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*Roxana Elena BLIUC, Andrei Ioan COSTEA,
Cozmin MIHAI, Sorin Ioan STRATULAT*

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The Role of Family in Medical Rehabilitation

Roxana Elena BLIUC¹, Andrei Ioan COSTEA², Cozmin MIHAI³,
Sorin Ioan STRATULAT⁴

Abstract

Medical rehabilitation is a lengthy process which implies the intervention of a multidisciplinary team and which challenges the patients' and their families' physical, psychological and financial resources. The family can be partner in providing medical care, a source of information or even a beneficiary of care in the situations in which caring for the patient leads to burnout. The patients surveyed within the research conducted at the Clinic for Medical Recovery, Physical Medicine and Balneoclimatology from Iasi, between October 2012 and December 2015, generally reported that, although the family, friends and neighbours play an important role in maintaining the quality of life for the medically rehabilitated patients, the physical and emotional support provided by them is insufficient. The results of the study recommend the family-centred care, as opposed to the approach centred only on the patient. By maintaining a close relation to the patient's next of kin, through programs for educating family members and by acquiring patients' individual needs from family sources the medical personnel can help the patients benefit from more help from their families.

Keywords: medical rehabilitation, home care, family, disability, family-centred care.

¹ "Gr. T. Popa" University of Medicine and Pharmacy, Iasi, ROMANIA.
E-mail: roxana.bliuc@gmail.com

² Stefan cel Mare University, Faculty of Sports and Physical Education, Suceava, ROMANIA. E-mail: drandreicostea@gmail.com

³ "Gr. T. Popa" University of Medicine and Pharmacy, Iasi, ROMANIA.
E-mail: dr.cozminmihai@gmail.com (Corresponding author).

⁴ "Gr. T. Popa" University of Medicine and Pharmacy, Iasi, ROMANIA.
E-mail: dr_sorin_stratulat@yahoo.com

Introduction

Medical rehabilitation concerns a wide range of diseases that affect patients from all social environments. Rehabilitation combines medical practice with principles of medical ethics, elements of social science and psychology in a collaborative attempt with the purpose of easing the sick person's sufferance, by improving the quality of life and functional capacity. Medical rehabilitation is not an isolated medical act performed by one medical specialist, but a dynamic and complex process, which expands over time and which involves, on one side, specialists from various medical fields, and on the other side, the patient and his family, who represent another important pillar in the patient's recovery. All channels of communication should be used, because there is tendency often noticed with families to avoid discussions about the disease, even if this constitutes the centre of concern of all the people affected by it. The main reason is the social stigma associated with certain diseases (Masoudi *et al.*, 2017). Thus, the specialist could recommend the family to contact other families in the same situation in order to create support groups. The treatment schedule can be adapted according to the family daily routine. Confidentiality must also take into account the family's right to privacy, not only the patient's (Rawson *et al.*, 2016).

Even in cases of severe disability, with minimum chances of progress, the family represent a stability factor in the unpredictable context of the affliction. Socialisation plays an important role in preventing disability, especially with elderly people, most probably because it helps them retain their cognitive capacities, which in their turn engage the motor ones (Makizako *et al.*, 2015). Choosing the correct way of involving the family in medical rehabilitation depends largely on the social norms of the community. The family can be a partner in ensuring medical assistance, a source of information or even a beneficiary of care. It is commonly known that a relative's disability can lead to depression, locomotive apparatus diseases caused by the patients' motion efforts, sleep disorders and even chronic diseases, such as diabetes or cardiovascular diseases (Riffin, Fried, & Pillemer, 2016; Rochette *et al.*, 2014). In situations of lack of discernment, family members have to take surrogate decisions and to be actively involved in applying the therapeutic strategy (Chen, Xiao, & De Bellis, 2016).

Western societies, influenced liberal individualism, promote patient autonomy and families have the tendency to act according to patient's wishes or in his interest. This approach, that compels the person to act on one's own, under the family supervision, presents the advantage of a more speedy recovery. On the other side, the unreasonable acceleration of treatment and lack of compliance to long-term treatment (noticed with the patients who are sole source of income for their families) do not constitute a real advantage. In eastern societies, the individual is regarded as a part of the family and the excessive attention and support can lead to a passive attitude (Fang *et al.*, 2017). Nevertheless, it was noted that, although the patients assisted by their life-partner are more insecure of their self-care abilities,

they recorded a higher level of adaptation to the new lifestyle imposed by chronic diseases and a higher adherence to treatment (Deek *et al.*, 2016; Diaconu *et al.*, 2014).

Social reintegration of the patient with disability begins with the reinstatement within the family. An active involvement of the patient in the family life can be complicated by the tendency to exaggerate one's sufferance in the attempt to obtain more attention from the close ones. Likewise, due to the fact that family members model their personality depending on the behaviour of those around them, the family and the patient, respectively, reflect by imitation the attitude and behaviour of one another (Riffin, Fried, & Pillemer, 2016). That is why, family counselling is recommended, in view of maintaining an optimistic and calm attitude, which is important not only for treatment success, but also for eliminating the stress caused by the long-term care of a sick person and by the suffering entailed by the pain of a close person. However, long-term or even indefinite care triggers adaptive mechanisms, which may lead to the conviction that no one else can attend to the patient's needs better than the family (Iacono *et al.*, 2016). Moreover, the family can command respect for the dignity of people with disabilities from society by cultivating a positive image of the patients and by keeping them involved not only in sedentary home activities, but also in the public space (Mauro, Biggeri, & Grilli, 2015).

In addition to that, the possibilities offered by the static interaction provided by virtual media are not to be neglected. For people with disabilities social networks represent a chance to interact and to find a place within the social structure, overcoming physical barriers imposed by lose of mobility (Baker *et al.*, 2013). In this context, the doctor-patient- family communication should take into consideration the necessity to adapt medical language both to the patient's and family's level of education, and also to the new means of disseminating the information through social networks (Carman & Workman, 2017).

A radical transformation of the living space in order to increase its accessibility affects the existence of the entire family. It is recommended that the removal of barriers should take into consideration the need to maintain a certain functionality of the space, which can match the patient's desire to socialise, to practise various hobbies or to ensure personal hygiene (Labbe, Jutras, & Coulomb, 2017). Younger family members who find themselves in the situations of assisting their relatives encounter problems connected to possible career sacrifices, continuing studies or raising children, while families in which elderly members become carers are often confronted with their own health issues (Coyne *et al.*, 2017). As well as medical personnel, family can also be affected emotional exhaustion (*burnout*), a concept studied in the professional field (Maslach & Goldberg, 1998).

In medical rehabilitation, the family can help the doctor, too, by monitoring the effects of treatment and by informing on the individual caring needs (Sheppard & Vitalone-Raccaro, 2016). Once the idea that modern medical treatments are

limited by important financial constraints was accepted, the desideratum of patient-centred care has been doubled by that of family-centred care. The model for family involvement was first applied in paediatrics, where the treatments receive parent or tutor consent and where medical personnel has to learn to collaborate with the family. They can assist patients in filing medical forms and in taking their medication, can supervise and improve their eating habits and encourage them to do exercise more.

The first step to consolidating the relationship between the medical personnel and the family is scheduling flexible visiting hours. The contact with the family is usually kept through medical nurses, who interact with the patients and their families more frequently than doctors do. Such meetings represent opportunities to obtain in-depth knowledge about the patient's needs, but also to instruct the family concerning their care and assistance (Deek *et al.*, 2016).

Furthermore, taking care of a special needs person requires great physical and emotional energy, hence the commonly known risk for carers to develop certain neuromuscular and mental afflictions (Bevans & Sternberg, 2012; Bourke *et al.*, 2017). Another legitimate perspective met in the specialty literature is the concept of "burden of care", which describes all the challenges encountered by family members who provide care for a patient (physical, emotional, social and financial issues) (O'Neil & Ross, 1991). Psychological counselling plays an important role in patient's rehabilitation and can equally address the family or other people that assist the special needs patient.

One of the main problems of the medical team remains the preoccupation on what happens after the patient is discharged from medical institutions. The current study intends to offer a series of answers related to the perception of patients who experience medical rehabilitation over the role of family in maintaining their quality of life. The objectives of the study were: (1) to evaluate patients' satisfaction on the existing relationships within the family; (2) to evaluate family cohesion; (3) to appreciate the role of family and those around the patients in increasing the quality of life; (4) to evaluate the emotional and physical support received from those around. The hypothesis of the study was that patients experiencing medical rehabilitation would consider the family and people around them as key elements in their care.

Methodology

The study was conducted on a group of 115 patients with ages over 18 years old, at the Clinic for Medical Rehabilitation, Physical Medicine, Balneoclimatology of CF Clinical Hospital of Iasi, surveyed between October 2012 and December 2015. Illiterate patients, patients who cannot sign informed consent forms and

those with severe dementia were not included in the study. The survey asked closed questions with answers connected to the patients' subjective perception over certain social, medical and bioethical elements connected to the quality of life. By quality, we understand the subjective evaluation of the positive aspects of life, but also the negative ones, which affect the physical, mental and social health conditions. The survey was completed by patients hospitalised.

Results

Descriptive statistics

Among the study group of 115 patients the largest group was for the age range of 50-59 years old (24.3%) and the smallest one, under 20 years old. The average age of the patients was 52 years old. Almost 50% of the patients belong to the 40-49 and 50-59 age ranges.

The male batch of study registered a frequency peak at the 20-29 years old range (28.6%), followed by another peak of 23.8% in the 50-59 years old range. No patient in the male group was below 20 years old. The female batch of study showed a bimodal distribution in which 24.5% of women were 50-59 years old, and 25.5% were 40-49 years old. The smallest category was that below 20 years old, followed by the age range above 70 (*Table 1*).

Table 1. Study group structure according to age range

Age range (years)	Male		Female		Total	
	n	%	N	%	n	%
<20 years	-	-	1	1,1%	1	0,9%
20-29 years	6	28,6%	-	-	6	5,2%
30-39 years	1	4,8%	18	19,1%	19	16,5%
40-49 years	2	9,5%	24	25,5%	26	22,6%
50-59 years	5	23,8%	23	24,5%	28	24,3%
60-69 years	2	9,5%	20	21,3%	22	19,1%
70+ years	5	23,8%	8	8,5%	13	11,3%

The distribution of the patients considering the marital status, shows a relatively homogenous group, with a higher percentage of married individuals (N=94, 81.7%), followed by unmarried individuals (N=12, 10.4%). Divorced patients represented only 7.8% from the total of patients (*Figure 1*).

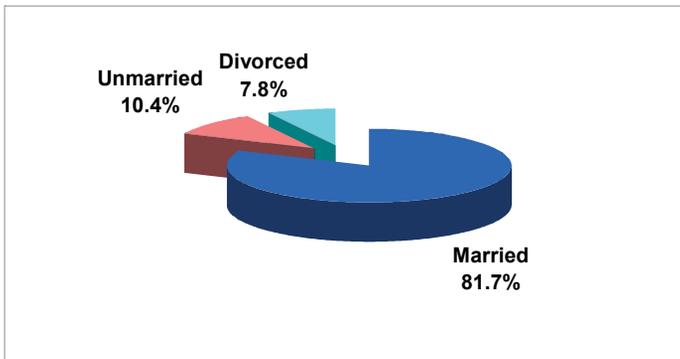


Figure 1. Structure of the group study according to marital status

Generally, most frequently 36.5% of subjects were very unsatisfied and 27% unsatisfied by the family relationships (Figure 2).

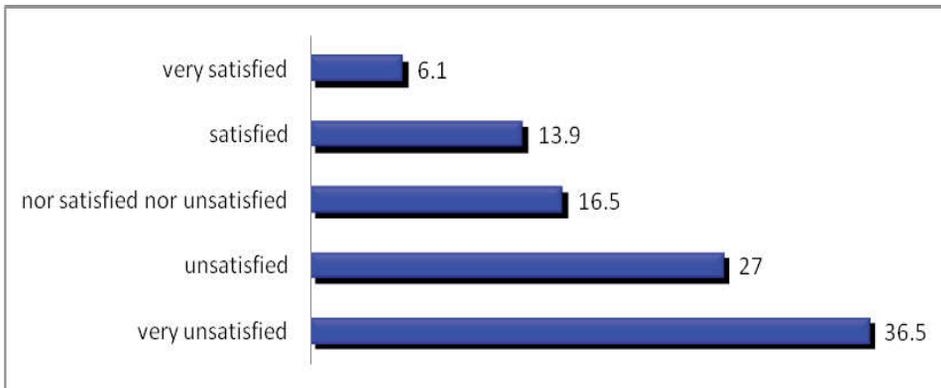


Figure 2. Percentile distribution of the degree of satisfaction regarding family relationships

66,7% of the subjects who declared themselves very unsatisfied and 51,6% of the unsatisfied ones did not have financial support, while 68,8% of the satisfied one and 71,4% of the very satisfied patients benefited from monthly financial support.

The dominant answer to this questions highlighted the fact that 33% of the subjects declared that family members help and support each other to a small extent, and in 29,6% of cases there is a high degree of mutual support (Figure 3).

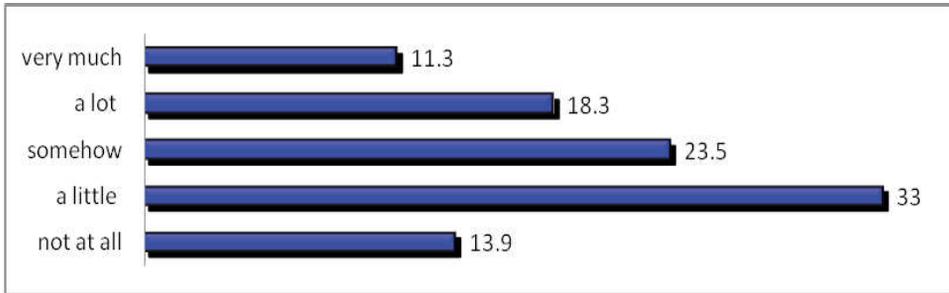


Figure 3. Percentile distribution of answers concerning mutual support within the family

19.1% of the subjects declared that intra-familial relationships are very important and 23.5% quite important for the quality of life, but 55.7% of the patients consider them important only to a certain extent (*Figure 4*).

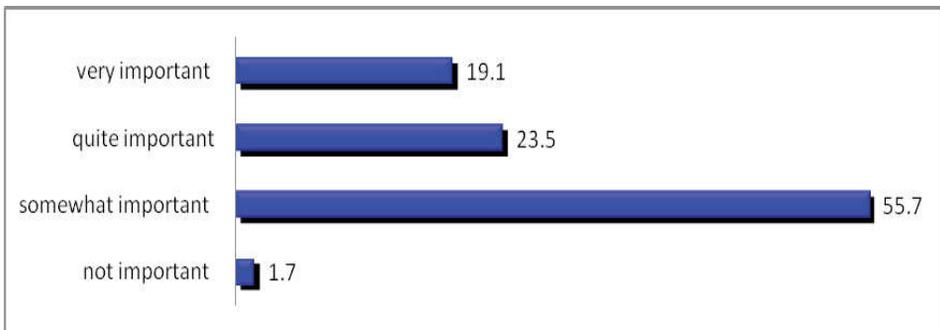


Figure 4. Percentile distribution of answers concerning the importance of family relationships

The importance of marital relationships was appreciated largely by 42.5% of the married patients, 41.7% of the unmarried and 44.4% of the divorced ones (*Figure 5*).

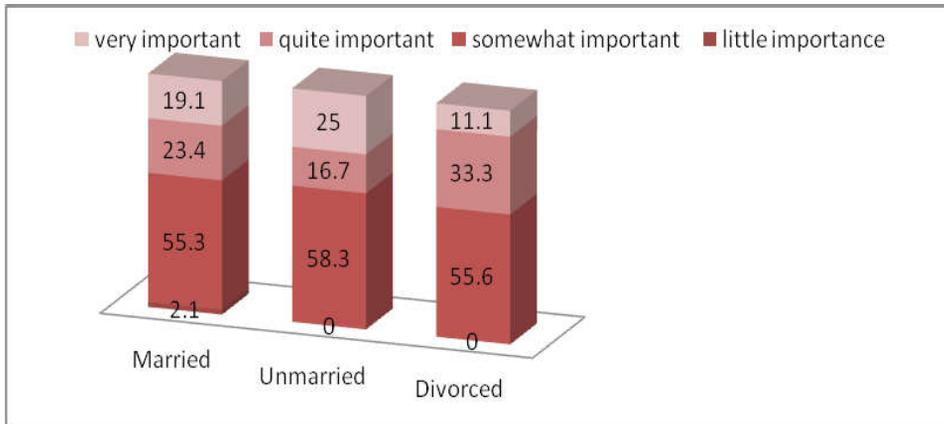


Figure 5. The distribution of family relationships in connection to the marital status 1

The surveyed people declared that they are helped a little (40%) or not at all (5.2%) by relatives, friends or neighbours in practical activities such as taking care of themselves, doing the shopping, doing the housework (Figure 6).

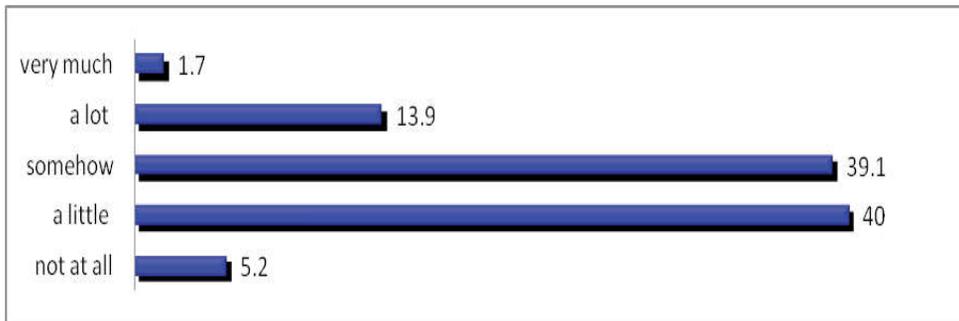


Figure 6. Percentile distribution according to the help received from other people for practical activities

For practical activities, 33.3% of the patients who did not benefit from family support did not receive help from other people, too, and 20.5% of the patients with little support from their families were help to a certain extent or high extent by other people. The patients who benefitted to a great extent from mutual family support did not ask for the help of other people (Figure 7).

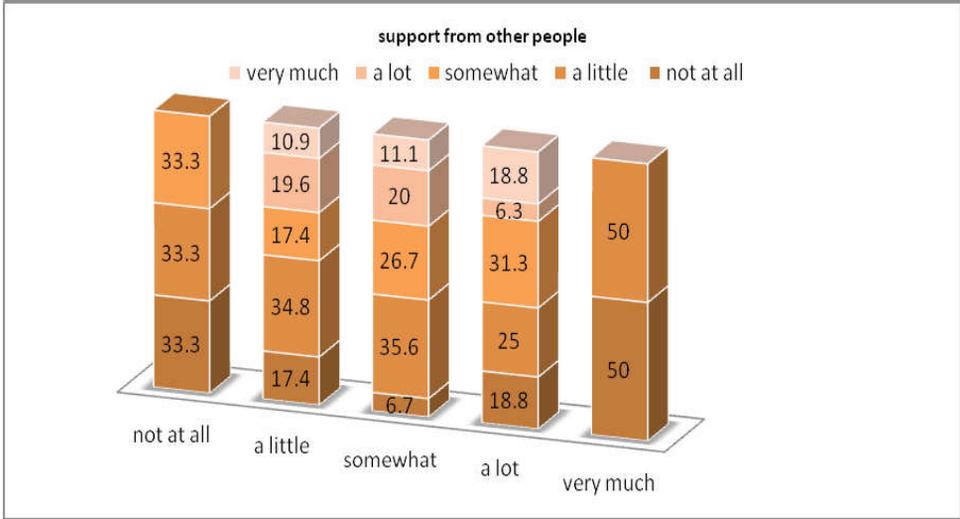


Figure 7. Distribution of help from other people for practical activities in connection to the mutual support among family members

Among the group studied, for 52.2% we noted a lack of emotional support or little emotional support from relatives, friends or neighbours, such as: listening to them or talking to them for encouragement (Figure 8).

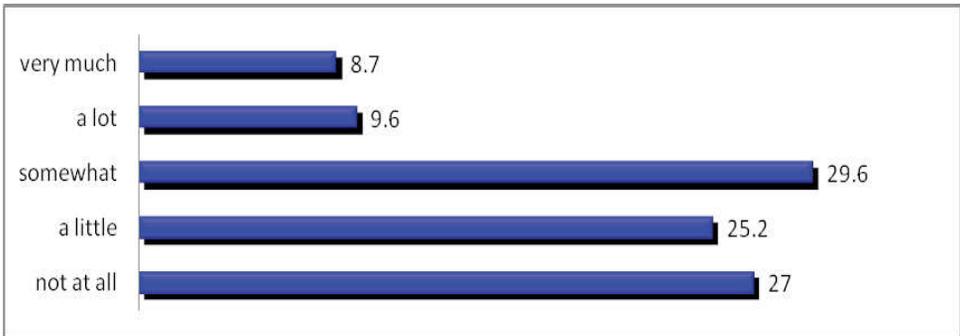


Figure 8. Percentile distribution according to the emotional support provided by other people

How important is the support of other people for your quality of life? The answer to this question highlighted the fact that 41,7% of the subjects believe that the support of other people is very important for their quality of life, and 36,5% believe it to be quite important (Figure 9).

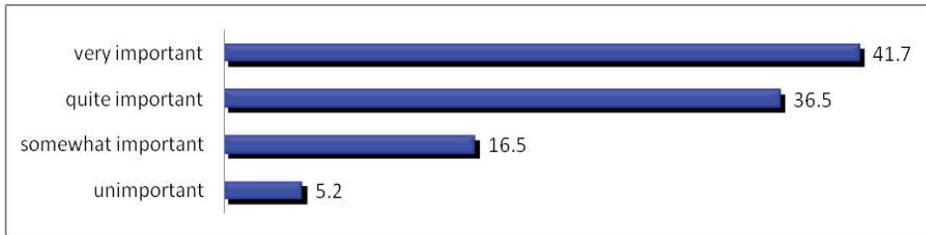


Figure 9. Percentile distribution according to the importance attributed to other people's help in ensuring one's quality of life

Discussion

Our study investigated the perception on the role of family in medical rehabilitation on a study group 115 patients in the Clinic for Medical Rehabilitation, Physical Medicine, and Balneoclimatology of CF Clinical Hospital of Iasi. The analysis of demographic characteristics showed a prevalence of married individuals (81.7%). As the study included unmarried and divorced people, not only the nuclear family, but also the origin, extended family constituted elements in our research. The results of the study show that family is important for the quality of life of medically rehabilitated patients, only 1.7% of respondents declaring it of little importance. That is why, in the recommendations made by medical personnel to patients one should renounce the perspective of an autonomous patient living alone in favour of a patient with a family life, in which treatment is applied in the context of social interactions.

The patient age determines a degree of dependency of the family, which varies according to the patient's role within the family: child, head of family or elderly person. The average age of the study group was 52 years old. Almost 50% of the patients surveyed belonged to the age ranges of 40-49 and 50-59 years old. The disability of the adult reverses the role of the patient from provider to assisted person. It produces strong emotional discomfort (anxiety, especially caused by the uncertainty of slow evolving debilitating diseases, such as multiple sclerosis or dementia, conflicting states, rejection or repulsion attitude or, on the contrary, hyper-protectiveness, feelings of guilt and helplessness) and physical incapacity (impossibility or low capability to contribute to housework and to participate in free time activities or lucrative activities). Because disability produces such radical changes in an individual's personal and professional life, his social environment perceives the patient differently. In these circumstances, it is recommended that both family and patient reappraise their long-term perspective and family relationships.

The adaptation effort is even higher, as in many cases the debilitating affliction is a consequence of accidents and sudden events (Wetzig *et al.*, 2017).

The age of family members is another important element in the success of rehabilitation, which can be compromised by the problem of parents as carers not knowing who will assist their child after their death or the hostility of siblings who feel neglected in comparison to the special-needs child (Iacono *et al.*, 2016). The solution could be a fair distribution of the caring responsibility among all family members. In the current study, family cohesion was reported by 53.1% of participants, and the rest of 46.9% indicated the fact that their family members support each other to a small extent or not at all. The existence of a chronically ill person in a family produces a series of behaviour changes for family members, with visible effects in the quality of family relationships (Postolache, Dima-Cozma, & Cojocaru, 2013). Frequently, the interaction with a special-needs person can lead to an increase of altruism, religiosity and tolerance. Family members educate their patience and calmness, and personal ambition and pride often concede to the patient's needs. Thus, the unity of the family strengthens, even if the caregivers experience a certain social isolation (Michalik, 2015).

In the current study, the satisfaction index reflects low levels of satisfaction, the majority of the patients being very unsatisfied or unsatisfied with the family relationships, but without mentioning whether the deterioration of relationships was caused directly by the disease. Nevertheless, approximately half of the patients feel that they still can rely on family in critical situations, which is a sign that the family continues to be perceived as protector of the individual. The support received from family members is highly important for patients under medical rehabilitation therapy in cases in which the physical autonomy of the patient is reduced. In addition, lack of support from the social environment increases the risk of diseases and living on one's own leads to a lower receptivity to lifestyle changes (Deek *et al.*, 2016). In the conditions of maintaining the trust in the family manifested by the study group, the encouragement of harmonious family relationships could have important benefits in medical rehabilitation and the patient's quality of life.

Intervention strategies of social assistance underline the therapeutic potential of the community, family, groups of friends and work group for the recovery of mental and social capacities of the disabled person, bearing in mind that because their incapacity for work adults with disabilities can often become social cases. The social environment constituted of family, friends, neighbours, work and school colleagues, community members keep the patient motivated in the therapeutic process rekindling the desire to reintegrate. Moreover, the financial, physical and moral support help the patient fight physical barriers encountered in the house or outside it, but also the social ones caused by losing one's autonomy, workplace, community respect or the embarrassment of appearing in public, as it is commonly known that there is a social stigma associated with certain diseases (Masoudi *et al.*, 2017).

In general, the patients surveyed receive emotional support or practical help for household activities from family or other people to a low or moderate extent. Family and community support are commonly recognized as protective factors for one's mental health, contributing to a higher resistance to stress (Linder *et al.*, 2014). The beliefs of the patients in our study group are consistent with the data from the specialty literature, namely that the support of other people is important or very important of the quality of life.

Social interaction and the effort for social interaction are generally low in patients who are satisfied with their family relationships and high in patients who are not content with the quality of family interaction. The psychological index recorded the lowest average value in the patient group that consider interaction of people and place in the community of low importance, and the highest average value in the patient group that attributes a great importance to interaction with the social environment. The majority of the subjects believe that interaction with people and places in the community has little or no importance at all on their quality of life, fact that suggest an increased attachment to family and friends and a lower level of trust in support and therapy groups. This result can be explained either by a lack of a consistent offer of psychological assistance centres and day-care centres for people with disabilities in Romania, or by a low degree of awareness on their existence, efficiency and utility. The precarious financial situation also contributes to this reticence to community programs, which most frequently are not covered by the National Health Insurance House.

The opinion of the patients surveyed on the role of family on improving quality of life for the medically rehabilitated patients is consistent with the data found in the specialty literature. They suggested the existence of cultural differences between western societies encouraging individualism and the eastern societies in which family members are more solidarity with each other (Deek *et al.*, 2016).

Conclusion

The present study shows that, even if family, friends and neighbours play an important role in maintaining the quality of life for the medically rehabilitated people, the physical and emotional support provided to them is insufficient. Taking into consideration the trust in family manifested by patients, it is highly recommendable that the medical act focused on a family-centred approach, as opposed to catering only to the care and information needs of patients, isolated from the social environment. By promoting a close relationship with the care-givers, through programs for educating family members and by gathering information about the patients' individual needs also from family sources, medical personnel can help the patients receive consistently more support from their families.

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