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The Family of People with Multiple Sclerosis: The Process of Family Stress Adaptation

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Abstract

Background: Multiple Sclerosis (MS) affects everyday functioning of individuals with MS, and their family dynamics. Furthermore, MS is a chronic disease with unpredictable course imposing a stressful experience on the entire family. Changes in family functioning patterns are necessary so that they can appropriately respond to complex demands imposed by the disease.
Objectives: This study aimed to evaluate predictive values of family resources in the encounter with stressful life events and family adaptation. These data are required to provide adequate family support systems.
Methods: The sample consisted of 62 people with MS. The following instruments were used: Family Adaptation Scale, Family Social Support Index, Financial Well-Being Scale, and Family Problem Solving Communication Scale.
Results: The results of this research indicate that subjective assessment of the quality of family relationships, measures of the quality of family communication ($\beta = 0.353$, $P < 0.001$), and measures of perceived family social support ($\beta = 0.272$, $P < 0.05$) are the only predictors of successful family adaptation.
Conclusions: The results infer that the processes essential for successful adaptation of people with MS occurs within their nuclear family. Therefore, adaptation to accidental crisis created by MS onset can be promoted by strengthening support and communication within the nuclear family.

Keywords: Adaptation, Family, Multiple Sclerosis, Psychological, Quality of Life, Relationship, Social Support, Stress

1. Background

Multiple Sclerosis (MS) is a chronic disease that is often referred to as "the thousand faces disease" because it affects many functions and results in a broad spectrum of invalidity (1). It is one of the most common progressive neurodegenerative and demyelinating diseases that is followed by damage to cognitive and motor capabilities of the afflicted person (2, 3). There is a constant increase in individual and family expenditure caused by disease progression (4) and unpredictability. With increasing disability, family social support becomes more important (5). Previous studies have confirmed that patients with MS can live normal lives if they are supported by family, friends, and society (6).

Social support mechanisms of patients have an impact on their quality of life, as well as the way they cope with MS (7). Coping with the loss of functions and external changes in the functioning of a person in all domains of life affects the individual and the family as a whole (8). Individuals afflicted with MS often need help, and this role is most often taken by a family member (9). The caregiver provides assistance with activities of daily living, personal hygiene, and movement (10). Furthermore, MS represents a threat to close family relationships and foremost relationships with children (11). A large number of women with MS decide against maternity (12). If they already have children, MS has a positive effect in developing empathy and increasing maturity in their children in comparison with their peers (13). On the other hand, a chronic disease afflicting the mother leads to negative psychosocial effects on the child (14). The very care for the child is characterized as challenging by those afflicted with MS (15).

The effect on the quality of life is determined by the level of social support, which was confirmed in previous studies (16, 17). Those, who have greater social support have been found to have a better quality of life (18). There is a relationship between the level of perceived social support

and one's level of status perception. Individuals with MS often feel isolated (19), while the entire family is coping with the feeling of helplessness, insecurity, and loss of control over the lives (20).

Families that wish to stay together must cope with many stressful influences that come with this disease. The financial burden on these families drastically increases (21). These families have significantly diminished levels of life quality (22) and, as a result, significant social problems (20). Organizing occupational activities for the afflicted family member (23) and involving a psychologist and a psychiatrist in the support program represents a great challenge.

McCubbin's model of family adjustment and adaptation response model offers a framework for understanding key processes associated with the adaptation to family stress (24). The current research was based on this model because understanding the adjustment processes is key to providing support for families with members afflicted with MS. This framework emphasizes processes involved in the families' efforts to balance between new demands and challenges placed before it and its available resources. This process is called adaptation. Good adaptation implies achieving new balance and harmony in a stressful situation. Key components in this model of family adaptation are stressful life events with special emphasis on chronic stressors; family coping strategies that can be divided to active and passive patterns of behavior that serve to sustain or strengthen the family as a whole; family resources, which can be defined as strengths and abilities that enable it to overcome crisis (cohesion, flexibility, communication, economic stability, social support, and similar constructs) (24, 25).

The assumption of this research was that MS, as a chronic disease, represents a stressful experience that places new demands on the family, forcing it to make significant changes in functioning patterns. These changes are necessary in order to fully integrate the illness in its everyday functioning and adequately respond to new complex challenges. In order to provide the family with adequate systemic support in the process of adaptation, the predictive value of family resources and stressful events on the positive outcome of family adaptation needs to be determined.

2. Methods

A pilot cross-sectional study was carried out in order to determine the predictive value of family resources, coping and stressful events in the adaptation of families with MS.

2.1. Sample

The sample consisted of 62 participants diagnosed with MS according to McDonald criteria (26). The highest percentage of respondents were females (66.1%), with a secondary level of education (62.9%). Their age was between 27 and 60 (M = 47.48, SD = 9.92). The values of the EDSS score (27) was between 0 and 4.5. All the respondents were members of the Multiple Sclerosis Society from different cities (Novi Sad, Sombor, Vršac) in the territory of Autonomous Province of Vojvodina, Republic of Serbia. The research was conducted in 2017 within the settings of these Multiple Sclerosis Societies.

Inclusion criteria were a confirmed diagnosis of relapsing-remitting MS, clinical stability for at least 30 days (without relapse symptoms), and after one year since the initial diagnosis was made prior to the beginning of the study.

In this research, relates to family functioning, and the structure and development phases of the family were taken into account. All people with MS involved in the research were married and had a minimum of one minor child.

Exclusion criteria for the study were the existence of other chronic diseases and psychiatric mental disorders.

Thus, in this way defined demographic, family, and medical criteria for including respondents in the study significantly balanced the pattern and increased objectivity, yet reduced the number of families, who could enter the study.

The descriptive characteristics of the participants are provided in Table 1.

Table 1. Descriptive Characteristics of the Sample

Characteristics	Values
Gender, No. (%)	
Male	21 (34)
Female	41 (66)
Education, No. (%)	
Primary school or less	6 (9.70)
High school	40 (64.51)
College	16 (25.80)
Age, mean ± SD	47.48 ± 9.92

2.2. Ethical Consideration

The study was reviewed and approved by the Ethics Committee of the Medical Faculty, University of Novi Sad, under number 01-2461/1.

The survey respondents were informed about of the study's purpose and methods. Prior to the survey, respondents gave a verbal and written consent to participate in

the study. Completion of the questionnaire was anonymous and in accordance with ethical principles of scientific research.

2.3. Statistical Analysis

All statistical data analyses were performed using the IBM SPSS Statistics for Windows, version 21.0 (IBM Corp., Armork, N.Y., USA). Additionally, the researchers used descriptive statistics, analysis of correlation and hierarchical regression analysis. Hierarchical regression analysis was used in order to determine the effect of predictors on family adaptation. Only a few participants had missing values, which were treated using k-Nearest Neighbors approach in the R software. For calculation of effect size of the model, effect size calculation for hierarchical multiple regression proposed by Soper was used (28). After effect size calculation, the researchers calculated post-hoc statistical power for HMA, using the method proposed by the same author (29).

Statistical significance of each independent variable was obtained using beta coefficients, and results were interpreted applying the odds ratio along with a 95% confidence interval. Values of $P < 0.05$ were considered statistically significant.

2.4. Instruments

All the instruments used in this research were based on the McCubbin's Framework of the Family Adjustment and Adaptation Response model. Free availability of English Instruments were used (30). Based on the recommendations of Guillemin et al. (31), the questionnaire was adapted to meet cross-cultural equivalence. Adaptation included a translation from English to Serbian by two independent translators (native speakers and English teachers) as well as a back translation.

The Family Adaptation Scale (FAS) (32) was used to measure family adaptation. It consists of ten items measured by a seven- point scale. It estimates the participants' satisfaction with their families, the relationships within it and its relationships with the community. This scale had high internal consistency in the original research ($\alpha > 0.85$). The value of Cronbach's alpha in the research was 0.914.

- Family Inventory of Life Events and Changes (FILE) (33) was used to calculate the index of family stress. It represents the frequency of stressful events related to life experiences. It measures the cumulative effect of life events and changes the family has experienced. The FILE is a list of life events and changes in the family, contains of 71 items and the respondent should mark (yes or no) normative or non-normative life event or family tension that happened to a family member or family as a whole in the past year. The level of stress produced by life events is represented by a cumulative score that spans from 0 to 71. The average number of stressful life events in a family reported by participants was 12 (SD = 9.02) spanning from 0 to 40.

- The Social Support Index (SSI) (34) is used to measure the level of informal social support. It estimates the degree to which families receive support from their communities, relatives, friends, and neighbors. It consists of 17 items and participants indicate their responses on a five-point scale. The level of social support can be measured through the value of the summary score. In the original research, the internal consistency index was 0.82. Two subscales stood out in the current research that were related to seeking support from significant others. The first subscale corresponds to seeking support from the community, friends, and relatives, while the second subscale relates to social support received from the nuclear family. The social support within the family subscale and social support from the community and friends subscale correlate weakly between each other (0.326). This shows that there was no ground to use the summation score as a general measure of social support. In the current research the social support within the family subscale had a reliability of 0.71, and the social support received from friends and community had a reliability of 0.80.

- The Financial Well Being Scale (FWB) (35) consists of 13 items that describe the financial stability of a family and its resources. The participants indicate their response on a four-point scale. The summary score indicates the level of family financial security. In other studies, this scale has shown good internal consistency of 0.85 (36), and in the current research, Cronbach's alpha coefficient was 0.77.

- The Family Problem Solving Communication (FPSC) (37) scale represents the measure of positive and negative communication patterns. The researchers asked family members to indicate how much a particular statement characterized their family on a four-point Likert scale. Each of the two subscales had five items and the authors of the scale allowed for the calculation of the summary score as an overall measure of family communication. Other studies have also confirmed high levels of internal consistency and the factorial structure of the questionnaire. In the current research, the Cronbach's alpha coefficient was calculated for the scale as a whole and was 0.84. The summation score was used as a general measure of the quality of communication within the family because the internal structure of the instrument has been checked and it was proven to be one-dimensional.

3. Results

3.1. Descriptive Statistics

In all scales used to measure values, Skewness ranged from -0.922 to 0.066, while Kurtosis ranged from -0.358

to 1.058, indicating that data did not deviate significantly from a normal distribution at any of the variables. Other descriptive data used for each of the scales are shown in Table 2.

The correlations between variables as well as their descriptive statistics are shown in Table 2. The criteria variable (family adaptation) correlated positively with social support from the community and with that from the family, as well as with the quality of communication within the family. The shown correlations of financial well-being did not have a statistically significant correlation with other measures of family relations quality. Other measures that correspond to different indicators of family relations quality achieve low to medium inter-correlation.

3.2. Effects of the Number of Stressors and Different Indicators of Family Life Quality and Relations with the Community on Family Adaptation

This research used hierarchical regression analysis in order to determine the effect of the number of family stressors, financial wellbeing of the family, quality of communication within the family as well as from the community on family adaptation. In the first step of regression analysis, this research introduced the number of stressors as a predictor, while in the second step, the following resources were introduced: Financial wellbeing, family communication quality, and social support in the family and from the community. The model is significant and it explains 32% of the family adaptation variance. As shown in Table 3, only those measures that represent the subjective assessment of the quality of family relations are significant predictors. To be more precise, this was the measure of the family communication quality ($\beta = 0.353$, $P < 0.001$) and the measure of social support within the family ($\beta = 0.272$, $P < 0.05$). Other measures, such as the number of stressors, financial wellbeing of the family, and social support outside of the family did not show significant predictive value. The number of stressors is not a significant predictor of family adaptations neither in the first step nor in the second. Based on the results, it could be concluded that subjective evaluation about constant relations in the family, i.e., family capacities in stressful and non-stressful situations, is predictive of family adaptation. On the other hand, situational and other time-limited factors, such as stressful events and material status and factors that are not directly tied with the family climate do not have a significant degree of predictability on the level of family adaptation. Cohen's f^2 effect size for the model was 0.457. Statistical power was tested post hoc, i.e., after performing the analysis. For effect size of 0.457, one predictor was added in the first step, and additional four in the second step, for P level 0.05, and 62 participants, the statistical power for our model was 0.991.

4. Discussion

It is important to mention that this research was one of the few that focused on the perspective of the patient. Previous studies have stressed that they considered processes and roles within the family the primary focus of their concern (15).

Some of the key factors that significantly endanger family functioning are as follows: MS affects people and their caregivers, at their most productive years of life, usually in young adulthood (38), chronic course of MS (39), and families cannot foresee the relapses, disease progression, or even the everyday functional capacity of the patient (40), and psychological aspects of the patients (41). All of the mentioned factors influence the development of dysfunctionality and the potential emergence of psychological hardship and poor life quality for the afflicted (42), as well as for other family members.

Many studies predict the importance of family functioning as a significant prognostic factor for the course of illnesses (43). This study encompassed two groups of traits that predict family adaptation on MS that have their origin in the family, not in the disease. The first group of predictors consists of stressful experiences with regards to the development and unexpected situations within the family. The second group corresponds to family resources and resilience to stress. Here, the authors considered financial well-being of the family, social support within the family, and from the community and communication within the family.

The results of this research suggest that there is a possibility that the importance of stressful experiences that are MS-specific probably have a high predictive value on family adaptation. However, stressful events that are grounded in everyday experiences do not have predictive value on family adaptation to life with a family member with MS. The subjects that were the topic of usual work with families that have a member with MS have not proven to be relevant in the current mode. Therefore, the researchers recommend that the therapeutic focus should be reoriented towards MS-specific stressors in order to mitigate the family preoccupation with these issues.

Communication between family members in problem situations has a direct effect on family adaptation. This indicates that families with positive and effective communication patterns are better adapted to solve newly formed problems. These findings correspond to other research on families (44).

There are instances in the literature that suggest that families go through a process of testing the trust they have on other people, and sometimes even hide the reality of the family situation (45), and this confirms the significance of communication. It is essential to discuss the

Table 2. Descriptive Statistics and Inter-Correlation Matrix

	1	2	3	4	5	6
1. Family adaptation	1					
2. Number of family stressors	-0.122	1				
3. Family financial well-being	0.149	-0.173	1			
4. Communication quality within the family	0.494[a]	-0.361[a]	0.188	1		
5. Social support within the family	0.476[a]	-0.262[a]	0.184	0.537[a]	1	
6. Social support from the community	0.270[a]	-0.045	0.261[b]	0.216	0.326[a]	1
M	5.23	12	1.39	2.19	3.96	3.52
SD	1.55	9.03	0.48	0.56	0.76	0.75
Range	1 - 7	0 - 40	0 - 3	0 - 3	1 - 5	1 - 5

[a] Correlation significance at P < 0.01.
[b] Correlation significance at P < 0.05.

Table 3. Results of Hierarchical Regression Analysis in Predicting Family Adaptation

Model	R^2	B	SE B	beta	95% CI
I step	0.015				
Number of family stressors		-0.021	0.021	0.122	-0.064, 0.012
II step	0.324				
Number of family stressors		0.015	0.021	0.085	-0.022, 0.045
Financial well-being		0.001	0.007	0.021	-0.662, 643
Family communication quality		0.970	0.374	0.353[a]	0.587, 1.831
Family social support		0.558	0.278	0.272[b]	0.074, 0.973
Community social support		0.215	0.246	0.104	-0.409, 0.448

[a] Correlation significance at P < 0.01.
[b] Correlation significance at P < 0.05.

illness with the children, a lack of information and non-communication often leads to the child's belief that their behavior affects the illness of their parents (46).

The other family resource that has been proven to be an important predictor of adaptation for a family with an MS-afflicted member is social support. Social support within a family is a direct predictor, and social support of the community is a significant correlate of adaptation (17), which was confirmed by other studies (47, 48). The social network that starts within the nuclear family and then spreads in relatives, friends, acquaintances and the wider social background has been recognized as a protective factor that protects from stress and influences recovery from stress (6, 49). The same has been observed with families that have an MS afflicted family member. This support within the family is considered, especially important while adjusting to new demands placed by the disease on the entire family and when there are changes in the family's way of life (44, 50). Family support programs (for instance psychosocial support, family therapy, and so on) prevent such problems (44).

Furthermore, this study, as well as, the previous studies (50), indicate the need for systematic review to examine the current situation in families and levels of support families of people with chronic illnesses have in order to create an appropriate professional intervention strategy.

4.1. Conclusions

The results obtained by this research showed that family resources are a significant factor in the adaptation of family members with MS, and this is in accordance with the model of family stress resiliency (24). This research found a direct effect of family communication and social support within the nuclear family. These findings point to the conclusion that key adaptation factor for families with family members with MS is located within the nuclear family. By strengthening support and communication within the nuclear family, one can improve adaptation to the accidental crisis that happened when MS entered the family.

The importance of this study is that it shows that the process of adaptation in families with a member with MS does not follow the same patterns as in families that do not have this accidental crisis. It is necessary to approach the family through specific problems that are enduring with a special accent on strengthening communication and support between family members.

4.2. Limitations

The most obvious limitation in this research was the small sample size. In order to adjust an appropriate sample size and set the necessary inclusion and exclusion criteria for potential participation, the population was significantly narrowed, and consequently, the sample size was reduced. As this study was the first-of-its-kind in its region and set up as a pilot cross-sectional study, the obtained results could be considered as a significant guideline for the design and implementation of further research.

Another limitation of this study lies in the fact that the study relied on only one member of a family in assessing the family functionality as a whole. For objective comparison, it would be interesting and useful to examine the perceptions of all members and possibly compare the differences in this respect.

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Footnotes

Conflict of Interests: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

Ethical Considerations: The study was reviewed and approved by the Ethics Committee of Medical Faculty, University of Novi Sad, under number 01-2461/1. The survey respondents were informed about of the study's purpose and methods. Prior to the survey, respondents gave a verbal and written consent to participate in the study. Completion of the questionnaire was anonymous and in accordance with ethical principles of scientific research.

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