
The Quality of Life (QOL) in Companions of People Diagnosed with Multiple Sclerosis (MS)

PhD. Maria Corina BRONȚ¹, Prof. Dr. Alexandra-Lucia Pop²

¹Faculty of Socio-Human Sciences, University of Oradea, Oradea, Romania

²College of Services in Tourism "Napoca", Cluj-Napoca, Cluj, Romania

ABSTRACT: The purpose of this sociological research is to investigate the quality of life of families with people affected by multiple sclerosis and to identify the factors that can influence this quality of life. The main objective of this research is to make a significant contribution to understanding the experience of families affected by MS and to identifying possible avenues of support and interventions to address their needs. According to the own scale, there are four factors (Utility, Mental and Psychological Exhaustion, Equilibrium, Social Capital) that directly influence the quality of life of multiple sclerosis companions. In the case of multiple sclerosis companions, the highest values are recorded by utility and social capital, while mental and psychological exhaustion record the lowest values. Thus, the higher the value of these factors, the better the quality of life.

KEYWORDS: quality of life, multiple sclerosis, companions, family, needs.

I. INTRODUCTION

Multiple sclerosis is a chronic neurological condition characterized by inflammation and de-myelination of the central nervous system. This disease affects millions of people around the world, and it not only affects individuals diagnosed with multiple sclerosis, but also their families. People affected by multiple sclerosis face significant physical, emotional and social challenges, and their quality of life can be greatly affected by this debilitating condition.

In this context, research on the quality of life of families with people affected by multiple sclerosis becomes a topic of crucial importance. Understanding the impact of illness on the lives of families is essential for developing appropriate support strategies and interventions that improve well-being and ensure a better quality of life for all family members involved.

II. QUALITY OF LIFE

Multiple sclerosis can have a significant impact not only on physical health, but also on the social and emotional lives of affected individuals. From a social perspective, multiple sclerosis can generate various challenges and needs [1].

In assessing the quality and well-being of companions' lives, it is essential to integrate both subjective indicators, which reflect the individual's perception of himself, and objective indicators, which provide a more objective perspective on the situation. It is also important to take cultural and social diversity into account, in order to adapt the measurements to the specifics of each community or society [2].

Quality of life from a sociological perspective is not just a subjective assessment, but is the result of interactions and social contexts in which individuals live. Sociologists examine the social and cultural factors that influence the perception and experience of quality of life.

Social and cultural context plays a crucial role in understanding and interpreting quality of life in sociology. Quality of life cannot be understood in isolation, but must be analyzed in relation to the social and cultural environment in which individuals and communities live. Cultural norms and values differ from one society to another and can influence how individuals perceive the quality of life. What is considered important and valuable in one culture may be different from what is valued in another culture. For example, some societies may emphasize material success and professional achievement as indicators of quality of life, while others may emphasize family relationships and community harmony.

On the other hand, social structures such as social class, gender, race, and ethnicity can have a significant impact on quality of life. People from marginalized or disadvantaged groups may experience a low quality of life due to inequalities and reduced access to resources and opportunities. Social inequalities can significantly influence access to health services, education, adequate housing and employment opportunities, having a direct impact on well-being and quality of life.

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Some sociologists have also explored how social inequalities can affect quality of life. For example, [3] argue that economic and social inequalities have an impact on mental and physical health, education, crime and many other aspects of life in society. The authors argue that in more egalitarian societies there are significant benefits to the well-being and health of all citizens. The paper explores how inequality can lead to social tensions, decreased trust and social cohesion, increased crime and mental health problems. The authors argue that inequality affects society through factors such as social status, anxiety about social position, envy and distrust of others. Wilkinson and Pickett argue that the solution to these problems lies in reducing economic and social inequality through appropriate public policies, such as progressive taxation, quality education accessible to all, and the promotion of well-paying jobs.

The same authors, in the work "The Inner Level" (2019)[4] investigated the relationship between inequality and quality of life, focusing on the impact on mental health. The authors present research that indicates a strong correlation between economic inequality and mental health problems such as anxiety, depression and chronic stress. The book explores how social inequality can contribute to stigmatization and discrimination against marginalized people, which can further exacerbate mental health problems. People from marginalized or resource-limited groups may have a lower quality of life due to reduced access to education, housing, health care and employment opportunities. Social inequalities can significantly affect the quality of life and well-being of individuals, contributing to poverty, poor health, poor education and reduced access to opportunities for personal and professional development. Understanding and addressing these inequalities is essential to creating a fairer society and improving the quality of life for all its members. Through social policies, inclusive education, anti-discrimination measures and the promotion of social justice, society can work to reduce inequalities and create a more conducive environment for equitable well-being and a better quality of life for all.

Finally, social capital is another important concept in the sociology of quality of life. It refers to the social networks, relationships and connections that individuals have within communities and society. Social capital has a significant influence on the well-being and quality of life of individuals, bringing multiple social, economic and emotional benefits. The French sociologist Bourdieu was one of the first to introduce the term "social capital" into sociology. He developed the concept of social capital as part of his broader theory of the different "capitals" present in a society. Bourdieu (2021)[5] emphasized the importance of social connections and networks in determining the position and power of individuals in society. At the same time, the American sociologist Robert D. Putnam (2020)[6] has written important works on social capital and explored the impact on communities and society in general, in which he analyzed the decline of social and community involvement in the United States and the effects of this decline on the lives of communities.

Social capital gives people the support and encouragement they need in difficult times. Strong social networks and social connections can provide emotional support, material support or useful information in times of crisis or hardship. Through these social relationships, individuals can become more resilient and better able to cope with life's challenges. At the same time, social capital can open doors to various resources and opportunities in society. Through social connections, people can access information, jobs, business opportunities and other benefits that can improve well-being and quality of life. Social capital can also encourage civic participation and community involvement. People with active social networks may be more motivated to get involved in community activities, volunteering and social initiatives, thus contributing to the development of the community and improving the quality of life for all its members. Last but not least, social capital can improve the quality of interpersonal relationships and promote mutual understanding and cooperation between individuals and groups. Positive social relationships can help create a climate of trust and respect within the community, which can generally improve the quality of life for all its members.

The sociology of well-being and quality of life brings a broad perspective to these essential concepts, highlighting the complex connections between the individual and society. By analyzing social interactions, inequalities and cultural factors, sociology makes a significant contribution to understanding and improving the well-being and quality of life for people around the world. We need to take these sociological perspectives into account when trying to discover how the quality of life of families with multiple sclerosis is affected.

III. RESEARCH METHODOLOGY

The present study starts from the definition of the research problem: What are the main difficulties encountered by the companions of sclerosis patients?

The main objective of this research is to determine and develop a profile of the companion of the sclerosis patient that highlights the main characteristics.

The data collection method was that of a non-probabilistic, questionnaire-based sociological survey. The research tool used was the questionnaire, made with the help of the Google Forms application. The answers were collected through the electronic box (email). The data were processed in the statistical program IBM SPSS Statistic 20.0, with a confidence level of 95% ($p < 0.05$).

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The research sample includes 102 people aged between 30 and 63 years old, living in Bihor, who care for at least one person with multiple sclerosis. In order to determine the socio-demographic profile of the multiple sclerosis patient, the age, level of school completed, marital status, place of origin and gender were analyzed.

IV. RESEARCH RESULTS

To determine the level of quality of life in companions of people diagnosed with multiple sclerosis, a proprietary scale designed based on the theoretical aspects studied in the specialized literature was used. The Cronbach Alpha value by including the 13 items is 0.825, well above the allowed limit (0.7) which means that an elimination of any variable including the one with a value equal to the coefficient does not bring an improvement.

Of the 13 statements included in the scale, 10 questions are reversed, never will always become and always will never become. Thus, the lowest level of quality of life would have a score of 30 points, and the highest score would be 120 points.

The average value of the quality of life level is 90.85, the lowest tested level is 56 and the highest 106. By adding up the scores of all the variables that make up the scale, 3 levels of the companions' quality of life can be determined: poor level with a score between [56-85), medium level with a score between [86-97], high level with a score between [98-106].

At the level of the analyzed sample, half (51%) of the respondents present an average level in terms of quality of life, a quarter (23%) identify with a high level, and the rest (26%) have a poor level of quality.

The value of the Kaiser-Meyer-Olkin Measure of Sampling Adequacy must be at least 0.4, for the application of Principal Components Analysis. According to the results obtained $0.684 > 0.4$ and the Sig value. associated with Bartlett's Test of Sphericity is statistically significant ($< 5\%$), so the procedure for reducing the number of variables is necessary.

The results for which Initial Eigenvalues are greater than 1 define four constructs:

Construct 1 named Utility with component items: I exercise or walk every day, I feel useful and satisfied at work, I think my spouse needs to change for our relationship to be good, I cry and get discouraged quickly, I live in fear of losing my job;

Construct 2 referred to Mental and Physical Exhaustion with component items: I suffer from headaches, I feel tired and powerless, I suffer from insomnia;

Construct 3 defined Equilibrium, component items: The program allows me to serve 3 meals/day, When I'm nervous I take painkillers;

Construct 4 named Social Capital, component items: My family is quite tiring, I avoid having house guests, I have no appetite.

The new constructs of the level of quality of life will be analyzed descriptively.

Table no. 1. Analyzing the constructs of the quality of life level scale

	Utility	Mental and Physical Exhaustion	Equilibrium	Social Capital
Mean	14.4118	10.0098	6.2843	9.0294
Median	15.0000	11.0000	8.0000	10.0000
Std. Deviation	4.09867	2.47160	2.35627	2.69380
Variance	16.799	6.109	5.552	7.257

According to Table no. 1, Utility records the highest average value (14.41). In other words, the companions are useful and at the disposal of patients with multiple sclerosis in satisfying as many needs as possible. Accompanying a patient with multiple sclerosis can bring a high level of physical and mental exhaustion, in this case the average value is 10, while the maximum value is 12. Regarding the social life of the companions of people with multiple sclerosis, it is a low one given the average value (9.03 out of 12). Maintaining an equilibrium between the most important aspects of life (professional, family, health) is quite difficult in the case of companions (average value 9.02 out of 8).

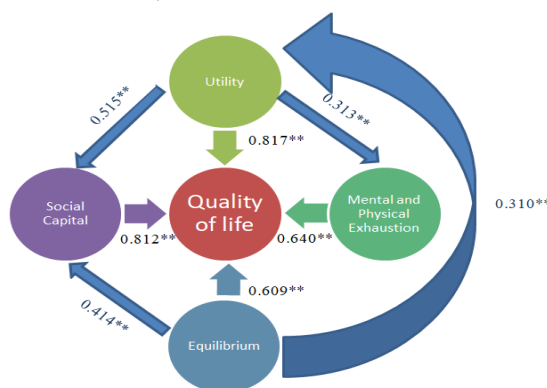


Figure no 1. The influence of variables on the quality of life

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There is a statistically significant direct relationship between Utility, Mental and Physical Exhaustion, Equilibrium, Social Capital and Quality of life ($p < 0.05$). Utility ($r = 0.817$) and Social Capital ($r = 0.812$) strongly influence the quality of life, while Mental and Physical Exhaustion ($r = 0.640$) and Equilibrium ($r = 0.609$) influence the quality of life moderately. In other words, the more the companions of people with multiple sclerosis feel more useful, more helpful and are surrounded and supported by other family members, friends, and close circles, the more the quality of life improves. Also, a high quality of life requires finding an equilibrium between all aspects of life (personal, material, financial, professional, social, emotional, health) so that everyday work and providing for the multiple sclerosis patient does not create a Mental and psychological exhaustion.

Utility influences significantly ($p < 0.05$), directly and with a medium intensity ($r = 0.515$) social relations and with a weak intensity ($r = 0.313$) mental and physical exhaustion. Putting others to use and helping people in the circle of family and friends strengthens and consolidates social relationships, but it can bring a level of stress and physical exhaustion.

Also, a state of equilibrium significantly influences ($p < 0.05$), directly and with a medium intensity ($r = 0.414$) social relations and with a weak intensity ($r = 0.310$) utility. In other words, the more the companion of the multiple sclerosis patient manages to find a balance in his life, the relationships with others become better and they can offer support to other people from their abundance.

V. CONCLUSIONS

The quality of life of families affected by multiple sclerosis is a particularly important and complex aspect. Multiple sclerosis is a chronic neurological condition that affects not only the diagnosed individual, but also the entire family network. Assessing and understanding the impact of the disease on families is essential to develop strategies and interventions that improve their quality of life.

Recent studies and research have shown that families supporting and caring for people affected by multiple sclerosis face many challenges and difficulties. Emotional pressure and increased stress, the need to cope with changes in family dynamics and financial difficulties are just some of the issues that families face on a daily basis. They can negatively influence the quality of life of families and have a significant impact on the physical and mental well-being of family members.

An important aspect in understanding the quality of life of families is identifying the resources and support available to them. Social and emotional support, access to appropriate health services, information and education about the disease, and involvement in community support networks can help increase resilience and improve quality of life for families affected by multiple sclerosis. Counseling and therapy services can provide a safe environment and support in managing emotions and stress, thereby helping to improve the quality of life for families.

In conclusion, the quality of life of families affected by multiple sclerosis must be a central concern in addressing the disease. An integrated and holistic approach is needed, including emotional support, financial support, access to appropriate medical services and information about the disease. By implementing effective interventions and involving all relevant factors, we can improve the quality of life of families affected by multiple sclerosis and contribute to creating a healthier and more favorable environment for all family members.

REFERENCES

- 1) Jelinek, G. (2016) *Overcoming Multiple Sclerosis- The Evidence-based 7 Step Recovery Program*, Ed. Allen & Unwin
- 2) Meyer, E. (2016) *The Culture Map: Decoding How People Think, Lead, and Get Things Done Across Cultures*, Ed. PublicAffairs
- 3) Wilkinson, R., Pickett, K. (2011) *The Spirit Level: Why Greater Equality Makes Societies Stronger*, Ed. Bloomsbury Publishing
- 4) Wilkinson, R., Pickett, K. (2019) *The Inner Level: How More Equal Societies Reduce Stress, Restore Sanity and Improve Everyone's Well-Being*, Ed. Penguin Press
- 5) Bourdieu, P. (2011) *Forms of Capital - General Sociology*, Ed. Wiley-Blackwell
- 6) Putnam, R. (2000) *Bowling Alone: The Collapse and Revival of American Community*, Ed. Simon & Schuster