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Marital life and family adjustment to multiple sclerosis

Abstract: *The functioning of a person affected with a chronic illness within a family is a complex and many-sided issue. As family members form a system reflecting a network of mutual relations, one of the members' illness will affect all those interacting with him / her emotionally. Keeping high-quality marital relations also becomes extremely difficult.*

The research covered 108 families (216 person) divided into three groups. We used an interview, the FACES IV questionnaire based on the Circumplex Model by David H. Olson and Dyadic Adjustment Scale (DAS) developed by Spanier.

Presence of multiple sclerosis (MS) in the family turned out to impact its functioning. The present research has found that the spouses' gender of key importance for the family. Those families in which the woman was ill were characterized by excessive rigidity. On the other hand, where the multiple sclerosis sufferer was male, the system was overly chaotic.

Based on the research, it is highly probable that the majority of families with multiple sclerosis sufferers adjust relatively well to the disease. It can be supposed that the majority of multiple sclerosis affected families have developed an adaptive mechanism that benefits the patient. Supposedly, successful coping with disease may be determined by the caregiver's gender. This does not mean, however, that such families are free from problems. The difficulties relate primarily to communication, excessive autocracy, developing their individuality and autonomy. Therapeutic support for the patient and his / her family should therefore be a vital component of the treatment process.

Keywords : *cohesion, flexibility, gender & family, multiple sclerosis, Olson Circumplex Model, quality of marital life*

Introduction

Multiple sclerosis is a chronic autoimmune illness of the central nervous system, whose origins have not been fully explained to-date (Hemmer, Nessler, Zhou, Kieseier, & Hartung, 2006). The estimated number of people with MS in the world is approximately 2.3 million (Lad et al., 2010; MSIF, 2013). Poland is one of the countries with a high incidence of multiple sclerosis. Epidemiologic studies from Poland showed that the incidence and prevalence of MS has risen in the recent years (Kapica-Topczewska et al., 2018).

Multiple sclerosis holds a special place among nervous system diseases. The condition is characterized by a complex and relatively diverse clinical course and set of symptoms, as the number and location of demyelination sites vary across individuals. As the disease progresses, it is increasingly accompanied by life-changing neurological, psychiatric and psychological manifestations affecting patients and their families. Typical symptoms of multiple sclerosis include pyramidal paresis, deficiency in sensation and motor coordination, blurred vision, dizziness, deficit in sphincter control, pain disorders as well as chronic fatigue

syndrome (Treder & Jodzio, 2014; Ghasemi, Razavi, & Nikzad, 2017). The neurological symptoms intensify with time, as does the disability. Throughout the course of the disease, multiple sclerosis sufferers and their families struggle with a number of problems, such as loss of employment, decline in social position and limited opportunities for activity. Cognitive impairment is an integral component of multiple sclerosis. While a large number of patients will also suffer from depression, they might possibly present with episodes of euphoria, inappropriate laughing/crying, anxiety disorders, bipolar disorder as well as other psychoses (Rodgers & Bland, 1996). Multiple sclerosis, just as any chronic illness, affects not only the sufferers themselves but also their loved ones. This is because the family forms a basic social entity performing multiple functions, including caregiving, economic and socializing ones, for its members. As rightly pointed out by de Barbaro (1999, p. 45-46), “[...] while the family exists for the individual, the individual exists within the family [...]”. Therefore, the family provides one of the crucial impact factors for the life and well-being of the family members, both in good health and in illness.

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Undoubtedly, the life of a family with a chronically ill member is a complex and many-sided issue. An especially interesting systemic approach which helps to understand families struggling with illness is the Olson Circumplex Model (Olson, 2011). The model defines a system through three dimensions: cohesion, flexibility and communication. Cohesion is described as an emotional bond between close family members who at the same time experience a sense of autonomy. Flexibility is defined as the extent and quality of change taking place within family systems (regarding leadership, roles, mutual relationship rules, and stemming from negotiation among family members). Communication is identified as the family members' ability to communicate effectively with each other (Olson, 2011). According to the hypothesis underlying the Olson Circumplex Model, the way in which a system operates is in a curvilinear relationship with its cohesion and flexibility and it is also in direct proportion to the quality of communication. The most efficiently functioning families are those whose levels of cohesion and flexibility are moderate (far from the extremes) and quality (effectiveness) of communication is the highest. As a result, an elevated or reduced level of cohesion and flexibility usually gives rise to family dysfunctions. That being said, Olson (1986) also emphasizes that systems struggling with chronic illness frequently exhibit extreme levels of cohesion and/or flexibility. This is because illness affects the family as a whole in that it leads to conflicts, disrupts communication and imposes new roles (Rolland, 1987; Ochojska, 2000; Bowen, MacLehose, & Beaumont, 2011; Treder-Rochna & Jodzio, 2018).

Many authors believe that family problems are widespread among persons suffering from multiple sclerosis (Long, Glueckauf, & Rasmussen, 1998; Ochojska, 2000), as the disease impacts on all of its members (cf. McPheters & Sandberg, 2010; Treder-Rochna & Jodzio, 2018). However, the situation of spouses of multiple sclerosis patients is particularly difficult and important (Courts, Newton, & McNeal, 2005; Buhse, 2008; Boström & Nilsagård, 2016; Petrikis, Baldouma, Katsanos, Konitsiotis, & Giannopoulos, 2019). Because it is the marital subsystem that forms the foundation for family life (Rostowska, 2008; Hakvoort et al., 2010). According to the spillage perspective (Hakvoort, Bos, Balen, & Hermanns, 2010), the behaviour and emotions of one subsystem spill over onto the other family members. So, if the spouses share a relationship of intimacy and understanding, the same will be true of the relations between other subsystems, e.g. parents – children, siblings. Marital satisfaction, understood as the partners having a subjective feeling that their relationship is successful and sound, provides value for the whole family. It is worthwhile to recall Spanier & Lewis's definition (1980, p. 826) of marital quality described as a subjective evaluation of a married couple's relationship on a number of dimensions and assessments.

Multiple sclerosis considerably affects the quality of a relationship (cf. McPheters & Sandberg, 2010; Tompkins, Roeder, Thomas, & Koch, 2013; Samios, Pakenham,

& O'Brien, 2015). The illness makes every day routines difficult, disturbing the balance in mutual relations. The healthy partner takes over the majority of tasks and the sufferer feels useless and unnecessary. In families struggling with multiple sclerosis, there is a regular occurrence of the healthy spouses being overburdened with care-taking. The wives of patients (Eriksson & Svedlund, 2006) are especially overwhelmed, which has no small effect on marital relations. The wives of multiple sclerosis patients notice a decline in marital satisfaction as early as in the first year after the disease is ascertained (Samios et al., 2015). The husband's illness negatively affects nearly all areas of marital arrangements, especially satisfaction, intimacy and passion (Keykhaei, Navidian, Mahmoud, Faghihi, & Alikhah, 2016). Finlayson & Cho (2008) report that patient care is a huge challenge where cognitive impairment and loss of independence are the case. Moreover, the marital bond and intimacy are disrupted by sexual dysfunctions, cognitive problems, fatigue, deteriorating disability, communication difficulties as well as the need for changing plans, goals and expectations. The couples who fail to deal successfully with a chronic illness usually cannot develop any effective coping strategies for a major crisis. In doing so, they fall back on previous patterns of action which turn out to be maladaptive under the circumstances. Moreover, the weakened marital bond affects the sufferer's health condition, contributing frequently to exacerbation of the disease and shorter periods of remission (Starks, Morris, Yorkston, Gray, & Johnson, 2010).

Also, the disease makes divorce more probable. It is estimated that 66 per cent of married couples fall apart especially when the multiple sclerosis sufferer is a woman (cf. Glantz et al., 2009; Pflieger, Flachs, & Koch-Henriksen, 2010). It has been established that the female gender, early detection (before the age of 36) and an absence of offspring increase the risk of the relationship falling apart (Pflieger et al., 2010). The healthy partners often find themselves unable to deal with the burden of the disease or adjust themselves to the resulting changes. The need to take care of the patient diminishes the physical fitness and the emotional condition of the married couple, while also cramping their social interactions (McKeown, Porter-Armstrong, & Baxter, 2003). Care providers looking after a multiple sclerosis sufferer are more exposed to the risk of depression, anxiety disorders, elevated levels of stress and inferior quality of living, compared to those taking care of persons suffering from other diseases (Aronson, 1997; Buhse, 2008; McPheters & Sandberg, 2010).

The primary literature also provides opposing opinions whereby a diseased partner may strengthen the marital subsystem, create opportunities for personal growth and give life a new purpose (cf. Rodgers & Calder, 1990; Ackroyd et al., 2011). Some of the couples examined by Rodgers & Calder (1990) declared that their responses had become better thanks to illness. This research shows that couples who successfully adapt to the disease display cohesive communicative styles and

coping strategies in difficult situations. Also, healthy spouses regard excessive responsibility as an opportunity to build deeper relations. However, a necessary condition is to maintain social interactions and one's own identity. At the same time, the spouses try to downplay the presence of multiple sclerosis, re-evaluate their expectations and show each other mutual respect (Starks et al., 2010; Boland, Levack, Hudson, & Bell, 2012).

According to the assumptions of the systemic theory, marriage forms the foundation for every family. A healthy and balanced relationship gives a sense of security and predictability, especially in a situation of change. It also supports and protects the entire system from the negative impact of stress (Rostowska, 2008; Hakvoort et al., 2010). Marriage forms the foundation for every family, contributing to better mental and physical health, for both men and women, longevity and financial prosperity, as well as enhancing the well-being of children (cf. Gove, 1973; Waite & Gallagher, 2000; Kim & McKenry, 2002; Carr & Springer, 2010; Hakvoort et al., 2010). At the same time, the take-over by one of the spouses of the role of care-giver is not without impact on the family (cf. Ross, Mirowsky, & Goldsteen, 1990; Perrone, Gordon, & Tschopp, 2006). Unfortunately, the disease is also known to erode the marital bond and so the family atmosphere turns sour. It is key for the spouse of a person with multiple sclerosis to take care of his/her own well-being and mental condition. That is why it is necessary to place the patient and his / her loved ones in a therapy programme.

The generally defined primary purpose of this research was a multidimensional and systemically profiled diagnosis of the functioning of families with persons with multiple sclerosis. The research focused on the perceptions of the family by both spouses, one of whom has been suffering from multiple sclerosis for a number of years.

The following specific goals have been identified:

- Identify the characteristic traits of the functioning of a family with a multiple sclerosis patient as perceived by the sufferer and his/her spouse.
- Identify the psychological structure and quality of the marital relations of MS sufferers.
- Determine the impact of the gender of spouses (healthy vs. ill) on selected aspects of the functioning of a family with an MS sufferer.
- Identify hypothetical psychosocial problems experienced by MS patients and their spouses.

While the question of families struggling against multiple sclerosis has received extensive treatment in psychological literature, the information on how such families function remains incomplete and rather incoherent. Surveys prevail, often on the phone. In addition, in most cases, important variables such as age, education, marriage or the family life cycle stage in which the family is located were not controlled. There is a small number of holistic studies that concern families suffering with

multiple sclerosis. Researchers tend to focus on the patients, less often on healthy spouses.

To my knowledge, my study is a first attempt to assess the results of family function with a multiple sclerosis patient in Poland, having at the same time situations of spouses of MS patients and the stages within the family life cycle. Thus, the research carried out is both of a global nature - they refer to the functioning of the family as well as structural - as they concern its members. The research tests also consider the MS patient's gender to show the differences in family functioning depending on the subject's gender.

The research was based on Olson's Circumplex Model (which is of a highly usable and universal nature), while taking care to fulfil the representativeness criteria for the samples. This means that the results can be generalized to a broader population of Western people.

Also, introducing control group II (a family in which one spouse suffered spinal cord injury having the clinical form of paraplegia) has made it possible to show the distinct model of functioning of MS families, which is a rare research theme. Researchers usually compare families with a sick person with families free from chronic diseases, which is too much of a simplification.

Method

Participants and Procedure

All participants gave consent to participate and the study was approved by the Polish Multiple Sclerosis Society (PTSR), the Pope John Paul II Center of Rehabilitation for People with Multiple Sclerosis in Borne Sulinowo and the Polish Association of Disabled.

The research covered 108 families (216 person - wives and husbands), aged from 40 to 64 ($SD = 4.46$), divided into three groups: the clinical group (multiple sclerosis group, MSG), control group no. 1 (healthy group, CI) and control group no. 2 (paraplegia group, CII). The clinical group (43 families, 86 person) consisted of families with a multiple sclerosis sufferer. The first control group (35 families, 70 person) comprised family systems free from chronic diseases, while the second control group (30 families, 60 person) was composed of families with one of the spouses suffering from spinal cord injury having the clinical form of paraplegia.

Both spouses (ill and healthy) were always examined. All study subjects were in legally recognized marriages. The investigation targeted full families having at least one child. A considerable portion of the families were in the fifth stage of the family life cycle when children leave the family home, with the mother and father being tasked to help them navigate through life choices and achieve independence. The stage within the family life cycle was determined based on an interview, as dictated by the model proposed by Evelyn Duvall (1977).

No statistically significant differences were noticed between the groups as to age ($F(2, 213) = 1.47, p = .23$), number of years in marriage ($F(2, 213) = 1.74, p = .17$) or number of years of school education ($F(2, 213) = 2.03$,

$p = .13$). Selected demographic parameters characterizing the study subjects have been presented in table 1. However, differences were observed in the distribution of the gender factor across the sufferers in the clinical and second control groups ($\chi^2(1, N = 73) = 7.06, p < .01$). Specifically, the incidence of MS was higher for women in the MSG and for men in CII. The differences arise from the nature of the disease. Multiple sclerosis affects mainly women. At the same time, 80-85% of spinal cord injuries are encountered in males (Kiwerski, Kowalski, & Krasuski, 1997).

In addition, none of the examined families participated in family therapy or in marital therapy. However, many families declared a willingness to participate in such therapy - especially families with a multiple sclerosis sufferer.

A total of 43 MS patients were examined (including 58% of women and 42% of men). The average time-span of the disease was 20.04 (SD = 8.41). The relapsing-remitting variant of the disease predominated (48%). Most of the patients required aid to move (a cane, crutch or walking frame). The most commonly cited symptom was fatigue (98%), followed in descending order of frequency by balance or coordination problems, physical limitations (e.g., diminished strength and stamina), sleep disorders, motor dysfunction, cognitive difficulties, sexual dysfunction.

All assessments were carried out by the author. Participants from all groups were examined individually. The sessions lasted about 90 minutes. Before being included in the research all MS patients had been assessed through Mini-Mental State Examination (MMSE) and Beck Depression Inventory (BDI). All patients with an MMSE score lower than 20 or displaying signs of major depression (BDI above 27 points) were excluded from the research. Prior to the study, written informed consent was obtained from all participants.

The protocol was approved by the Ethics Board for Research Projects at the Institute of Psychology, University of Gdansk, Poland. After completing the research, the participants were told about the aim of the study, thanked, and fully debriefed.

Measures

Clinical interview with the sufferer and his / her spouse was the research tool. Clinical interview included, inter alia, questions concerning basic socio-demographic

data, the duration of marriage, as well as information about the patient's illness.

The main family assessment instrument was the FACES IV questionnaire based on the Circumplex Model by David H. Olson (2011) adapted for use in Poland by Margasiński, (2013), the Polish translation is called FACES IV-SOR (SOR). The test has good psychometric properties: the reliability of given SOR scales, determined with Cronbach's alpha coefficient, ranges between .70 and .93. Polish normalization was performed on a group of 499 Polish individuals from 150 families. The confirmatory factor analysis reflected the original test structure.

The questionnaire consisted of 62 items grouped into 8 principal scales: Balanced Cohesion, Balanced Flexibility, Disengagement, Enmeshment, Rigidity, Chaos, Family Communication Scale, Family Satisfaction Scale. A psychometric interpretation of the results is in order. The family systems operates beneficially depending on how high it has scored on the Balanced Cohesion and Balanced Flexibility Scales, as opposed to scores on the Imbalance scales where a high score on Disengagement, Enmeshment, Rigidity and Chaos means that the family system works badly (Olson, 2011).

The quality of marriage was assessed using The Dyadic Adjustment Scale (DAS) developed by Spanier (1976), adapted for use in Poland Cieślak (1989). The Polish version of the DAS showed satisfactory internal consistency: Cronbach's α at .89 for the entire questionnaire, .85 for dyadic consensus, .89 for dyadic satisfaction, .78 for dyadic cohesion and .67 for affectional expression (Cieślak, 1989). The scale distinguishes four aspects of marital adaptation, namely: Dyadic Consensus, Dyadic Cohesion, Dyadic Satisfaction, Affectional Expression.

A general score is calculated as a sum of scores obtained for the individual statements. The scores are given on a scale of 0 to 151. The Polish adaptation produced by Cieślak (1989) specifies that a mean score obtained by women is 110.09 (SD = 18.6) and 109.83 (SD = 17.3) for men. A score below 100 is considered to be low, while scores above 115 high (Cieślak, 1989).

Results

The initial statistical analysis focused on inter-group differences in the functioning of the family. An arithmetic

Table 1. Selected demographic parameters characterizing the study subjects: means (standard deviation in brackets), variability bands (minimum to maximum variable value).

	Multiple Sclerosis Group (MSG)	Healthy Group (CI)	Paraplegia Group (CII)
Age	52.97 (4.91) 40-63	53.83 (4.38) 43-64	54.21 (4.08) 43-63
Education	13.19 (2.36) 8-17	14.04 (2.71) 8-19	13.42 (2.76) 8-19
Length of marriage	28.34 (4.71) 10-40	28.8 (4.08) 20-39	29.63 (3.05) 23-36

mean was calculated from the scores obtained by both spouses on the individual scales in FACES IV questionnaire. This was done to establish the manner in which the family is perceived to function by the spouses. The analyses used one-way between-groups ANOVA and a post hoc Tukey test for comparison purpose. The dependent variables were expressed each time as the average of scores awarded to the spouses on the individual scales in the FACES IV questionnaire. Independent variables were defined as membership in one of the surveyed groups (MSG \times CI \times CII). The mean scores with F statistics (*F-test*) are presented in Table 2.

Families with a person suffering from MS and those with a paraplegic person scored significantly lower on the Balanced Cohesion scale than the group with families free from chronic illness ($F(2, 105) = 11.99, p < .001$). Two cohesion levels are present: low (disengaged systems) and high (enmeshed systems). A statistically significant difference was observed between the groups related to the intensity level of cohesion: disengagement ($F(2, 105) = 11.37, p < .001$) and enmeshment ($F(2, 105) = 4.76, p < .01$). Compared to CI families, MSG families obtained a considerably higher score on the Enmeshment scale. No inter-group differences were observed between the CI and CII groups. A statistically significant difference was also observed on the Balanced Flexibility scale ($F(2, 105) = 6.74, p < .01$). The families in the CII group scored lower than those in the CI group, but no inter-group differences were observed between MSG on the one hand and CI and CII on the other hand. The surveyed groups differed in the intensity of extreme flexibility levels: low (rigid systems)

and high (chaotic systems). Compared to CI families, MSG families obtained a considerably higher score on the Rigidity scale ($F(2, 105) = 13.61, p < .001$). In terms of chaos, families with a paraplegic person obtained a significantly higher score than those with an MS sufferer and those free from chronic diseases ($F(2, 105) = 4.55, p < .05$). Furthermore, families with an MS sufferer also scored better than CII families on communication ($F(2, 105) = 3.38, p < .05$) and family life satisfaction ($F(2, 105) = 3.14, p < .05$).

As the next step, marital life was evaluated. The analyses used one-way between-groups ANOVA and a post hoc Tukey test for comparison purpose. The dependent variables were the average of the scores obtained by the spouses in the individual scales of Spanier's DAS questionnaire. The independent variable was defined as membership in one of the surveyed groups (MSG \times CI \times CII). The mean scores with F statistics are presented in Table 3.

The data in Table 3 show that like married couples free from chronic diseases, those having an MS sufferer rated their general relationship quality as better than married couples with a paraplegic person ($F(2, 105) = 6.63, p < .01$). Married couples with an MS sufferer also scored higher than those with a paraplegic person on the individual components of marital quality, i.e. cohesion ($F(2, 105) = 6.55, p < .01$), satisfaction ($F(2, 105) = 8.62, p < .001$) and affectional expression ($F(2, 105) = 16.04, p < .001$). No statistically significant differences were identified based on the DAS questionnaire subscales between married couples with an MS sufferer and those free from chronic diseases.

Table 2. Inter-group differences in the functioning of the family on the individual scales in FACES IV questionnaire (SD in brackets).

	Multiple Sclerosis Group (MSG) n = 43	Healthy Group (CI) n = 35	Paraplegia Group (CII) n = 30	F
Balanced Cohesion	27.01 (4.31) a	30.57 (4.79) b	27.95 (4.23) a	11.99***
Balanced Flexibility	24.77 (4.65) ab	27.62 (4.91) b	23.56 (4.43) a	6.74**
Disengagement	15.03 (3.82) a	12.58 (4.99) b	17.51 (3.45) c	11.37***
Enmeshment	17.86 (4.79) a	17.74 (3.55) b	16.71 (6.31) ab	4.76**
Rigidity	20.57 (4.02) a	14.51 (3.08) b	21.91 (3.24) a	13.61***
Chaos	17.51 (5.55) a	17.08 (3.77) a	19.67 (3.81) b	4.55*
Family Communication	37.92 (6.77) a	39.66 (8.95) a	34.38 (6.26) b	3.14*
Family Satisfaction	40.19 (5.35) a	39.98 (8.25) ab	36.94 (4.23) b	3.38*

Mean marked with the same letter (a, b or c) do not statistically significantly differ between groups at the level .05 (post hoc Turkey test).

* $p < .05$; ** $p < .01$; *** $p < .001$.

Table 3. Inter-group differences of the marital life in the individual scales of Spanier's DAS questionnaire (SD in brackets).

	Multiple Sclerosis Group (MSG) n = 43	Healthy Group (CI) n = 35	Paraplegia Group (CII) n = 30	F
General Score	111.99 (11.16) a	112.44 (20.02) a	99.03 (12.55) b	6.63**
Dyadic Consensus	49.63 (8.94) a	50.41 (5.81) a	49.06 (5.99) a	0.16
Dyadic Satisfaction	35.74 (6.09) a	37.14 (6.49) a	30.86 (6.53) b	8.62***
Affectional Expression	8.61 (2.04) a	9.35 (2.15) a	6.83 (2.42) b	16.04***
Dyadic Cohesion	16.18 (3.19) a	15.66 (4.36) a	13.27 (3.38) b	6.55**

Mean marked with the same letter (a, b or c) do not statistically significantly differ between groups at the level 0.05 (post hoc Turkey test).

* $p < .05$; ** $p < .01$; *** $p < .001$.

An important modifier of the manner in which families function was the sufferer's and healthy spouse's gender, which was considered in the further stages of the analysis. A two-way ANOVA was performed in a 2 gender (males vs. females) \times 2 health condition (MS individuals vs. healthy individuals) setting where the dependent variable was represented by the scores obtained on each FACES IV scale. Separate analyses were conducted for each individual scale.

A two-way ANOVA was performed for the total score on the Rigidity scale of the FACES IV questionnaire. The results showed no significant main effects for gender ($F(1, 82) = 3.12, p = .08$) and health condition ($F(1, 82) = .02, p = .89$) for the Rigidity scale. The interaction model of both factors was statistically significant ($F(1, 82) = 19.48, p < .001; \eta^2 = .19$) (cf. Fig 1). Simple effect tests comparing the individual pairs of means showed that diseased women obtained significantly higher scores than diseased men on the Rigidity scale. The relationship was not significant for healthy spouses. Sick women also obtained significantly higher results on the Rigidity scale than healthy women.

The results showed no significant main effects for gender ($F(1, 82) = 1.11, p = .29$) and health condition ($F(1, 82) = 3.42, p = .07$) for the Chaos scale. A statistically significant interaction effect of gender and health condition was observed for the Chaos scale ($F(1, 82) = 7.03, p < .01; \eta^2 = .08$) (cf. Fig. 2). Simple effect tests comparing the individual pairs of means showed that healthy women obtained significantly higher scores on the Chaos scale than healthy men. This relationship was nonsignificant, however, for diseased persons. Moreover, healthy women scored higher than diseased women.

As the next step, a two-way analysis of variance was performed for the total score on the Communication scale. The results showed no significant main effects for gender ($F(1, 82) = .86, p = .77$) and health condition ($F(1, 82) = .88, p = .35$) for the Communication scale. A statistically

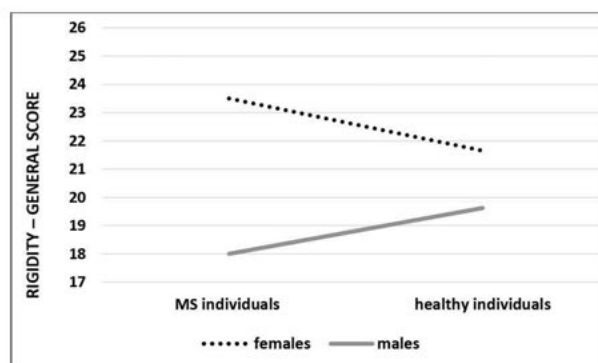


Figure 1. Rigidity scale of the FACES IV questionnaire - the interaction model of both factors.

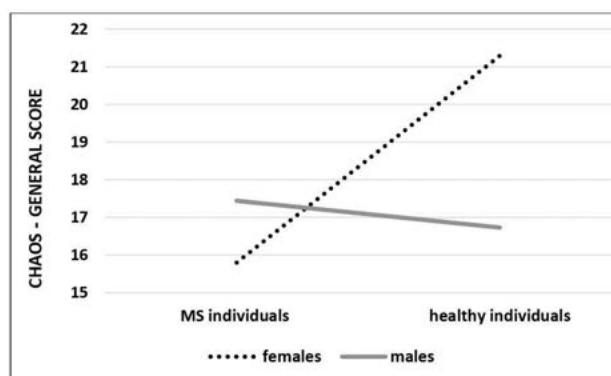


Figure 2. Chaos scale of the FACES IV questionnaire - the interaction effect of both factors.

significant effect of interaction between health condition and gender was confirmed ($F(1, 82) = 9.45, p < .01; \eta^2 = .17$) (cf. Fig. 3). Simple effect tests comparing the individual pairs of means showed that diseased women obtained significantly lower scores on the Communication scale than diseased men. Healthy women obtained significantly higher scores on the Communication scale than healthy men. Healthy women also scored significantly

higher than diseased women. Remarkably, the specified profiles are complementary or inverted in relation to each other, and in statistical terms, they resemble the cross interaction model. This implies that diseases invert the character of relationships determined by gender.

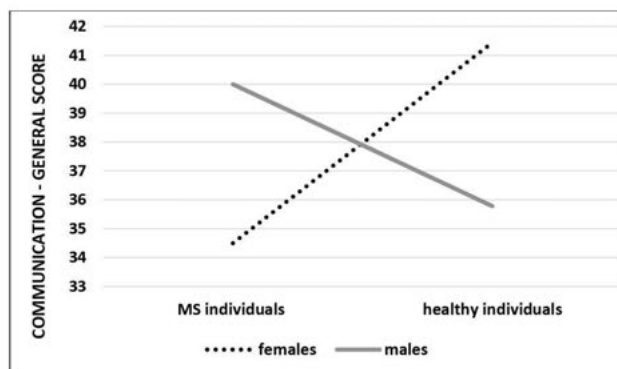


Figure 3. Communication scale of the FACES IV questionnaire - the interaction effect of both factors.

Discussion

Multiple sclerosis undoubtedly affects all areas of family functioning, adaptation and quality of life (cf. Ochojska, 2000; McPheters & Sandberg, 2010; Treder-Rochna & Jodzio, 2018). Consequently, MS affects not only the patients themselves but also their families. It is worth noting that MS holds a special place among nervous system abnormalities because it is a chronic and incurable illness, which, in addition to neurological symptoms, may possibly be accompanied by psychiatric and psychological symptoms (Rodgers & Bland, 1996; Ghasemi et al., 2017). Moreover, Poland is one of the countries with the highest incidence of MS (Kapica-Topczewska et al., 2018).

In the context of the present research, it has been established that MS not only affects the functioning of the family, but it also affects to a large extent the healthy spouse through its consequences. Most of the families with MS sufferers had good skills in coping with change. The obtained results are consistent with the data published by other authors (Ochojska, 2000; Bowen et al., 2011). However, there are cases of overly rigid families, especially where the sufferer was a female. Such families are characterised by an autocratic, overly harsh style of upbringing; low problem-solving skills; excessively stereotypical roles; and many clearly articulated rigid and strictly enforced rules. The functions are clearly established, and their range is very limited. The rules, once made, are never changed. The model is characterised by a clear hierarchy of roles and rules, which are usually linked to the father's key position as the head of the household. It can be surmised that the dominating position is assumed by the healthy spouse who introduces clear rules, exerts forceful control and adopts an autocratic style of management. Rigid family systems are characterised by emotional distance and a fear of open expression of feelings (Olson & Gorall, 2006), thereby making commu-

nication difficult. According to previous research, family systems in which the man adopts care-giving duties towards his spouse who is suffering from MS are characterised by numerous communication problems (Good, Boower, & Einsporn, 1995). Moreover, the diseased women who were surveyed rated communication as being less effective than the diseased men did.

A reverse pattern occurs in terms of flexibility when the MS sufferer was male: the healthy wife then rated their families as being chaotic, that is to say, devoid of leadership, discipline or clear rules. Thus, it can be supposed that the life situation in this case has caused the husband's status to change. On the one hand, he has ceased to be the head of the household, and on the other hand, there is no one to assume his role, thus fuelling the sense of chaos, unease and passivity. Interestingly, families with a paraplegic person were characterised by excessive chaos. It is worth noting that the majority of study subjects in this group were men, which probably implies that they had ceased to play a dominant role in their family system. In these families, there was a lack of clear leadership, appropriate discipline or fixed and clear rules. Changes in rules are frequent, perhaps even dramatic, with constant, never-ending negotiations. It is also possible that the paraplegic spouse has ceased to be a partner, because he has failed to meet his wife's expectations. Male disability generates the need for the wife to adopt his tasks. Consequently, women feel overwhelmed with too many obligations. This is observed in the wives of patients with MS (Eriksson & Svedlund, 2006). Many authors believe that taking care of a sick person may lead to physical or mental strain, mood swings and a feeling of isolation or maladjustment (Aronson, 1997; Gibson & Frank, 2002; McKeown et al., 2003; Patti et al., 2007; Buhse, 2008).

These conclusions were confirmed by the results of the author's own research on the quality of marital life. That is, spouses struggling with paraplegia rated their relationship as unsatisfactory and did not express emotions or attachment to each other. However, couples struggling with MS evaluated the quality of their marital life differently. Despite the difficulties, they considered their marriage to be successful and satisfactory. The results suggest that when facing a crisis such as a chronic illness, the spouses would take care of and show emotions to each other. The illness had strengthened the marital subsystem, making it more cohesive and integrated. It should be noted that 98 per cent of the study cases never thought or talked about divorce. It is highly probable that families taking care of an MS sufferer form a strong marital coalition. The study subjects' relationship was a long-standing one. It is possible that many of these couples had managed to overcome the limitations caused by the disease. The present results are consistent with the data from other authors (Rodgers & Calder, 1990; Starks et al., 2010; Boland et al., 2012). The researchers believe that an illness in an adult strengthens the marital subsystem, making it more cohesive and integrated. It should be noted here that when enjoying a high quality of marriage, partners thrive emotionally (Hoover, 2004) and cope better with stress

(McPheters & Sandberg, 2010), which provides benefits for the well-being of the entire family (Hakvoort et al., 2010). The literature also provides contrasting opinions (Ochojska, 2000; Courts et al., 2005). For example, those examined by Ochojska (2000) stressed that their marital life was abound with conflicts and considered their mutual relations to have deteriorated significantly. Moreover, the majority of authors thought that the quality of marital relationships with one of the partners suffering from MS is considerably lower than that of the general population (cf. Ochojska, 2000; Tompkins et al., 2013), especially when the sufferer is male (McPheters & Sandberg, 2010; Samios et al., 2015).

The present research suggests that the majority of families struggling with MS adapt relatively well to the disease. The study subjects were satisfied with their family life. It was found that bonds between the spouses were strong and the partners cared for and showed attachment to each other. Supposedly, successful coping with the disease may be determined by the caregiver's and patient's gender. It should be noted here that diseased women adapt better to the illness than diseased men (Casetta et al., 2009; Neves, Rente, Ferreira, & Garrett, 2017). Furthermore, Casetta et al. (2009) suggested that women are more flexible and cope better with disabilities. A previous study also showed that men taking care of their wives with MS enjoy a better quality of life than women taking care of their sick husbands (Patti et al., 2007; Neves et al., 2017).

Undoubtedly, the disease alters family arrangements in that it calls for the reorganisation of the family system. It is therefore necessary to examine the family in the context of the need for a constant struggle against a terminal, chronic and unpredictable illness such as MS. In examining the problems related to the functioning of families struggling with a chronic illness, as pointed out by Anne M. Meijer and Louis Oppenheimer (the creators of the excitation-adaptation model, 1995), it should be remembered that what is untypical and out of order in family systems free from illnesses may be typical or even beneficial in families with a sick person. It is possible that low flexibility seen typically in the surveyed families with an MS woman has an adaptive role, as it provides a sense of security and predictability under difficult conditions. Leadership eliminates a sense of chaos and insecurity. This, however, does not mean that such families are free from problems. As mentioned earlier, the difficulties are related primarily to communication. Moreover, a family's low flexibility leads to excessive autocracy. A statement provided by the daughter (an adult woman) of a female MS patient is remarkable in that context: "This is just the way it is. Dad is always right. I know there is no point in arguing."

It should be noted here that the majority of the surveyed families taking care of MS sufferers were characterised by excessive cohesion. Such families share close emotional relations and mutual loyalty, but have a tendency for excessive identification. An elevated level of cohesion may be seen as "a positive adaptive mechanism," which should come as a natural systemic response

to a crisis in the form of illness (Meijer and Oppenheimer, 1995). Certainly, tight emotional bonds typically observed in families with an MS sufferer are advantageous under the conditions of a chronic illness. An atmosphere of closeness provides a sense of security and readiness to give help, but it may also make it difficult or impossible for the other family members to develop their individuality and autonomy. An unreasonably strong focus on the family seems to be disadvantageous for the adult children of MS sufferers (cf. Treder-Rochna & Jodzio, 2018).

Research suggests that the majority of the studied families with an MS patient develop an adaptive mechanism that psychologically benefits the patient. However, this does not mean that such families are free from problems and setbacks; rather, it implies the need for psychological aid for the patient and his/her family as a crucial element of the diagnostic and therapeutic process.

A particular area of concern is high rigidity typically associated with families with an MS sufferer. Therapeutic efforts should aim to increase flexibility and reduce autocratic management styles. The key task is to improve communication, practice openness, reduce emotional distance between family members, teach free expression of feelings, and allow to clearly articulate one's needs. Excessive rigidity often results in overprotective treatment of the patient (Barbaro, 1999). Initially, this seems to benefit the patient, but in the long term, it contributes to dependence, lack of autonomy, feelings of inadequacy and helplessness, and excessive reliance on others, as well as exclusion from family life (being labelled as sick) and partner strain. Overcoming these defective mechanisms not only reduces the healthy spouse's burden but also improves the patient's self-esteem.

Another cause for alarm is the family's high cohesion. It is possible that families with an MS sufferer are affected by emotional entanglement or disproportional closeness, which—though a source of safety and support under normal circumstances—turns into co-dependence. This seems to be unfavourable to the children of MS sufferers. As the problem is complex and multi-faceted, it has been described in a separate earlier article (cf. Treder-Rochna & Jodzio, 2018). Nonetheless, therapeutic efforts should aim to eliminate dysfunctional modes of family functioning, leading to parentification and children having difficulty in becoming independent and leaving the family home (*ibid*).

Therapeutic intervention allows correcting unhelpful modes of functioning, e.g. overprotectiveness, spousal neediness (hypothetical mechanism for families with an MS female) and dedication or self-sacrifice for the sick spouse (hypothetical mechanism for families with an MS male). It is crucial for the psychologist to find a balance between daily care and individual identity through teaching the healthy spouse how to self-care and address one's feelings and needs. It seems necessary to incorporate various forms of counselling for couples into the general treatment programme for MS. This will enable to prevent many difficulties—or at least minimise their destructive influence—by working to avoid a profound dysfunctionality. Some married couples require intensive therapy, while for

others, educational measures and periodical interventions will suffice to normalise their functioning in a difficult situation and maximise their own potential.

Limitations

Even at the outset of this project, it was obvious that it would be impossible to meet all the methodological requirements. Research into the functioning of the family in the context of a systemic approach has to overcome numerous complications brought about by the necessity to simultaneously describe multiple variables related to the family structure, its dynamics and the interactions taking place between the individual family members. In the face of a rich and complex reality of living in a family, the question suggests itself: is it possible to provide a full description of how families operate? Despite these difficulties, an attempt was made at a psychological analysis of family systems with a multiple sclerosis patient. However, it has become very difficult to reach a large number of such people. As clinical experience indicates, some of multiple sclerosis sufferers are single, as they had decided, in view of their health condition, not to start a family. The varied clinical picture and progressing disability make it difficult to uphold partner relations and to start a family. Moreover, a large number of patients are separated or divorced (cf. Glantz et al., 2009; Pflieger et al., 2010). A large portion of married couples, in which one of the spouses has multiple sclerosis are childless.

Doubts arise as to reference group II (families where a spouse has suffered spinal cord damage presenting clinically as paraplegia). I still think that comparing – exclusively – families with a sick person to families free from chronic illness is too much of a simplification. In such a case, it is difficult to determine whether the observed results (dependencies) are universal, i.e. typical of the majority of affected patients, or specifically associated with a particular patient group. Reference group II has been included with the aim of establishing distinct hypothetical models of functioning exhibited by families struggling with various diseases (multiple sclerosis, paraplegia). Separate treatment would be in order for the collected material on the functioning of families with paraplegia, an issue which this article has only hinted at. Those affected had reported severe and numerous psychological and social problems, even in comparison with the families of multiple sclerosis sufferers.

Compliance with Ethical Standards

The author declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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