



UNDERSTANDING MULTIPLE SCLEROSIS: FAMILY AND PATIENT PERCEPTION ON DIAGNOSIS AND FACING DISEASE

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ABSTRACT

Introduction: Multiple sclerosis (MS) is a stigmatizing and degenerative disease that impacts on the organic and emotional functioning of those affected. Objectives: To evaluate the experiences and expectations of patients and caregivers in MS coping, to identify the impact profile in caregivers and patients with MS.

Method: Exploratory research with a qualitative approach. The sample was comprehensive, including all subjects with MS and their main caregivers registered in the IX Regional Health Management of Paraíba / Brazil. Interviews were conducted with structured scripts, with the bearer and the caregiver. The data were evaluated by content analysis, in its modality of thematic analysis, proposed by Bardin (2011).

Results: MS follow-up needs to be extended beyond medication; being indispensable the qualified support to the family, as well as to the main caretaker, who is vulnerable to emotional illness due to work overload.

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INTRODUCTION

Although multiple sclerosis (MS) does not always cause behavioral or personality disorders (HÄMÄLÄINEN *et al.*, 2005), it is possible that both the person with MS and those around them have feelings of confusion or anxiety. In this sense, we affirm that MS is a stigmatizing disease that, because it is incurable and degenerative, affects the organic functioning and the emotional area of the affected person, impairing their social interaction, thus constituting a singular experience that takes into account the emotional flow of the patient, family and caregivers. Its clinical picture can be confused with other degenerative diseases of the central nervous system, so its diagnosis is obtained by exclusion of other pathologies and requires greater investigative complexity.

Due to the high demand for technological devices, many cases remain without diagnostic conclusion, which leads to an underreporting of the disease throughout the country. In view of the problematic approach, the following questions arose: what is the impact caused by the diagnosis of MS, for the patient and the family? What are the expectations of caregivers and patients in coping with MS? What is the place of the multidisciplinary team in coping with the caregiver and patient of MS?

Considering that the number of cases recognized as MS has gradually increased over the years, it was decided to carry out this investigation to identify the impact of the diagnosis of MS on the lives of patients and their families, in order to evaluate the experiences and expectations future of patients and caregivers in MS coping, to identify impact on caregivers and patients with MS to discuss the degree of approximation between life expectancies between caregivers and MS patients.

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MATERIALS AND METHODS

Exploratory-descriptive research, qualitative, which had as a research site the IX Regional Health Management of Paraíba (IX GRS-PB), in which there is the registry of MS patients, in the city of Cajazeiras where it is located and another 14 municipalities of the high backwoods of Paraíba, which constitute its area of coverage. The data were collected in the cities of Cajazeiras, São José de Piranhas and Uiraúna, where MS patients resided during the period of the survey, one patient and their primary caregiver in each city. Considering the criteria: to be able to establish verbal communication and to agree to participate in the research, by signing the Term of Free and Informed Consent (TCLE) and having a link through registration with IX GRS-PB. The project was sent to the Research Ethics Committee of the Federal University of Campina Grande, Cajazeiras campus, and was approved on 04/27/2015, through CAAE: 37179914.7.0000.5575. Data collection was performed during the months of June and July 2015, and the data obtained through interviews, having as an instrument two structured scripts, one for the MS patient and the other for the caregiver, containing objective and subjective questions: Socio-demographic issues, such as: age, marital status, schooling, family income, medical history, as well as subjective issues addressing how to deal with the patient and caregiver facing MS and what are their future expectations.

Initially, the addresses of people with MS were requested to IX GRS-PB, in order to allow home visits. In the possession of the address, home visits were made to MS patients and their families (primary caregiver), in order to clarify the objectives of the research and request their adherence to participate in the study, with the request of the signing in the TCLE. From the interview records, the data analysis was done by means of the description and sociodemographic characterization of the research participants, and the qualitative data were evaluated by means of the content analysis, in its modality of thematic analysis, developed by Bardin (2011). The first step in the organization of the material was the transcription of interviews, resulting texts. For the qualitative analysis of the data the following steps were followed: initial reading of the transcribed texts, seeking to have a global understanding of the material; identification of the units of meaning that emerge of respondents' speeches; discovery of nuclei; interpretation and discussion of the nuclei of meaning found. After this classification and aggregation, the participants' discourses were analyzed in light of the relevant literature.

The data were presented in descriptive tables with the following codes: E - Interview (numbered from 1 to 6, according to the order of the approaches); (...) - Part of the original text that is not relevant to the analysis; [] - Emotional flow perceived by the interviewers during interviews. In the text, patients are identified by P and caregivers by C, followed by the order of the interview. So C1 is the primary caretaker of P1, and so on. Thus, in the discourses, E1 = P1, E3 = P2; E5 = P3; E2 = C1, E4 = C2, E6 = C3.

RESULTS

Characterization of the sample

Socio-demographic and other data of the patients interviewed: In order to visualize the participants of the study, tables were created, being the first one representative of the socio-demographic and emotional data of the interviewees. The sample consisted of two men and one woman. Their age was 30 to 57 years, which were the family providers before the diagnosis. At the time of this research the income is reduced to a minimum wage, the 30-year-old beneficiary of the INSS and the other retiree. The youngest signaled having completed high school and a technical course. The 57-year-old attended elementary school. The woman was 60 years old and said she had incomplete elementary education and income from a minimum wage. Predominantly in the families surveyed, the role of primary caregiver fell on the female sex. The men declared that they owned their own car, unlike the woman. Emotion is positive and confident about treatment, being "happy," just for one patient and two expressing sadness.

Subjectivity of Multiple Sclerosis

Table 2 presented the category "Interviewees' experience about Multiple Sclerosis" and a subcategory, disease. With regard to the disease subcategory, the following registry units were identified: prior knowledge, limitations and treatment. Table 3 made it possible to identify the category "Changes experienced by the patient after diagnosis" and a subcategory, relationship. Regarding the relationship subcategory, the following units were identified: family, professional and marital life. Table 4 identified the category "Changes experienced by the caregiver after diagnosis" and a subcategory, relationship. Regarding the relationship subcategory, we identified the units of registration: social, professional and marital life. Table 5 made it possible to identify the category "Prospects for the future" and a subcategory, therapeutic.

Table 1. Socio-demographic and emotional data of patients interviewed

Characters	Patients		
	#1	#2	#3
Race/Ethnicity	Brown	Brown	Black
Medical Background	No	No	No
How Long Do You Know You Are a Carrier Of MS?	5 Years	9 Years	7 Years
Are You Conscious About What Is Multiple Sclerosis Disease?	No	Yes	No
What Symptoms Bothers More At The Moment?	The inability to walk alone	Muscle weakness	Fatigue
What Symptom Makes You Feel More Dependent on a Caregiver?	Difficulty in locomotion	Difficulty in locomotion	Difficulty in locomotion
Are You Expecting An Improvement In Your Illness Over Time?	Yes	Yes	Yes
How do you feel now: happy, sad, fulfilled?	Sad	Happy	Sad
Household Income	4 Wages	4 Wages	2,5 Wages
Number Of Residents In The House	7	3	3
Do you have a car?	Yes	Yes	No

Source: interview form.

Table 2. Content analysis for the category "Multiple sclerosis interviewees' experience"

Category: Interviewees' experience about Multiple Sclerosis		
Subcategory: Disease		
Registration Units	Context Units	
	Patient	Caregiver
Previous knowledge	"It got everyone that way, worried right? Sad. Because no one knew what that was, right?, sclerosis." E ₃ P3	"I myself did not know this disease, I did not even know it existed." [voice failed] E ₂ C1
Limitations	"Another Sunday I wanted to go to Mass on foot but my sister. (...) I miss walking." E ₁ P1	
Treatment	"(...)we came to the secretary of health of Cajazeiras to ask for this medication, so I do not have to go to João Pessoa to get it" E ₃ P2	

Source: interviews.

Table 3. Content analysis for the category "Changes experienced by the patient after diagnosis"

Category: Changes experienced by the patient after diagnosis	
Subcategory: Relationship	
Registration Units	Context Units
Familiar life	"After the illness, the relationship with the family worsened (...). Now instead of me working for them, it's them working for me" E1 P1 "(...) I do not intend to have any more children, because my daughter, when she was born, this caused a lot of concern in me ... E3 P2 " (...) I can not work anymore, I stay on a bed, I have no friends. " E5 P3
Professional life	" (...) before I had a life perspective like any other young person has, work" E3 P2
Marital life	"(...) I really was a wife for him" E1 P1

¹The minimum wage in Brazil is R \$ 934.00 (nine hundred and thirty-four reais).

Source: interviews.

Table 4. Content analysis for the category "Changes experienced by the caregiver after diagnosis"

Category: Changes experienced by the caregiver after diagnosis	
Subcategory: Relationship	
Registration Units	Context Units
Social life	"(...) I want to go out at night, she can't be alone, if I want to leave I have to find someone." E2 C1 "If I go out, sometimes if I go to the fair, if I take some time, he stays, stays ... he cries" E6 C3
Professional life	"(...) I even got a new work, but I could not go because I'm not two. (...) I wanted to, right? But I could not. "[Emotional voice] E2 C1 "If I want to work I can not, but I do not feel like I want it. [laughs] "E6 C3
Marital life	"Today in the life of couple I only take care of him" [referring to sexual life] E6 C3

Source: interviews.

Table 5. Content analysis for the category "Prospects for the future"

Category: Perspectives for the future		
Subcategory: Therapeutics		
Registration Units	Context Units	
	Patient	Caregiver
Improvement	"Five years from now I hope I'm better, I really want to get better so I can go to Mass every Sunday, I want to walk on foot ..." [nostalgic voice, sad facial expressions] . E1 P1 "I will improve (...)". E5 P3	"By the time and what the doctor says, I think he won't get better, because this medication he takes is just for softening, right? Not to improve. "E6 C3
Cure	"... I hope that better drugs will come first and that they can come if necessary until the problem is cured ... to diminish the lesions they have in the brain" [optimistic voice]. E3 P2	"We know there's no cure, right?, but do control, right? And that is our perspective, of being controlled and that there is, like, a medication that is less suffered for him. "E4 C2

Source: interviews

Regarding the therapeutic subcategory, the following registry units were identified: improvement and cure.

DISCUSSION

Sex: It is believed that the higher prevalence of males in this study is due to the small number of cases interviewed, since according to the World Health Organization (WHO), MS is more common among women (WHO, 2013), which is related to the sphingosine-1-phosphate receptor 2 (S1PR2) protein, present in blood vessels and to a greater extent in women.

When activated, S1PR2 allows the passage of white blood cells, which causes the attack on the nervous system, generating inflammation that culminates with sclerosis (ORENGO *et al.*, 2014).

Purchasing power: The interviewees were low income and two patients were affected at a productive age. Epidemiologically, WHO (2013) portrays that the first symptoms appear around the age of 30, when people are economically more active, affecting the top of their

professional and loving life, launching themselves into the job market and seeking to start a family. Therefore, these patients will not contribute economically to their country because of the limitations of the disease, besides requiring treatment expenses. It is therefore urgent to create public policies that are aware of the real costs that the MS requires and to rationalize funds for the integral care of these people.

Gender of the caregiver (female): There is a historical background that justifies this predilection. The culture of female submission / subservience in Brazil dates back to colonial times. The men had the family support and the active participation in the life in society, whereas the women were the housewives, submissive to the children and husband. According to Follador (2009), the exception to the rule would be low-income women who worked to provide family support, thus entering male space. In the nineteenth century, women began fighting for rights, trying to match them with men. This increases their participation in the economic life of the family. There is, however, no abandonment to the pragmatic image of a housewife attached to her, being socially expected to assume the role of family caregiver.

The accumulation of roles as a mother, wife, caregiver and professional requires a lot of personality, requiring skill in getting around problems. Many need to give up working life, generating a considerable degree of frustration, since the age group of the sample comprises the age of greater performance in the labor market. According to Bicalho *et al.* (2008), the family caregiver is an easy victim of chronic emotional illness, remaining invisible to health intervention measures because there is no visibility or social recognition for their work. Thus, the diagnosis of MS directly and indirectly alters the family dynamics and, especially, the personal and professional life of the caregiver, who needs to assume a new role in the patient's demands, helping him in all his daily activities. The physical and psychological stress to which this care provider submits predisposes him to emotional pathologies. Diseases related to mood disorders, such as anxiety and depression, are more prevalent in this group than in the general population (SONG and SINGER, 2006). Thus, there is a need to pay special attention to caregivers and to planning interventional measures to relieve the stress to which they are subjected daily.

Schooling: The direct relationship between level of education, income and understanding of the disease was evidenced. According to the National Household Sample Survey (BRASIL, 2011), the higher the educational level, the greater the proportion of individuals accessing the internet; and the higher the monthly household income per capita, the higher the percentage of people with access to the network. These data tell us that families with higher purchasing power and with more educated members tend to have more access to knowledge about MS. This analysis is corroborated when interviewing the patient and caregiver with higher level of schooling / income, who used non-colloquial technical terms to refer to the symptoms and clinical course of the pathology. The opposite was observed in the collections with the other participants with low level of schooling / income. In these, predominance of terms that showed little knowledge about the disease, its clinical course and its symptoms. Still on disease information, Kantor, Brighth and Burtchell (2017) state that patients receive inadequate support after diagnosis; being the Internet and social networks used to know the pathology.

Thus, the authors reflect on a 2009 survey of Internet use among Israeli MS patients. It turned out that most believed that web information was as reliable as that of books. In contrast, studies conducted in 2011 showed that American and Italian patients doubted the quality and reliability of online information and had difficulty accessing or understanding the information they wanted. Information should be carefully passed on and in pedagogical language aimed at caregivers, whether in health posts, self-help groups, religious and spiritual communities or other spaces. What is important is for universities to study and think interdisciplinarily, with multidisciplinary teams, to provide a way out of emotions and to generate sources of practical information needed to provide the best support and guidance to caregivers of those affected by MS.

Relationship between automotive vehicle ownership and multidisciplinary follow-up: Chronic patients such as those with MS need multidisciplinary support: physiotherapy, speech therapy and psychology. Such professionals are not always available in primary health care, hence the relevance of the Family Health Support Center (NASF), which represents the multi professional team geographically closer to the patient, working in the vicinity and facilitating community access. In spite of this, it is not uncommon for the user to travel from considerable distances, necessitating an appropriate means of transportation for his movements. Greater multidisciplinary support was found in families who owned vehicles. This multi professional service reduced the incidence of complications in the chronic patient, because in the family that did not have transportation, the lack of physiotherapy caused deep venous thrombosis (DVT) in the patient due to the limited mobilization of the lower limbs due to the restriction of ambulation triggered by MS. There are home support groups available through the SUS, such as the Best at Home Program (Brazil, 2013), which provides multidisciplinary support to chronic patients and others who need these professionals in their residence, for a certain time or not. Despite this advance in basic care, the access and availability of this service are still restricted in the SUS.

Interviewees' Experience About Multiple Sclerosis: Chronic diseases incapacitate and cause financial suffering and expense to families, as well as the monetary deficit on the health system. Not least, it also has negative effects in the quality of life of people affected (MALTA, SILVA Jr, 2013). Despite the recent increase in cases, the disease remains unknown. Patients and caregivers researched became aware of the existence of the pathology after diagnosis. Those who had more resources and access to alternative means of communication, such as the Internet, have acquired a better understanding of how the disease process occurs and the difficulties to come, as the years go by. Unanimously, all the patients blamed the difficulty of locomotion as the situation that worsened dependence on a caregiver. The locomotive restriction leads to a fall in the quality of life of the patient, since in addition to limiting the daily activities of daily family life, deprive them of social life. All the interviewees were linked to the IX Regional Health after the diagnosis signed by the neurologist. Once the link has been established, monthly treatment for MS patients can be received free of charge from the government.

Changes experienced by the patient after diagnosis: Limitations of pathological progression not only amputate the freedom of movement of MS patients, but also compromise

their leadership role in the family, moving them from the provider to the role of the member that requires the most expenses and care in the home. Or they make it difficult to realize dreams of a promising professional life, since the labor market is still restricted to this type of labor. It is essential, therefore, to maintain family support, because to feel loved, reduces the weight of the burden, which many call themselves, for loved ones. Walking on the street and even personal hygiene are affected, compromising the quality of life and autonomy. Multi professional follow-up would help to park the progression of these limitations. In addition, the change in sexual life was pointed out by the interviewees. "Sexuality is an inherent component of the life of all human beings, developing in a continuous process that begins before birth and only ends with death" (GALATI *et al.*, 2014, p.243).

An active sex life is an important indicator of quality of life. By affecting not only the dynamics of the movements but also the emotional health of patients, sex within the matrimonial life of patients is extinguished gradually, as much by the motor limitation as by the shaking of the confidence towards the partner. Support for the couple, through the guidance of qualified professionals, encourages the resumption of sexual practice, clarifying doubts as to the possibilities of achieving pleasure with the partner, using different ways of the usual, often prejudged due limitations. These interventions greatly benefit the well-being of patients. Meneses *et al.* (2013) state that in order to optimize mental health and the sexual functioning of patients, it is essential that healthcare professionals approach the issue. From the recognition of the problem we can come up with possible solutions. In addition to the sexual, motor and financial limits of autonomy, Bichuetti *et al.* (2018) pointed out that Brazilians with MS are more predisposed to suffer from anxiety and depression because they perceive the disease as severe and understand the risks associated with the use of medications.

Changes experienced by the caregiver after diagnosis: The main changes reported relate to the changes experienced in the social, professional and marital life spheres. The full art of caring requires a great deal of abdication by the family caregiver, who starts to replace the essential activities of daily life, previously performed by the patient himself. Giving bath, food and medicine are just part of the daily tasks of a caregiver of a patient in advanced stage of the disease. Thus, emotional dependence results from the patient's reliance on that person, in addition to the daily experiences exchanged between them. To give up a job, a relationship, a social life among other activities, to dedicate oneself to the sick family member demands a lot from the family.

Physical and emotional overload was evident in all interviewees. The Home Care Program, instituted in 2002 by the Ministry of Health, through Law 10.424, was redefined in 2013, through ordinance No. 963 of May 27. In article 19, assignments II and V, are part of this new proposal: identify and train family members and / or caregivers of users, involving them in the care, respecting their limits and potentialities (BRAZIL, 2013). Therefore, an integrated action of the health team within the home would benefit the health not only of the patient, but also of the caregiver. Yamashita *et al.* (2014) affirm that identifying the social network of caregivers facilitates in the elaboration of strategies of action of the teams with the families.

Prospects for the future: MS is an incurable disease, with outbreak control only. The prospect of medicine evolving and discovering its cure in the near future sows hope in the emotional state of illness for both the patient and caregiver. The expectation for patients and family members is positive and strengthens as everyone has qualified information on the pathology. While this reality does not materialize, skilled care beyond medication is needed in all families accompanied by the multidisciplinary team. A basic follow-up network for patients whose illness is in progress and also for the newly diagnosed would improve the relationship of those involved with the disease, its stigmas and its chronic complications that affect the physical, mental and emotional health of the binomial patient / caregiver, as proven

Conclusion

Despite scientific advances, MS still has no cure. Because it is chronic and degenerative, the affected patients suffer damages that extrapolate the organic commitment, damaging the mental health. The diagnosis of this condition is complex and is rarely given safely after the onset of the first symptom. Therefore, caution is necessary before its determination. The prognosis of each patient is unique, so it is imperative to follow up with a professional specialist. Special attention should be paid not only to the patient but also to the family and, above all, to the primary caregiver. The expectations of healing, although utopian, permeate the dreams of the families addressed. However, while this reality does not exist, the extension of care beyond medication, offered free of charge, is necessary in all families accompanied, as well as in the others that will still be diagnosed. To truly understand pathology, the boundary of the organic barrier must be broken. The integral vision surpasses epidemiological, pathophysiological, clinical and therapeutic knowledge. The professional sensitivity makes aware of the emotional sickness that affects the vulnerable individuals, the valuation of this perspective and the elaboration of strategies of action to cover them, will make the difference within each home that faces the reality of the chronic patient daily.

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