

THE ROLE OF FAITH IN HEALTH PROMOTION IN PATIENTS WITH MULTIPLE SCLEROSIS

O papel da fé na promoção da saúde em pacientes com Esclerose Múltipla

El papel de la fe en la promoción de la salud de pacientes con Esclerosis Múltiple

Original Article

ABSTRACT

Objective: To understand the perception that people with Multiple Sclerosis (MS) have of their personal suffering and to verify whether faith is an internal resource used by them to lessen their suffering. **Methods:** Study with qualitative approach, centered on the themes - suffering, faith and sense of coherence (SOC), by using semi-structured interview. The study included 15 patients with MS belonging to a support association for MS patients (Portugal). The interviews took place from September to October 2015, in a place previously agreed with the interviewees. For categorization of the data obtained through the interviews, themes previously established were adopted. Hermeneutics was used as theoretical and methodological basis in the thematic analysis of the participants' discourse. **Results:** On the theme suffering, the categories allow to understand the impact of suffering on patients with MS. On the theme faith, the categories allow to understand that, in the presence of the MS stressor events, beliefs, spiritual and religious practices can help patients meet the challenges that arise in their health-disease continuum. On the theme sense of coherence (SOC), the categories allow to realize that the SOC in these patients is acquired when they develop the ability to identify, mobilize and use resources in the confrontation of and relief from their suffering, with faith representing one of those. **Conclusion:** Faith, as a general resistance resource for the person with MS, when mobilized to tackle the disease, provides the acquisition of a SOC that allows these patients to achieve positive health outcomes, and should be a resource offered by the health professionals.

Descriptors: Multiple Sclerosis; Faith Healing; Health Promotion.

RESUMO

Objetivo: Compreender a percepção que as pessoas com Esclerose Múltipla (EM) têm em relação ao seu sofrimento pessoal e se a fé é um recurso interno que utilizam para diminuir o sofrimento. **Métodos:** Estudo de abordagem qualitativa, centralizada nos temas sofrimento, fé e sentido de coerência (SOC), a partir de entrevista semiestruturada. Participaram do estudo 15 pacientes com EM pertencentes à uma associação de apoio ao doente com EM (Portugal). As entrevistas decorreram de setembro a outubro de 2015, em local previamente acordado com os entrevistados. Para a categorização dos dados que resultaram das entrevistas, partiu-se de temas estabelecidos a priori. Utilizou-se como fundamentação teórico-metodológica a hermenêutica na análise temática da fala dos participantes. **Resultados:** No tema sofrimento, as categorias permitem compreender o impacto do sofrimento nos doentes com EM. No tema fé, as categorias permitem compreender que, perante os eventos estressores da EM, as crenças, as práticas espirituais e religiosas podem auxiliar os pacientes a enfrentarem os desafios que se apresentam no seu continuum saúde-doença. No tema sentido de coerência (SOC), as categorias permitem perceber que o SOC nestes pacientes é adquirido quando desenvolvem a capacidade de identificar, mobilizar e utilizar recursos no enfrentamento e alívio do seu sofrimento, sendo a fé um deles. **Conclusão:** A fé enquanto recurso geral de resistência da pessoa com EM, quando mobilizada para enfrentar a doença, contribui para a aquisição de um SOC que permite ganhos em saúde para estes pacientes, devendo ser um recurso oferecido aos pacientes pelos profissionais de saúde.

Descritores: Esclerose Múltipla; Cura pela Fé; Promoção da Saúde.

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RESUMEN

Objetivo: Comprender la percepción de las personas con Esclerosis Múltiple (EM) respecto su sufrimiento personal y si la fe es un recurso interno utilizado para disminuir el sufrimiento.

Métodos: Estudio de abordaje cualitativo centrado en los temas sufrimiento, fe y sentido de coherencia (SOC) a partir de la entrevista semiestructurada. Participaron del estudio 15 pacientes con EM de una asociación de apoyo al enfermo con EM (Portugal). Las entrevistas se dieron entre septiembre y octubre de 2015 en un sitio de acuerdo a los entrevistados. La categorización de los datos de las entrevistas se ha iniciado a partir de temas establecidos a priori. Se utilizó la hermenéutica como fundamentación teórico-metodológico para el análisis temático de las hablas de los participantes. **Resultados:** En el tema sufrimiento, las categorías permiten comprender el impacto del sufrimiento en los enfermos con EM. En el tema fe, las categorías permiten comprender que, mediante los eventos de estrés para la EM, las creencias, las prácticas espirituales y religiosas pueden auxiliar a los pacientes a afrontar los desafíos que se presentan en su continuum salud-enfermedad. En el tema sentido de coherencia (SOC) las categorías permiten percibir que el SOC en esos pacientes es adquirido cuando desarrollan la capacidad de identificar, movilizar y utilizar recursos para el afrontamiento y alivio de su sufrimiento, siendo la fe uno de ellos. **Conclusión:** La fe en cuanto un recurso general de resistencia de la persona con EM, cuando movilizadora para afrontar la enfermedad contribuye para la adquisición de un SOC que permite ganancias en salud para esos pacientes y debe ser un recurso ofrecido a los pacientes por los profesionales sanitarios.

Descriptor: Esclerosis Múltiple; Curación por la Fe; Promoción de la Salud.

INTRODUCTION

Several authors have pointed out that spiritual/religious beliefs constitute a factor of resistance (and not merely of resilience) to human pain and/or suffering⁽¹⁻³⁾.

In a previous study⁽⁴⁾, an attempt was made to understand the concepts of suffering and faith in people with multiple sclerosis (MS), in the various stages of the disease, including those in palliative care units. Associations were found suggesting that faith functions as an inner resource for the person's resistance to suffering, as it enables them to understand and manage the suffering caused by the disease, as well as improves their internal sense of coherence, as the individual transcends, experiences and assigns a less negative meaning to their suffering.

Regarding the definition of faith, the authors used philosophical theology⁽⁵⁾ (Christian orientation), as opposed to spirituality⁽⁶⁻⁸⁾. Thus, succinctly, faith refers to the confident surrender to the designs of a transcendental

entity, in which one recognizes a deep love. It is, therefore, an experience far beyond the pure human rationality and that holistically⁽⁹⁾ involves the human being undergoing such experience. Faith may, or not, be linked to religious life experiences, marked by symbolic rituals. Spirituality, so far as it is concerned, is linked to a broader and more diffuse dimension of beliefs, usually defined around the ability to attribute meaning to the world⁽¹⁰⁻¹³⁾.

The concept of suffering can be understood as a multidimensional and dynamic experience of severe stress that occurs in the face of events that threaten the integrity of the person as a whole, in which the regulatory processes, which would normally lead to adaptation, when become insufficient, lead to exhaustion of the individual^(14,15). The concept of sense of coherence (SOC)⁽¹⁾, for its part, comprises three dimensions that help the individual to adapting and overcoming their suffering in a healthier way, to the degree that they are able to understand suffering (dimension: sense of comprehensibility); to manage and mobilize the different resources at their disposal (dimension: sense of manageability); and to give a new meaning to this suffering, making it less negative (dimension: sense of meaningfulness).

Considering these assumptions, the authors have analyzed, in an earlier stage, the possible relation between the reduction of suffering in chronic patients with MS and their dimension of faith, in the theological sense. Seeking to gauge the correlation (or not) between these two experiences that are so deeply subjective, complex, and simultaneously so human, a measuring instrument was constructed and validated to evaluate the influence of faith in the management of human suffering. In this instrument, four categories were analyzed: intrapersonal suffering; interpersonal suffering; the awareness of suffering, and spiritual suffering⁽⁴⁾.

Given the nature of the phenomenon under study, and for a better understanding of it, the authors, in addition to the quantitative methodology, resorted to the qualitative methodology, which privileges the understanding about the meanings attributed to the events by the participants of the research⁽¹⁶⁾. Thus, the objective was to understand the perception that people with Multiple Sclerosis have in relation to their personal suffering, and whether faith is an inner resource that they use to reduce suffering.

METHODS

This is a study of qualitative approach, centered on the concepts of suffering, faith and sense of coherence. Hermeneutics constitutes its theoretical and methodological rationale⁽¹⁷⁾. The term hermeneutics expresses the art of

interpreting⁽¹⁷⁻¹⁹⁾, considering how the interpretive concepts of detachment, appropriation, explanation and understanding are placed between language and the lived experience. Its initial function is to understand how to orient in a situation. Understanding is not related to the presentation itself, but to the probability of being. One should not forget, when taking the methodological consequences of this analysis, this point: to apprehend a text is not to verify an inert sense included in it, but to present the possibility to be pointed out by the text⁽¹⁹⁾.

Through an association for support of patients with multiple sclerosis, the MS patients who had previously participated in the quantitative study of the main investigation *Suffering and Faith in People with Multiple Sclerosis*⁽⁴⁾, in Portugal, were invited by the author to later integrate this qualitative study. In close collaboration with the association, patients who demonstrated preservation of communication and cognition were selected for the study. The participants who accepted the invitation chose the place where they would like to be interviewed, reaching a total of 15 MS patients. The criterion adopted for delimitation of the sample size was the saturation of the content of the information presented by the research participants. It is considered that the theoretical saturation of categories occurs when no relevant or new data emerges⁽¹⁶⁾.

The interviews were held from September to October 2015. Each interview had an average duration of 30 minutes. An iPod-type audio recorder was used to record the interviews.

The understanding of the text and the interpretative process of the thematic contents of the life narratives of

the study participants could be represented through the interview, transcribed into texts, and interpreted by the author⁽²⁰⁾. Interviews are one of the relevant methods in the qualitative research of the hermeneutical type, as they enable the collection of descriptive data from the interviewees' discourse, supporting the researcher on the development of ideas concerning the way the research participants can understand the world⁽²¹⁾. Taking into account the subjective nature of the research, the semi-structured interview was used as an instrument for collecting information, this being one of the methods regarded most adequate when one intends to learn of the experiences and perceptions of the participants⁽²²⁾.

The guiding questions of the interview (Chart I) were based on the concepts mentioned (suffering, faith and sense of coherence), which resulted in themes; and, from the interviews emerged the categories based on the themes.

For the thematic analysis of the narratives, we tried to understand them through a process involving several stages: the reproduction of the interviews in text, the superficial comprehension, the structural investigation and the comprehensive apprehension of the text⁽²⁰⁾. This is a participatory process, arranged in the form of a spiral, as it relates the parts of the text to the whole and reciprocally⁽²⁰⁾.

The study was approved by the Ethics Committee of the Abel Salazar Institute of Biomedical Sciences (ICBAS), University of Porto (UP), under opinion no. 060/2014. Any element that would allow the identification of participants or persons cited was suppressed and assigned a letter (p=participant) and a number for identification of each interview. The informed consent form was filled out by each participant.

Chart I - Themes, categories and guiding questions. Portugal, 2015.

Themes	Categories	Questions
Suffering	Inner distress; chronicity; threat to the integrity of the personal identity.	<ul style="list-style-type: none"> - What has changed in your life after learning that you have MS? - Can you identify a moment in this process of illness that has been too painful and has been considered by you with much suffering? - Some say that one learns from suffering. Do you agree with this view?
Faith	Confidence; being unconditionally loved; Grace of God.	<ul style="list-style-type: none"> - Do you consider yourself a person with a religious faith? Of what kind? - Characterize how you live your faith.
Sense of coherence (SOC)	Sense of comprehensibility; sense of manageability; sense of meaningfulness	<ul style="list-style-type: none"> - Do you understand why you are in suffering? - When in suffering, how do you try to reduce it? - Do you often feel in suffering?

RESULTS AND DISCUSSION

The interviews were conducted in places of reference for the patients. The 15 patients were interviewed (at their request) in different places: one was interviewed in a palliative care unit; two were interviewed at their workplace; four were interviewed at their home, and eight were interviewed at the hospital during treatments for MS.

As these 15 patients had participated in the first phase of the investigation (quantitative study)⁽⁴⁾, the authors had already obtained their sociodemographic characterization: the mean age of the participants is 45.33 years, minimum 31 years and maximum 60 years. Six participants are men and nine are women. Of the 15 participants, 7 (seven) had secondary progressive multiple sclerosis (SPME) (which is initially characterized by bouts of remission and, later on, becomes progressive, developing a gradual loss of function, with recoveries that are often incomplete); 7 (seven) had relapsing-remitting multiple sclerosis (RRMS) (characterized by outbreaks lasting from days to weeks, and then disappearing), and 1 (one) had primary progressive multiple sclerosis (PPMS) (characterized by slow crisis, with steady worsening of symptoms and involving areas of the central nervous system (CNS), without remission of the initial crisis). The average number of years of diagnosis is 12.13, with a minimum of 1 year and a maximum of 36 years.

Data concerning the themes suffering, faith and sense of coherence (SOC) are presented next:

Chart II deals with the theme *suffering* and with the three categories: inner distress, chronicity, and threat to the integrity of the personal identity.

The MS is a disease that presents with outbreaks and remissions, giving the patient a false sense of security and confidence in its stabilization, sometimes leading them to consider the possibility of experiencing cure. This uncertainty⁽²³⁾ causes suffering in people and families who experience these situations with the disease. In the different categories identified in the theme of suffering – inner distress, chronicity, and threat to the integrity of the person – it is possible to identify the impact of this suffering on their lives.

In the category *inner distress*, feelings of fear were identified, in association with the presence of outbreaks of the disease, the loss of autonomy, and the degree of disability that they may experience in the near future (P1, P7, P9, P13).

MS, as a chronic and highly disabling disease⁽²⁴⁾, has an important social dimension, since the age range for the diagnosis is between 20 and 40 years of age^(25,26), that is,

in young adults, a period that is crucial for academic and/or professional development. Through the discourse of the participants, the suffering posed by the incapacitation caused by the disease at the level of work and employability (P4-5, P8-9, P13-15) is identified in the category *chronicity*. The participants verbalize that they feel able to work, to produce, although at different speeds (P3). Fatigue is a very present symptom (P8-9, P12-14), leading them to express that they have experienced feelings of social marginalization when they divulged to their employers their health condition (P3). Despite the condition of suffering they are undergoing due to the chronicity of the disease, the participants report that “they have learned”, that is, they were subjects of their own learning (P2, P5 P13-15), face to face with the suffering caused by the disease⁽²⁷⁾.

With regard to the category *threat to the integrity of the personal identity*, the origin of the suffering in the study participants seems to be related to symptoms or processes (physical or of other nature) (P4, P8, P10-11, P13-14) that pose a threat to the integrity of the person⁽²⁸⁾. The participants verbalized that they feel threatened in their integrity when they perceive the loss of links (P1), experience feelings of social discrimination (P3, P7, P8), experience feelings of despair and distress (P2, P4, P8, P14) and experience the loss of autonomy (P4, P7).

As to the theme of faith in the face of the MS stressful events, spiritual and religious beliefs and practices can help patients meet with the challenges brought by the disease. God is the ultimate meaning of the believer’s existence. The Christian faith characterizes the life of those who believe in God. Thus, the Christian faith translates into welcoming into your life the love and grace of God confessed in Jesus Christ. The certainty of unconditional love on the part of God and the justification of sin by the grace of Christ provokes inner security in those who believe, inducing them to confront any obstacle, preparing for love and solidarity⁽²⁹⁾.

In relation to the theme *faith* (from a Christian theological perspective), three categories were named: confidence, being unconditionally loved, and grace of God (Chart III).

In the category *confidence*, some study participants revealed trust in a supreme being (P5, P11), which transcends them and gives meaning to their lives and motivates the existence of each person⁽¹⁰⁻¹²⁾. However, they point out that this supreme being could intervene in a more beneficent way (P2, P8), helping them to eliminate suffering instead of relieving it, because they feel that the confidence placed in Him has been ignored by Him.

As to the category *being unconditionally loved*, it is verified that, in the face of adversity and disease, the feeling of being unconditionally loved by God leads the person to

Chart II - Theme: Suffering. Portugal, 2015.

<p>Category: Inner distress</p> <p>Question: What has changed in your life after learning that you have MS?</p> <p>P1 <i>"It has changed a lot [pause] ... I was afraid of being in a wheelchair. I already knew other people who had the disease and were in a wheelchair. At the time I was still working and walking and I was very scared ... very afraid that one day I would be like that [looking at the wheelchair that he currently uses]."</i></p> <p>P1 <i>"Mudou muito [pausa]... fiquei com medo de ficar numa cadeira de rodas. Já conhecia outras pessoas que tinham a doença e andavam numa cadeira de rodas. Na altura ainda trabalhava e andava e fiquei com muito medo...muito medo de um dia ficar assim [olhando para a cadeira de rodas que atualmente usa]."</i></p> <p>P7 <i>"[...] but I, always with that fear of going out and falling, I do not feel at ease. Sometimes I go to places that are not right, safe, and we are there, full of fear..."</i></p>
<p>Question: Can you identify a moment in this process of illness that has been too painful and has been considered by you with much suffering?</p> <p>P9 <i>"I, sometimes on the street, I was afraid that sometimes it would happen to me, as I have sometimes arrived from work... but this is not something deadly at once!"</i></p> <p>P13 <i>"A lot of things have changed [between crying and laughing], a lot... I've been looking more at my son, fearing that I might not see him [pause, silence]... see him growing up!"; "I recently injured myself on the leg [showing the area], I broke my leg and I'm afraid to use excessive strength and do some stupidity again [...]" "Aaaaahhh I'm afraid I will not be able to play soccer again with him [son], run again, ride a bike again. "; "But, I don't know, fear persists, [...] We are afraid!"</i></p>
<p>Question: Some say that one learns from suffering. Do you agree with this view?</p> <p>P5 <i>"We have to accept that, get a book and start reading... and force myself to do things that... to be patient!"</i></p>
<p>Category: Chronicity</p> <p>Question: What has changed in your life after learning that you have MS?</p> <p>P4 <i>"[...] I do very little at home and am super tired. [...] I's been two years since I stopped working.</i></p> <p>P5 <i>"Childhood educator [...] it is very complicated. I could not make it, and the very people in the group were the ones who suggested me to ask for retirement. I was 49 years old. I was missing a lot, when I outbreaks occurred I stayed at home for 1 month [...]"</i></p> <p>P8 <i>"It makes you tired, it makes you really tired. I've been at home since I was 40, [...] but I was forced to stop working because of the outbreak that I had, which left my whole body numb."</i></p> <p>P9 <i>"Some days I feel super tired indeed... I forget... now I'm on leave. I've been on leave for two years and..."; "I used to played soccer, that's it, there was always some activity to be done. I quit everything, I cannot!"; "I have several sequels. Everything has changed! Everything! I don't feel like doing anything."</i></p> <p>P12 <i>"I used to like to do anything at home, that a man likes to do [...] vacuuming the car, washing, I don't do much, but I get really tired."</i></p> <p>P13 <i>"[...] I need strength and I do not have it."</i></p> <p>P14 <i>"I get too tired."</i></p>
<p>Question: Can you identify a moment in this process of illness that has been too painful and has been considered by you with much suffering?</p> <p>P1 <i>"I thought I was good with the treatments, that I would get better... but it doesn't look like [pause]... over the last 20 years, I've been getting worse and worse."</i></p> <p>P3 <i>"I thought I would succeed and that I would get a job. But I don't have it, unfortunately, I do not. If it happens that we come to an employer and, in the middle of the interview, we tell him we have a chronic problem but that it does not a reason for quitting doing things. Ok, with more difficulty, slowness, but we get there. Then they say 'aaahh' and unfortunately no one wants to know about that."</i></p> <p>P6 <i>"... the loss of memory was what shocked me the most... [pause] I am unlearning, more and more."</i></p> <p>P7 <i>"[...] What has cost me most was to stop working."</i></p> <p>P10 <i>"[...] then, as age passed, I felt more limitations"; "and then, for getting out of the car? It was the biggest problem for me!"; To get out of the car, wow, it cost me a lot. I was exhausted!"</i></p> <p>P11 <i>"Truly, what changed in my life... it was when I had the outbreaks."</i></p> <p>P14 <i>"[...] for having Sclerosis, I became out of work."</i></p>

Question: Some say that one learns from suffering. Do you agree with this view?

P2 “[...] in order to take the medication, I go every 4 weeks, I take the computer with me, I watch some movies, and I spend a different moment there, but... I feel tired during that day, no wonder, so many hours there...” One learns, one learns, for example, ready, since I have this problem I’ve learned, for example, in my case, at work, to know how to control myself, and to know how to stop when I am exaggerating.”

P5 “But I have a lot of pain, I really have to stay very quiet!”

P13 “Aaaaahhh ... through suffering one learns but, at the same time, one becomes more stubborn. I’ve become more stubborn, I’ve learned to fight more. To struggle to be more independent. “

P14 “Yes, yes, no doubt, no doubt. We learn much more through suffering (...) I have learned over the years to attach value. This is what we must do, to attach value to the people who are by our side (...). Attach value to our health!”

P15 “Yes, yes, I’ve learned from suffering. It is like this, I’ve realized that I had to live with it (...). With this disease, I’ve learned that one should not make plans in life (...) One day at a time. That way one manages to live well.”

Category: Threat to the integrity of the personal identity

Question: What has changed in your life after learning that you have MS?

P10 “Lack of independence! It’s traumatic! It is, indeed. This causes me a lot of suffering and sadness because, sincerely, I was a person who did not stop at home, I really like handwork and even that, I cannot do, because my right side was the one that was affected. I cannot even write.”

P11 “It was in the first year. Because I had never heard of this disease, I did not know what it was, and thereafter it was like that, there were very strong outbreaks but, fortunately, it’s in remission. It’s all gone, but I remember that, at the beginning, maybe during the first treatments, I felt almost paralyzed!”

Question: Can you identify a moment in this process of illness that has been too painful and has been considered by you with much suffering?

P2 “Three years ago the shock was realizing what this was ... but what cost me most was thinking that I might not be present for my children.”

P3 “[...] at the time of the examinations at the University, when I had a tonsillitis and had to miss an exam ... Aahhh, and it cost me! I, now of all times, I cannot undergo the exam, I had to miss it! I had to miss it! And then I just thought ‘what now?’!”

P4 “[...] it was when I had an outbreak and I stopped waving my hand... my right arm. I wanted to feed the girl, care for the girl, alone at home and I couldn’t, I couldn’t!”

P7 “[...] what made me suffer the most is that, sometimes, I want to be with my colleagues from the ranch, that I love the ranch, and not being able to go there.”

P8 “People are afraid of this disease. Me, having it, I’m not so afraid, but other people, when they know I have this disease, they say like this ‘you have that?!’ By doing this, they scare me! They make the disease even worse than it is. There was an outbreak that made me [...] I even thought I was going to die. I really thought I was going to die, it was such a thing... my mother, who was there by my side, said that my eyes were rolling back, only because of the suffering that I was going through! I was conscious and all that! It was such a horrible suffering!”

P9 “Yes, yes, I have a very difficult time for me. That’s when I got my whole body asleep. It took a long time... about 2 months! I had no sensitivity in the body.”

P14 “It was in 2009, no, in 2010, by the end of the year, when I stopped seeing. I only had contact with people, my vision did not focus. And just knowing that I would come close to my daughters and could not see them [expression of facial anguish in a grimace], it was the worst thing in the world! I always said ‘wheelchair is the last thing I wanted!’ But no, not being able to see, it’s much worse, my God, a thousand times worse! Not seeing the people we like, not being able to take a look at them, sometimes they have a smile on their face and it’s the eyes that tell you that... it costs me so much!”

Question: Some say that one learns from suffering. Do you agree with this view?

P13 “The worst moment was to fall into reality! It was. When I started the treatments.”

P7 “It’s like this, you learn something ... you know, we have never experienced something like that, have we? (...) How can we get around something like that?”

Chart III - Theme: Faith, Portugal, 2015.

<p>Category: Confidence</p> <p>Question: Do you consider yourself a person with a religious faith? Of what kind? Characterize how you live your faith.</p> <p>P2 “I asked myself, ‘My God, why me?’ Isn’t it? If I’m a good boy, I treat my children well, I treat my wife well, I do not steal, I do not kill [gesturing and enumerating with the fingers]... I don’t know... why... if I go every year to São Bento, by the way, I go to São Bento to ask for other people who are sick and everything. And now ‘me?! But why?!’. That’s it, I was like this at first... a little angry with God, right? But then it passed... “</p> <p>P3 “I believe... that a special person has appeared for... that special person, they say he had a Father. This Father is called, in my religion, attention, God! Aaaaahhhh and I ‘fire, and that God could not have come to Earth?!’ So excuse me, if He was Uno, or whatever they say, that, honestly... I am putting doubts, if this God or this Jesus was only Love, only Love, only Love, why is it that people have,... have... ready, pathologies? “</p> <p>P5 “(...) This faith allows me to see things with... another eyes. Different eyes, which most people do not see, do they? People see the bad things [emphasizing the word ‘bad’] and I see the things... the Good and the bad things. This is given to me by faith, the belief.”</p> <p>P8 “When I get worse, I turn to my Faith. Even so, I’m keeping faith that God is going to take this disease of me for good. Yes, yes, yes, I hope that one day one finds the solution to this. I used to go to mass on Sundays, but the truth is one, I, ever since, since, since this came to me... I know that God exists but I started thinking that God... that He has left me behind, me. [...] Does God exist?! Why did... why did this disease come to me? I remain the same but now I go when I feel like [to mass]. He reminded of me to give me this disease, but he forgot me to take it away! “</p> <p>P11 “I have Faith that Someone dominates us. We don’t walk here by chance. Now this Someone... I do not know... could help me more ... but He helps this way, it’s not that bad [laughing].</p>
<p>Category: Being unconditionally loved</p> <p>Question: Do you consider yourself a person with a religious faith? Of what kind? Characterize how you live your faith.</p> <p>P8 “There’s something that moves me inside, that I cry, I do not know what it is, I cannot explain it to you. I can’t even understand myself. This has helped me with the disease, it’s not just the job, it’s not only the job. It makes me believe that there is Something that has a supernatural force, stronger than what we can imagine. For me, there is something that helps me in terms of the disease. It gives strength, gives strength, it seems to fulfill us. It’s like this, people in a certain situation are ‘breathless’, they want to breathe and cannot, and there is Something that fills our chest with air and lets us breathe, that’s all.”</p>
<p>Category: Grace of God</p> <p>Question: Do you consider yourself a person with a religious faith? Of what kind? Characterize how you live your faith.</p> <p>P5 “I have Faith. How do I live it? I am grateful for the disease every day, everything I have, even the disease, I also thank, because it is all part of the experience, our life experience, and then I see everything with the eyes more open, I see everything with more color. I do not see black.”</p> <p>P15 “Yes. I’m Catholic. For me faith is like this: it means one has a belief in a Thing that they do not know, in fact, but that the force is so great that I think we can ask and there are things in which we are helped and that leads us to believe even more! I also know how to thank. [...] I feel good, I am very capable of asking, able to thank...”</p>

go through an experience of liberation, that is, of pure grace, of unconditional gratuity. The expression of this feeling appears through the narrative of one of the participants (P8).

Through the discourse of the participants and in a theological (Christian) perspective, faith in a transcendent entity (considered divine) guarantees, even in moments of great suffering, even if one suffers intensely or dies, the comfort of the experience lived with God and that everything

will end up well (given the belief in the afterlife), that is, the belief in the existence of a meaning for suffering that is not constructed by us (hence not understood as merely psychological by the interviewees), but rather a meaning that is a gift, a *grace of God* (category) and that gives them peace (P5, P8, P15).

Regarding the theme *sence of coherence* (SOC), three categories were defined, namely: sense of comprehensibility,

Chart IV - Theme: Sense of coherence (SOC). Portugal, 2015.

<p>Category: Sense of comprehensibility</p> <p>Question: Do you understand why you are in suffering?</p> <p>P4 “No, no, I am really fine with myself. I live with the disease very well. [...] I do whatever I feel like, I am lucky for having... possessing material goods that allow me to do that, right? Many also do not have that, but this... it all happened after the disease. In a natural way... material goods happened after I got sick, I’ve had bad times, but... but... the best ones have prevailed.”</p> <p>P7 “That’s the way it is, it’s hard for me to understand it, because I was a woman full of life and this happened all of a sudden... and I... I don’t know, I have the revolt for having to be me, ready, for this being given to me.”</p> <p>P9 “No, in the face of what I have seen of other colleagues [people with sclerosis] and everything, I still feel quite, quite happy. It’s true, but I’ve seen these things, and I say ‘...I’m still very well!’ That I can still, I have autonomy... I do not understand anything! I sometimes in the morning when I get up I think, not think, I am sure, I’m more tired than if I’ve been working all day, even harder, that’s true! Sometimes in the morning ... it makes me feel really down.”</p> <p>P14 “(...) attach value to the people who are by our side. The human value is far superior to what we see, far superior! To attach value to our health. We do not have the notion of the value that people around us have, for example. Knowing that we can reach... I think everyone should... [shaking his head], I think I can see clearly now ‘I have to take enjoy today, because I don’t know if tomorrow I’ll be fine, so I can walk, hang out with my daughters’.”</p>
<p>Category: Sense of manageability</p> <p>Question: When in suffering, how do you try to reduce it?</p> <p>P1 “I think of good things ... of the family.”</p> <p>P2 “That’s the way it is ... the best way is to grab my children and attach myself there [pointing to the wife and smiling with a small sob saying] to my wife! But hold on more to the kids.”</p> <p>P3 “Volunteering! With the same woman, M, the way she likes to be called.”</p> <p>P4 “I do not think much about things. I watch TV...”</p> <p>P7 “Look, I go to my mother’s. I spend the afternoon with my mother.”</p> <p>P8 “Look, I go home and I turn on the computer and listen to music.”</p> <p>Q9 “One thing that sets me free me a little bit and gives me a little more joy, is this sport that I’m practicing ... it’s paragliding.”</p> <p>Q11 “I have to leave the house! I have to go out!”</p> <p>Q12 “I’m always positive, I don’t block myself. I try to have more and more knowledge. I read, I read, I try to be informed.”</p> <p>Q14 “What I try to do is relax; I have always been like this. What I do is lie down on my bed, shut the door of the room, preferably without noise and I’m quietly there. Step by step I manage to get relaxed.”</p> <p>P15 “I try to forget. Forget. Working, working, one forgets.”</p>
<p>Category: Sense of meaningfulness</p>

Question: Do you often feel in suffering?

P1 “What I really liked was to have a normal life. I enjoyed working and hanging out with my friends so much ... being like this [bedridden]... so life for me... well, seriously, it’s worth nothing... nothing!”

P2 “Nooo, sorry... eeeeh what? [whispering]... honestly... last year it was frequent, a lot of times. Whenever I got the outbreaks... I felt really down, even ... as they say it in Portuguese ‘tacky!’.”

P3 “I’ve already thought about giving up. I’ve already tried to commit suicide because of this. I did not make it! [Smiling]. What a bummer! [Ironic].”

P4 “No, no, I am really fine with myself. I live with the disease very well. [...] I do whatever I feel like, I am lucky for having... possessing material goods that allow me to do that, right? Many also do not have that, but this... it all happened after the disease. In a natural way... material goods happened after I got sick, I’ve had bad times, but... but... the best ones have prevailed.”

P6 Ah, sad [sighing]... my limitation is so great, from the cognitive point... that... that I have an image, a negative image of myself, I suffered a lot for losing my abilities, yes! I am a service director, with responsibility, a very intellectual job, and this is the worst that could happen to me. Losing my cognitive abilities. This is painful. “

P9 “No, in the face of what I have seen of other colleagues [people with sclerosis] and everything, I still feel quite, quite happy. It’s true, but I’ve seen these things, and I say ‘...I’m still very well!’ That I can still, I have autonomy...”

P10 “No, no, I’m considered an optimistic person. I’m happy with everything. Money, I do not have financial problems, I even think I have more than I should. My house, my family, I love being at home. Before I was not used to hang out, and I feel sorry that I don’t do it! In fact, I don’t even know the world! (smiling).”

sense of manageability and sense of meaningfulness (Chart IV).

When addressing the theme sense of coherence (SOC), the category *sense of comprehensibility* portrays how the person perceives the stimuli, from the internal and external environment, as a systematic, condensed, organized and clear reference; which does not imply that the person seeks the stimuli to which they are subjected, but rather that they understand why they happen in such way. From the participants’ discourse, some demonstrate having this capacity developed through the use of material resources, optimism, positive perception and family support (P4, P14). Others, on the contrary, expressed feelings of revolt and maladaptation, demonstrating that they have not yet been able to develop this capacity (P7, P9).

As for the category *sense of manageability*, the participants’ discourse shows that almost everyone (even those patients who report not understanding their suffering) demonstrate the development of their management capacity, describing how they mobilize and use the general resources of resistance, namely art, sport, work, volunteering, contact with nature, relaxation and escape from reality, which helps them to ‘endure’ this suffering (P1-15).

Finally, in the *sense of meaningfulness*, the participants’ discourse demonstrates that they have developed the capacity to attribute a new meaning to life when verbalizing that they can identify the resources they have and manage them to deal with the disease and the suffering it causes (P4, P9, P10). However, other participants express feelings

of anguish, loss of perspective and hope of having a future, revealing that they have chosen to give up and, in the limit, when already desperate, have attempted suicide, thus demonstrating that they have not yet accomplished the effective development of this capability (P1, P2, P6).

Thus, it should be argued that hope refers to a positive outlook for the future. It leads the individual to acting, enabling him to facing the problems. It is characterized as a universal concept, which encompasses the quality of life and is related to the health status. The individuals, when experiencing illness, when they face it with hope, put their energy to the expectation of restitution of health and well-being⁽³⁰⁾.

Thus, developing hope is highly relevant for MS patients and their family as it motivates them to expect better days.

FINAL CONSIDERATIONS

In this study, different scenarios were unveiled by the patients with MS. They experience greater suffering at the family level when they feel they are losing their autonomy and feel that they represent a burden on their loved ones. On the other hand, they express a desire to see “the children grow up”, expressing feelings of fear and distress because they feel they can lose this possibility in the near future. This suffering should alert health professionals, as well as members of MS patient support associations, to the important role of families in the lives of patients.

Providing support, information and clarification of the doubts of the patients and their families may alleviate the anguish manifested by the participants. Also at the social level, suffering is expressed by the participants through the verbalization of feelings of sadness and indignation, because they feel prevented from playing an active role in the society in which they are inserted. Once again, professionals and associations are required to play a role in sensitizing and informing the society of the value and dignity of these people, and of the contribution that each one can give socially.

It can be understood that faith, as general resource of resistance of people with MS, when mobilized to confront the disease, provides the necessary “strength” and motivation to maintain the daily “struggle”, through the confidence in a superior being who is always present and love each one unconditionally. Finally, the SOC in these patients is acquired when they develop the capacity to identify, mobilize and use, beyond faith, other resources in coping and alleviating their suffering, gaining a new understanding and attributing a new meaning to reality. Despite the suffering they experience, the acquisition of the SOC promotes the health of these patients. This fact should alert health professionals to the need for creating conditions necessary for MS patients to practice meditation, prayer or any other practices of spiritual expression that have the ultimate goal of promoting the faith, always directed to the specific beliefs of each patient.

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