem – oriented methods of stress coping. Compared with other members in a family, the couples with multiple sclerosis have less significantly employed good problem oriented methods to cope with stress ($p = .006$ and $r = .194$).

No significant correlation was found among the caregivers of MS patients in terms of such parameters as age, gender, employment, ethnic group, education, the age of inception, the term of the disease, and the utilization of problem – based approaches to coping with stress.

The quality of life of the caregivers and their stress coping methods were significantly correlated ($p = .001$ and $r = .468$).

Those, therefore, who make use of good stress coping methods, have a higher quality of life.

In the following figure, too, the findings drawn from the correlation between the total quality of life and the total stress coping methods used by the family members of MS patients are as following:

9 families (64.3%) with a low quality of life used average approaches to coping with stress but only 5 families (35.7%) used good methods. In families with an average quality of life, however, the frequencies of average and good coping methods were 23 (26.7%) and 63 (73.3%), respectively.

Meanwhile, all 16 families (100%) with a good quality of life used good methods of stress coping.

In the centers under study, a significant correlation was found between the total quality of life and stress coping methods by means of a χ^2 - square test ($\chi^2 = 23/989$) where the error level $\alpha = .05$ and $P_v = .001$.

The correlation value for Spearman correlation coefficient was $r = .468$.

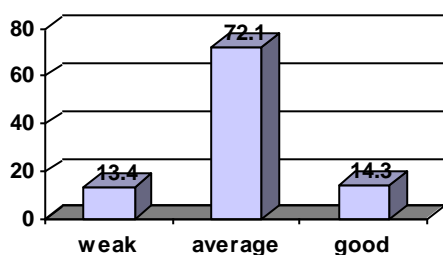


Figure1. The percentage of the total quality of life for the families of the members of MS Society, Ahvaz

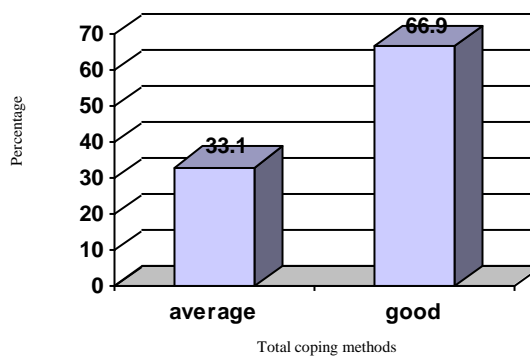


Figure2. The percentage of the total stress coping methods for the family of a member of MS Society, Ahvaz

Table1. The absolute and relative frequency distributions of the total quality of life and their relation with the total coping methods used by the families of members of MS Society, Ahvaz

		total coping methods		results
		average	good	
The total quality of life	0-100	number 9	5	χ^2 :
	weak	(percent) (62.3%)	(35.7%)	23.989
	101-200	number 23	63	P_v :
	average	(percent) (26.7%)	(73.3%)	.001
201-300	number 0 (0%)	16	$r =$	
good	(percent)	(100%)	.468	

This paper is designed to explore the quality of life and stress coping methods among the families of MS patients as members of MS Society, Ahvaz, Iran.

The families' quality of life was average in terms of physical, psychological, and social aspects. The psychological quality of men's lives was higher than those of the women.

There was a significant negative correlation among the quality of life, in general, the socio – physical qualities, and the age of the caregivers. The younger persons had a higher quality of life and better socio – physical aspects.

Taken together all the aspects studied, the quality of life of the caregivers was significantly correlated with their education.

Thus more educated caregivers experienced a better quality life.

No significant correlation was achieved among the caregivers' quality of life, education, monthly income, ethnic group, kinship ties with the patient, and the term of the illness.

More than 50% of the caregivers used good coping methods where the men and the women mainly used good and average methods, respectively, as it holds true about the excitement oriented coping strategies but problem – oriented ones are apparently less used by the MS patients' wives, though more by the caregivers with higher education.

Other demographic parameters were not significantly correlated with coping methods. Finally, a significant correlation was found between the caregivers' quality of life and their stress coping methods.

As such, those who use better coping methods will experience a higher quality of life.

4. Conclusion

Lim and Zebrack reported that the treatment and giving care to the people with chronic illness will multilaterally affect the caregivers' life and may lead to such repercussions as degeneration of physical health, degradation of social and family life, rising stress, anxiety, and depression.

Therefore, as an effective agent, stress coping methods have a major role to play in shaping the caregivers' life. King and Hinds argue that the family relations are likely to be affected, besides a low – quality life, by the disease resulting in an utilization of ineffective coping methods,

increasing tension, and degraded psycho-physical life.

These people's insufficient knowledge of quality life will certainly have implications for their social and career life, thus the socio-economic conditions may be deteriorated as well.

Figved et al (2007), in a study entitled "caregiver's burden in multiple sclerosis", reported that the caregivers are largely under too much stress and their life quality is remarkably challenged by their efforts to give care. They attribute the patient physical disability to the caregivers' severe stress.

Alshabaili et al (2008), in a work titled "family caregiver's quality of life in multiple sclerosis among Kuwaitis", stated that it is much more important for those caregivers who had looked after MS patients for a long time and had a lower education and knowledge, in addition to their unemployment.

Despite the interpersonal differences like different impressions of the quality of life, multiple questionnaire items, and the potential lack of honest responsiveness, and given the limited literature in Iran on caregiver's quality of life in multiple sclerosis as well as the findings of the present paper and the correlation between quality of life and education, it appears that the focus on raising awareness among caregivers and patients as to give insights into the nature of the disease, their care giving and treatment efforts, and also psychological counseling programs intended to help them use coping methods all contribute to an improved quality of life.

Furthermore, any improvement in the effective adjustable factors of quality of life (e.g. raising awareness, psychological counseling, insurance and economic support, and health service delivery) along with appropriate training programs on coping methods are likely to raise their performance and efficiency as well as their psychological health in the society at large.

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