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Original Article

Multiple sclerosis and occupations: what I want to be able to do, but cannot always do

Esclerose múltipla e ocupações: o que quero conseguir fazer, mas nem sempre consigo

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Abstract

Introduction: Multiple Sclerosis is an autoimmune disease that affects the Central Nervous System. People with Multiple Sclerosis may experience difficulties in their occupations due to the interference of the clinical condition in their physical, emotional, social, and cognitive health. **Objective:** Considering the complexity of the illness process in these people's daily lives, the objective of this study is to understand how the occupations and realization of values of people with Multiple Sclerosis present themselves. As a theoretical foundation, Viktor Frankl's Occupational Science and Logotherapy stand out. **Method:** This is a qualitative, exploratory, descriptive research with a case study design, carried out in August 2022. For data collection and analysis, semi-structured interviews and Content Analysis were used, respectively. **Results:** Modifications, adaptation, transition, and occupational ambivalence based on the diagnosis stand out. The participant maintained a care routine that became the main occupations of her daily life and attribution of what it means to be independent. Furthermore, even in the face of the inevitable difficulties of life, the encounter of meanings can be referred to through the realization of attitudinal values based on the perspective of Logotherapy. **Conclusion:** It was possible to understand that occupations, in this case, express the realization of values, being intentional and meaningful for those who carry them out, enabling the encounter of meanings, the doing composed of forms, generating meaning and purpose to their existence.

Keywords: Activities of Daily Living, Autonomy, Cases Reports.

Resumo

Introdução: A Esclerose Múltipla é uma doença autoimune que atinge o Sistema Nervoso Central. Pessoas com Esclerose Múltipla podem apresentar dificuldades em suas ocupações devido às interferências do quadro clínico em sua saúde física, emocional, social e cognitiva. **Objetivo:** Considerando a complexidade do processo

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de adoecimento no cotidiano dessas pessoas, o objetivo do presente estudo é compreender como se apresentam as ocupações e a realização de valores de pessoas com Esclerose Múltipla. Como fundamentação teórica, destacam-se a Ciência Ocupacional e a Logoterapia de Viktor Frankl. **Método:** Trata-se de uma pesquisa de abordagem qualitativa, exploratória descritiva com delineamento de estudo de caso, realizada em agosto de 2022. Para a coleta e a análise dos dados, foram utilizadas a entrevista semiestruturada e a Análise de Conteúdo, respectivamente. **Resultados:** Destacam-se as modificações, adaptação, transição e ambivalência ocupacional com base no diagnóstico. A participante mantinha uma rotina de cuidados que se tornaram as ocupações principais do seu dia a dia e atribuição do que é ser independente. Além disso, mesmo diante das dificuldades inevitáveis da vida, pode ser referido o encontro de sentidos por meio da realização de valores de atitude com base na perspectiva da Logoterapia. **Conclusão:** Foi possível compreendermos que as ocupações, neste caso, expressam a realização de valores, sendo intencionais e significativas para quem as realiza, possibilitando o encontro de sentidos, o fazer composto pelas formas, gerando sentido e significados à sua existência.

Palavras-chave: Atividades Cotidianas, Autonomia, Relatos de Caos.

Introduction

Multiple Sclerosis (MS) is an autoimmune, inflammatory and demyelinating disease targeting the Central Nervous System (CNS). The brain, brainstem, optic nerves, and spinal cord are commonly damaged (National Multiple Sclerosis Society, 2024).

Therefore, the clinical signs and symptoms of MS are varied due to the multiple structures affected, with common symptoms being: fatigue, spasticity, gait instability, urinary retention or incontinence, cognitive impairment. The latter can be presented through attention deficits in executive functions and, in more severe cases, dementia (National Multiple Sclerosis Society, 2024; Rodrigues, 2020; Sampaio et al., 2020; Cabeça et al., 2018).

Regarding the clinical course of the disease, it follows two phenomena: outbreak and progression. Outbreaks are understood as acute inflammatory processes that occur in the CNS of a person with MS and can last days or weeks and, when resolved, may or may not leave sequelae. Progression does not depend on inflammation, it is a continuous process of deterioration in the CNS, and new symptoms may appear along the way. It is worth mentioning that each person will present different processes in relation to time, symptom and course of the disease (Didonna & Oksenberg, 2017; Rodrigues, 2020).

Even though it is a singular process, the literature organizes four categories of the disease: 1. Recurrent-remitting: there are outbreaks, with total or partial recovery, however, in the period between outbreaks there is clear clinical stability; 2. Secondary progressive: the disease begins in the relapsing-remitting category and assumes a gradual progression, with or without flare-ups; 3. Primary progressive: continuous progression since diagnosis, however, there may be small improvements in the course; 4. Progressive remitting: continuous progression since diagnosis, but it is possible to observe flare-ups with or without full recovery of affected functions, and there is progressive worsening independent of flare-ups (Didonna & Oksenberg, 2017; Rodrigues, 2020).

According to Rodrigues (2020), a peculiar issue in relation to MS concerns the prognosis. Although there are some signs of prognosis, it is difficult to determine the evolution of the disease at an individual level due to the plurality of highly debilitating symptoms. The author also states that uncertainty regarding the prognosis is inherent to this pathology and promotes emotional suffering, and says that MS is "a disease where the only certainty is the uncertainty of the future" (Rodrigues, 2020, p. 27).

In this scenario, it is possible that the person diagnosed with MS will experience interference in their daily lives, whether through physical losses or emotional states. In the occupational sphere, interferences were identified, such as the case study presented by Preissner et al. (2016); the literature review by Campos & Toldrá (2019); and the study by Pimentel & Toldrá (2017) addressing the use of the self-healing method to assist people with MS in body perception, reduction of symptoms, improvement of functional capacity.

For Romero-Ayuso (2010), the main characteristic of an occupation is having a meaning for the person and culture. Thus, an occupational being is constituted over time and culture (Reed et al., 2013). Consequently, occupations can be carried out collectively by groups, communities and populations or individually, therefore, occupations involve elements of the person and the environment in which the occupation is carried out (Fogelberg & Frauwirth, 2010). Furthermore, occupations refer to any activity or task necessary for self-care (e.g., eating, dressing), productivity (school, work, household activities), or leisure activities (World Federation of Occupational Therapists, 2012), and occur over time in different contexts, they have objectives, meanings and usefulness for people. Occupations involve several daily activities, which also promote different experiences during the activity (American Occupational Therapy Association, 2020).

Thus, considering the importance of occupations for human beings and to better understand them, the perspectives developed within the scope of Occupational Science stand out as a theoretical reference. Occupational Science allows us to understand occupations in their nature, in their relationship with health and well-being and the factors that can influence and modify occupations (American Occupational Therapy Association, 2020; World Federation of Occupational Therapists, 2012).

In this context, we ask ourselves: what is it like for a person with MS to stop or modify the performance of pleasurable occupations or that were previously part of the routine? Testa (2019) believes that, when a person is diagnosed with MS as a chronic, incurable disease, with an unknown prognosis, that person may experience moments of anguish and despair. Even in this situation, for the author, individuals with MS can find strategies to continue living and face the disease, seeking the meaning of life.

Regarding the meaning of life, Frankl (1987) believes that, faced with life's adversities, we choose how to position ourselves. For the author, we are not free from problems, illnesses, suffering, but we are free to decide how to face each situation.

Frankl's concepts walk through the understanding of meaning and, in Frankl's Logotherapy, meaning is giving shape to a specific situation, living with meaning is related to employing aptitudes, abilities, emotions and will in the service of a certain circumstance that cannot be changed, which may be related to love for someone or doing things for oneself and others (Carrara, 2016).

For people who are diagnosed with MS, the diagnosis may represent a situation of intense suffering, changes in routine, fear, uncertainty, but, for Frankl (1987), individuals can find meaning in suffering, such as through Living Values and Attitude Values (Testa, 2019), for example. Living Values are understood as what the world can provide, for example, love, kindness, nature, truth; Attitudinal Values are related to coping with circumstances. In the case of MS, for example, the circumstance cannot be changed, so the person can find meaning in this process by developing different ways to do so (Frankl, 1987; Testa, 2019).

In this scenario, we are faced with a chronic disease, with an uncertain prognosis and related to various situations at the individual and social level. MS may be related not only to functional decline, but to occupational losses and psycho-emotional suffering. Therefore, this study sought to answer the question: what do the occupations and realization of values of people with MS look like? Furthermore, it aimed to: understand the occupations and evaluate the realization of values of people with MS.

Materials and Method

Type of research

This is a qualitative research with an exploratory and descriptive nature, with a case study design.

The qualitative approach refers to various perspectives, modalities, approaches and techniques, therefore, it is a polysemic term, that is, it refers to various practices that seek to understand subjective social questions (González, 2020). For Minayo (2017), qualitative research deals with the magnitude of phenomena, seeks singularity and meanings, being the type of research that pays close attention to the sociocultural dimension that is expressed through beliefs, values, opinions, representations, forms of relationship, symbols, uses, customs, behaviors and practices, thus making this type of research complex and necessary to answer questions from different areas.

According to Yin (2015), the case study method investigates a phenomenon in its real environment, that is, it seeks to know about the object in its context with its particularities. Still according to the author, this is a relevant method for answering “how” and “why” a certain phenomenon happens.

According to Gil (2008), case studies have the following purposes: explore real-life situations whose limits are not well defined; describe the situation in the context in which a particular investigation is being carried out; and explain causal variables of a given phenomenon in very complex situations in which other methods, such as experimental ones, are not possible.

Search location

The research was carried out in August 2022, remotely, using the Google meet platform, totaling 2 (two) synchronous meetings. We emphasize that the study participant was presented with the possibility in person and at home, but the remote modality was chosen due to the functional status and availability of the participant.

Study participant

A person diagnosed with Multiple Sclerosis participated in the study. They found out about the research through an invitation on social media. The participant met the inclusion criteria, which were: being a person diagnosed with Multiple Sclerosis; both sexes; over 18 years of age; show interest in voluntarily participating in the research; read and accept the Free and Informed Consent Form (TCLE).

Collection procedures

The research followed the following steps: Semi-structured Interview; Expressive Activity Workshop and use of Field Diary as a recording instrument. These three procedures were used following the needs of the research design, and for better data triangulation. Therefore, the text sequence will describe the procedures and how they were used in this study.

An interview guide was used, which consisted of two parts. The first contains sociodemographic data of the participant and the place where the research was carried out, including: age, sex, education, marital status, profession, monthly income, means of transport, housing, whether they have a paid job, time since diagnosis, comorbidities, whether is monitored on a public, private network or both and by which professionals they were regularly monitored. In addition to these data, the Kurtzke Expanded Disability Status Scale (EDSS) was attached to the interview script, an instrument used to evaluate and monitor the progression of the disease through the weighting of 8 (eight) functional systems, namely: Pyramidal Functions, Cerebellar Functions, Brain Stem Functions, Sensory Functions, Bladder Functions, Intestinal Functions, Visual Functions and Mental Functions. On this scale, the higher the score, the greater the disabilities present (Kurtzke, 1983).

The second part consisted of questions about occupations, with the following questions: 1. *Tell me who you are?* This question aimed to get to know the participant and understand how they perceived and identified themselves. 2. *Tell me about your occupations throughout your life?* With this questioning, the objective was to understand the occupational trajectories, what the participant did in different periods of her life; *3. Tell me what your occupations are currently like?* With the aim of obtaining information about what the participant currently does (at the time of the research) and possibly analyzing whether there were any interferences after the MS diagnosis; 4. *Is there meaning in these occupations?* The objective was to understand the “why” of the occupations that this participant has carried out; 5. *Are there meanings in the occupations you carry out? If so, which ones?* This question, as well as question 4, intended to obtain information about the subjective dimension of the person during the process of occupying themselves, their intrinsic motivations and feelings during the occupation; 6. *We understand how to realize value in something we create and offer to the world. When you engage, are you offering any value? If so, what would it be?* With this question, the aim was to evaluate the realization of values for the participant; 7. *How do you evaluate this* *moment of participation in the research?* This questioning aimed to encourage the participant to express their participation, as well as the researcher's guidance.

The second stage of data collection was the Expressive Activity Workshop, which was used as a possibility to understand and collect information about the experiences of people with Multiple Sclerosis. The Expressive Activity workshop was recorded through photography and through two open-ended questions that were audio recorded: *Tell me about what you produced. And what was it like for you to participate in the Expressive Activity Workshop?*

The Expressive Activity Workshop was used in this study with the aim of providing the participant with a creative space so that she could freely express how she feels and thinks in relation to the occupations she carried out and, later, talk about what she produced.

At this stage, plastic materials were made available to the participant, such as colored pens, glue, glitter, blunt scissors, A4 paper, ballpoint pens, colored pencils, crayons, magazines for cutting and pasting, among others. Along with this material, the participant was instructed to express themselves freely, about how they felt about their occupations, as described below: *Today, we are going to carry out another stage of the research and I offer you some materials: colored pens , glue, glitter, blunt scissors, A4 paper, ballpoint pens, colored pencils, crayons, magazines for cutting and gluing. With this, I invite you to express how you feel and think regarding your occupations.* At the end, the participant was invited to answer the following questions: *Tell me about what you produced. And what was it like for you to participate in the Expressive Activity Workshop?* It should be noted that this stage was carried out in a synchronous remote format. At this point in the study, the participant was informed at the end of the interview that they would carry out an expressive activity workshop, which was carried out 7 days after the first stage of the research due to the participant's availability, with the command given only on the day of the activity.

The participant was welcomed and received the information that they could have as much time as they needed, that they could close the camera if they felt necessary and that the researcher was available for any difficulties or needs that arose. The participant needed approximately 1 hour to complete the activity.

The Field Diary was also used in this study. According to Oliveira (2014), the field diary is an instrument of descriptions, notes about the investigation being conducted. For Freitas & Pereira (2018), this instrument allows a review of practice and allows for a critical analysis of intervention approaches.

For this study, we highlight that this instrument was relevant because it favors the qualitative analysis of the data and the particularities that emerged in the collection process. The field diary allowed the researcher to write down the participant's characteristics and personal feelings in relation to each meeting with the participant, which contributed to data analysis and the conduct of the case study.

Data analysis procedure

The qualitative analysis of the data was developed based on the answers to the questions, which were recorded in audio, transcribed in full, with the texts, when necessary, undergoing linguistic corrections, however, without eliminating the spontaneous nature of the statements. Data recorded in photographs and audio recorded from the Expressive Activity Workshop and the researcher's field diary were also analyzed.

Regarding the analysis method adopted, there is Content Analysis proposed by Bardin (Bardin, 2011). According to the author, content analysis is a set of communication analysis techniques, which follow the analysis organization criteria: pre-analysis, exploration of the material and treatment of results.

Data validation

After full transcriptions and corrections, when necessary, the transcriptions of her interview and expressive activity workshop were sent to the research participant so that they could read, add or modify any information contained in the transcription.

The participant completed this step and returned it to the researcher. When returning, the participant indicated in the body of the text by highlighting colors what they would like to add, in green, and what they would like not to be mentioned in the results, in red. The researcher reinforces that the results presented follow these requests.

Ethical issues

All precepts of the Declaration of Helsinki (Associação Médica Mundial, 1964) and the Nuremberg Code (Código de Nuremberg, 1947) were met, respecting the Norms for Research Involving Human Beings 466/12 (Brasil, 2012), 510/16 (Brasil, 2016) of the National Health Council and the guidelines for research procedures at any stage in a virtual environment published by the National Research Ethics Commission (Comissão Nacional de Ética em Pesquisa, 2021). Accordingly, the letter for analysis of the research project was forwarded to the coordination of the Research Ethics Committee. Thus, the present study was approved by the Research Ethics Committee of the Institute of Health Sciences of the Federal University of Pará, under number 5,502,603. All participants read and signed the Free and Informed Consent Form (TCLE).

Results and Discussion

The results and discussion present content that responds to the research objective. For a better understanding of the study, we will present two categories, which were titled “About Alana” and “About the realization of Alana’s values”.

About Alana

The name Alana means the one who is “Harmonious”, “Beautiful”, but it also means “Landmark of Conquest”. There is a probable explanation that the name arose among the Celtic people with origins in *Allan, Allen*, through the Gaelic *Ailène, Ailin*, with its meaning “stone” or “rock”, in reference to a landmark of conquest (Dicionário de Nomes Próprios, 2008). Given these characteristics and definition, we present the case of Alana, a woman who presented herself as competitive, cheerful and very willing to overcome challenges.

Alana, when invited to tell about herself, reported: *"Me! I am a human being who has had a boom in life. (Alana)."* Alana was single, 36 years old, a Pedagogue by training, she was diagnosed with Multiple Sclerosis at the age of 24 and, according to what she told us, the diagnosis came at an inopportune time, according to the following report: *"I had never heard of in Multiple Sclerosis. Then, I was full of things I wanted to do alone. I was full of things to do, (…), at the age of 24! (Alana).*

Alana characterized herself as a happy person, but who, at times, felt the desire to be alone, as reported below: "cheerful, sometimes I get very irritated, sometimes I want to be alone, you know?". She also considered herself an objective person: *"So, (…), to resolve things well, (…), well, (…), in an objective way, in an objective way, you know?"* (Alana).

Alana also presented her preferences: *"I like sports. I like winning! I'm very competitive!"* (Alana). This characteristic of Alana was presented in several reports during the meetings, *"I love competing! I like winning!"* (Alana).

To the researcher's eyes, Alana presented herself as a happy woman, with a contagious smile, sweet speech, calm, interested, with a lot of willingness and desire to express herself, in addition to overcoming many daily challenges imposed by the diagnosis. Alana, for the researcher, was a woman who allowed herself to change in the face of a markedly adverse situation, Multiple Sclerosis.

Alana, when asked about her occupations, began by presenting her conception of occupation:

> *Of things that I do, of things that only I can do. They can't do it for me, I always want to be able to do it, however, I can't always do it.* (Alana).

The report presented aspects of Alana's individuality, *"things that only I can do"* (Alana) and a possible desire to get involved in occupations that are not always possible: *"I always want to be able to do them, however, it is not always that I can"* (Alana). This difficulty in occupational involvement could be linked to the functional condition in which Alana found herself.

Regarding her functional condition, until the day of the interview, Alana was at level 6 (six) on the EDSS scale. This means that the person needs constant intermittent or unilateral assistance (canes, crutches) to walk around 100m with or without rest and 2 (two) or more Functional Systems in Moderate Disability (Brasil, 2015). In the case of the participant, she reported a diagnosis of neurogenic bladder, neurogenic intestine and needing an assistive mobility device. Alana also had visual difficulties and provided specialized support for these demands.

However, despite the difficulties, Alana presented herself as a motivated and active person and, when asked about what her occupations were like throughout her life, she reported: *"Look, I always think about doing a lot of things because I want to forget and/or escape from MS and tell myself that I can and do things"* (Alana). From then on, it was possible to understand that Alana's occupational involvement entailed meanings of belonging and usefulness, that is, based on this report, we can think that Alana tried to tell us that: having her limitations entailed many difficulties, but human doing it allowed him, for a moment, to forget his diagnosis and provide her with usefulness in what she wanted to accomplish. This possibility of understanding that Alana presented to us reflects what Wilcock (1999) wrote about occupations as a constant movement of what we are, do and seek to be, as well as the means of becoming different and of what is necessary for well-being.

Therefore, it is understood that when Alana, intentionally, seeks to do something to feel good and say yes to life, despite MS, she experiences an occupational process that transforms her and that can cause her well-being, as it realizes a value attitudinal. However, for Romero-Ayuso (2010), when occupations do not achieve the expected objectives, they can also interfere with the person's sense of efficacy, therefore, we cannot say whether in all occupations Alana could have the same feelings of potential.

When asked about what her occupations were like throughout her life, Alana says that she always thought about doing many things to forget about MS and recalled, in a nostalgic tone, the moments when she was a volleyball player:

> *Look, I always think about doing a lot of things because I want to forget and/or escape MS and tell myself that I can and do things. I used to play ball (volleyball), travel, I was on the Pará national team for 4 years of my life. I traveled and gave, signed autographs, a lot of things. But, after the sclerosis, I tried sitting volleyball, but then it didn't work out very well because my knee hurt a lot. And then I tried,* (…), *because, well, I like sports. I like winning! I'm very competitive*! (Alana).

In Alana's report, we noticed that the occupations were related to the desire for competence and, even after the diagnosis, the desire to remain active led her to the path of adapting the activity, but that also had to be interrupted by physical pain.

It is also believed that Alana's sporting experience could be a factor that enhanced her desire and engagement in occupations, since, in most sports, competition is necessary to have a winner, with those with better resourcefulness always receive highlights. So, whenever Alana returned to the subject of competition, it led us to think that Alana was competing with her own ability and skills:

> *Currently, I'm trying to do my routine. Monday, Wednesday and Friday, I will train. I do weight training. And,* (…), *I do pee physiotherapy to train the bladder,* (...) *And Tuesday and Thursday I have hydrotherapy, I have to walk in the pool. I know how to swim too. Before I swam. When the University was nearby, I swam. I wanted to compete! I love competing! I like winning!* (Alana).

This report also shows us that their occupations were related to maintaining health, well-being and personal satisfaction. This is because Alana's routine was permeated by treatments that became her main occupations, such as Physiotherapy, Bodybuilding and hydrotherapy, for example, and no longer the sports she previously practiced.

After the diagnosis of MS, there may be occupational changes. The study by Franco et al. (2022), in research that aimed to understand the difficulties and contextual factors (environmental and personal) that acted in the daily activities of people with MS, found that the participants presented greater difficulties in relation to mobility and life activities, such as walking long distances and carrying out household tasks.

Preissner et al. (2016) also describe that occupations can suffer interference associated with MS. Thus, the person may have difficulty performing tasks that they like or need to do, causing changes in their occupational routine.

In Alana's case, she expressed with a sad voice that the change in independence was related to the need to constantly communicate to her family what she wanted to do. The participant interpreted this as, despite being a matter of care on the part of the family, the loss of her independence:

> *Today, it's as if I have to tell everyone where I'm going* (as if I've lost my independence). *Everyone wants to know where I'm going. Then it's like I'm trapped, sometimes. I know and I also understand that people care about me. Because I can't do everything I want to do. I understand. But I stay. Then, I go,* (…), *I go and end up diminishing myself. Even the tone of my voice, it's not a very incisive tone, you know,* (...). *I'm more,* (…), *I'm going to learn, I'm going to see what's the best way to do it. I will try,* (…), *I am always here to try to do the best, always.* (Alana).

It was possible to reflect that the understanding of being independent will not always be associated with doing something without help, in isolation, but also receives influence from others and the context in which they are part. Therefore, we think that, for Alana, independence would be related to being able to occupy herself without the need for approval or release from another person.

In this context, independence from an occupational perspective is related to the person's satisfaction in relation to their participation in the occupation, that is, if even with physical aids or performance assistance the person feels satisfied with the way in which they perform their occupations, so it is independent in this aspect (American Occupational Therapy Association, 2020). In this sense, Alana reports: *"Today, it's as if I have to tell everyone where I'm going (as if I had lost my independence)"* (Alana). Thus, we can understand this perspective of independence that involves individual capabilities and the environment in which one lives.

Therefore, Alana showed us that MS caused occupational changes over time, changes that were, until the time of the research, beyond physical limitations, in the field of emotions, self-perception and relationships. Furthermore, Alana went through an occupational transition; This occurs from a problematic situation which results in change and/or continuity of habits that are developed in occupations. Occupational transitions are commonly described in studies that address changes or maintenance of health behaviors (Fritz & Cutchin, 2017).

Occupational transitions could be noticed when Alana stopped being a player and became a person with MS with pain that limited her from continuing to play the sport. But, despite the difficulties, Alana made an effort to remain active and, like a born competitor, competed with her own limitations to stay active and healthy, carrying out her therapies and treatments. As for the meanings of the occupations she carries out, Alana, in a few words, attributes it to independence: *"like, I do it to make me feel more and more independent"* (Alana).

It is understood by meaning, based on the perspective of Occupation Science, as being a subjective dimension that occurs from the completion of the occupation, therefore, arising from the interaction between the person and the environment, generating singular value on what has been accomplished (Carrasco & Olivares, 2008; Jáuregui & Lucero, 2013). Salas & Lanas (2019) understand meaning as the subjective effects from occupational experiences, effects that influence experiences.

Given this, we understand occupational meaning as being the intrinsic and subjective reason that a person attributes to their occupation. In Alana's case, when asked about this meaning, she reported that she was busy to feel independent. For Reed et al. (2013), occupations have always been part of humanity, as human beings are occupational beings. Thus, we understand that occupations are also part of culture and, culturally, value is added to doing and people are expected to carry out their activities independently. Therefore, it is believed that, when Alana attributed meaning to independence, this feeling could have an influence on what was culturally constructed, since, for Romero-Ayuso (2010), occupations occur over time and are influenced by culture.

In this case, independence is sometimes related to being able to do something, and sometimes it is compromised by having to depend on someone to carry it out or for supervision. The duality of feeling in relation to an occupation is what we understand as occupational ambivalence (Hoppes, 2005). This process can occur whenever the occupation was carried out routinely and, after some loss, the level of difficulty or impediments increased. Or, when occupations do not achieve the expected objectives, this can also interfere with the person's sense of efficacy (Romero-Ayuso, 2010).

Thus, we understand that Alana's occupations went through modifications, adaptations, transitions and ambivalence. However, even in the face of this situation, the participant maintained a care routine, care that became the main occupations of her daily life and attribution of what, for Alana, is to be independent.

On Alana's realization of values

Alana, when asked about realizing values, reported:

> *I think so. Because I,* (...), *there are so many people who, theoretically, have all the movements. That you don't have multiple sclerosis and that you don't do it because you're lazy, that sort of thing. But what should I do? to change,* (...). *My example may change. People about looking at life differently. In addition to having to change myself, my example, I can change someone else's life too. To see that I can do it. To see that this other person who looked at me can also achieve it if they want. Because we only change when we want to.* (Alana).

Alana told us that her example can change other people, because, even with her limitations, she carried out activities, challenged herself and, despite the diagnosis, she chose to be active, and her way of living changed herself and, her life, became what I offered to the world: *"In addition to having to change myself, my example, it can change someone else's life too"* (Alana). For her, her occupations were also what she offered to the world, intending to contribute to those who needed to respond to adverse and limiting situations.

The realization of values can be understood as a way to find meaning in life (Frankl, 2011); From this report by Alana, we can understand that we are facing an attitudinal value. This means about the attitude that Alana adopted in the face of her suffering and difficulties caused by MS. This attitude made her decide to follow a routine permeated by activities, and this inspired her to continue, which she highlighted as being an example for the world.

Alana highlighted that many people may stop doing something out of laziness – the participant's expression – but that, despite having MS and its limitations, she carried out activities within her possibilities, and this made her a reference of strength, determination and of love for life. For Frankl (2011), the value of attitude is the reason why there is always a meaning to life, because, even when faced with immutable suffering, being deprived by the health condition of producing something for someone or experiencing experiences as value, the way a person experiences their suffering becomes a value that is given to the world.

We also have Alana's production, carried out in the expressive activity workshop as the second stage of the research. This tool has already been used in other case study design research, citing Corrêa (2009), who used free expressive activity. Gomes (2021) also used this tool with the aim of accessing new data regarding the experiences of people who were on hemodialysis. Therefore, it presented itself as a sensitive and efficient instrument for case study and, in Alana's example, it was also possible to notice these aspects.

Alana chose to express herself through drawing (Figure 1), which portrayed a person with many challenges and reported: "I exclude myself, but I challenge myself to achieve"; "They seem like they don't believe in you/me", "I feel diminished" and "sometimes sad".

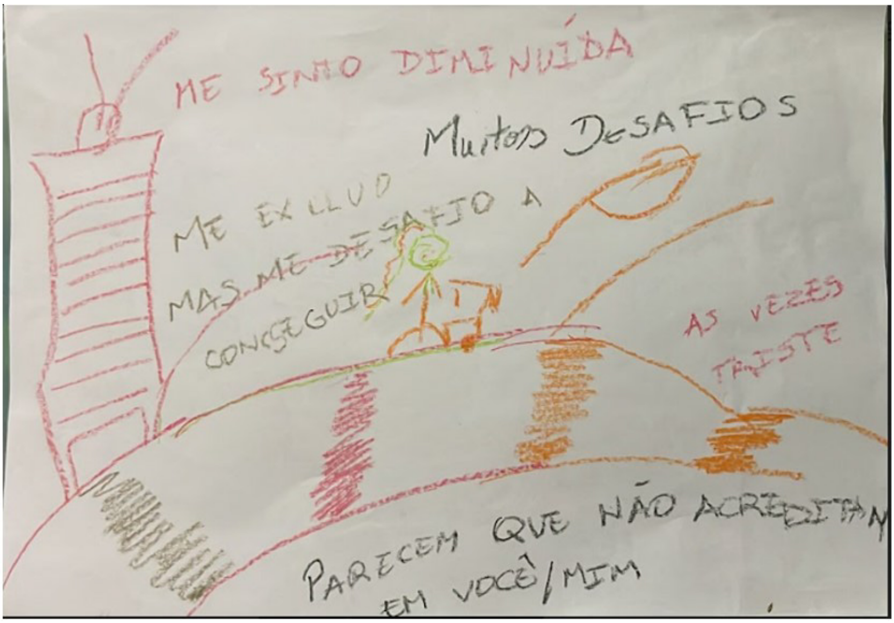

Figure 1. Production of the Expressive Activity Workshop - Participant Alana.

Source: Field research. Subtitles for the figure: "Me sinto diminuída" means "I feel diminished"; "Me excluo, mas me desafio a conseguir" means "I exclude myself, but I challenge myself to achieve"; "Muitos desafios" means "A lot of challenges"; "Às vezes triste" means "Sad sometimes"; "Parecem que não acreditam em você/mim" means "It seems like they don't believe in me".

Through this workshop, the participant was able to materialize her thoughts and feelings in relation to her occupations. During the first part of the research (interview), Alana reported that she had many challenges, and that she sometimes found it difficult to communicate what she wanted and in the way she wanted. However, the workshop provided the opportunity for the participant to organize her thoughts and represent, through drawing, her feelings and thoughts in relation to her occupations.

In this scenario, it was possible to notice that the expressive activity workshop as a research tool proved to be sensitive not only to understand about the occupations, but about the possibility of the occupations being part of or the realization of meaning in the participant's life. This makes us reflect that occupations can be a way to transform suffering into the realization of meaning.

Despite being full of words like “difficulty” and “sadness”, we highlight something that became a characteristic of Alana (in the researcher’s eyes): challenge. Alana wrote in front of what would be the biggest challenge: “I exclude myself, but I challenge myself to achieve it” and has an arrow pointing forward.

It is understood that, despite the difficulties and all the feelings of regret that Alana had when working, in the situation she found herself in, the participant chose to continue challenging herself and trying to carry out her occupations. This pointed us to the perspective of Logotherapy, as Alana was faced with a difficult and unchanging situation, she was dealing with feelings of sadness that could be a result of her diagnosis, but Alana took a stand and said “yes” to life and decided to continue challenging herself.

Despite being faced with a situation that cannot be changed, Alana was challenged by life to change herself and, despite the diagnosis and given what she could do, Alana reported that keeping busy is what made her alive:

> *Look, I think it's to feel alive. Again, like I once was. Not exactly, but still. Like, feel alive. Feel useful. Feeling capable of doing anything. And always do more, do better, carry more weight. Then, when I go to the gym, I look at the teacher and say to him: I did it! 15 reps, 20 reps. And he looks like this… 'yeah, Alana!' So, I don't diminish myself, I always want more to do, I always challenge myself to do more, do something different, something like that. Feeling alive.* (Alana).

In this way, we understand that Alana's occupations could be a means for realizing values and finding meanings, the work composed of forms, senses and meanings was what made Alana feel alive. According to Frankl (1987), living is related to fulfilling the tasks posed by life, which are required of each person. And this could be seen in Alana's report, because what life demanded of her was being accomplished and was the reason she felt alive.

Final Considerations

Through this case study, it was possible to meet a woman with MS, who spoke about her difficulties in living and participating in everyday activities. During the research, the participant had space to talk about herself, reflect on her tasks and how she felt when carrying out her daily tasks. He experimented with expressive activities and was able to use creativity as a means of communicating to the world about himself and his occupations.

Through the analysis of the materials, it was possible to obtain data and reflections about the participant, about the occupational context, about values from the perspective of Logotherapy. Therefore, the study presents a reading and results to analyze MS from a perspective that encompasses both clinical and experiential and occupational aspects of the pathology. Regarding the occupational context, the case presented shows that there are modifications, adaptation, transition and occupational ambivalence following the diagnosis of MS and during the experience of being a person with MS within the singularities of this case.

Based on the case studied here, the occupations in which she participated, for the most part, were those related to health care related to MS, providing a strong indication for thinking about how and where people allocate their time. This study reveals that people with MS may face difficulties in carrying out their occupations due to functional losses and symptoms of the disease, as is the case, for example, with pain.

Furthermore, the study led to the understanding that, despite being faced with a limiting and unchanging situation, it is possible for people with MS to realize values through the occupations they develop. The realization of values according to Franklian understanding is the way to find meaning in life. Therefore, we believe that, by understanding and talking about the values she offers to the world and how she positions herself in the face of limitations, the participant was able to reflect on her existence and understand that, despite the difficulties, she is accomplishing something unique, and that no other person can accomplish.

As potentialities of the study, we highlight the method used, which was sensitive and suitable for triangulating data and collecting information and systematization necessary for the case study. As limitations of the study, we highlight access to the participant. This is because even though 3 (three) formats were available for meetings (remote, home, in-person), the remote format was the only one accepted, and in this format, we faced difficulties, such as connection instability and difficulties in managing the platform. However, these limitations were overcome with help and guidance. We also highlight the need for studies with larger populations that can investigate aspects related to occupations and the possibilities of loss and grief in the context of Multiple Sclerosis, as well as health care.

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Author's Contributions

Jeice Sobrinho Cardoso participated in preparing the research, obtaining, analyzing and discussing data, in addition to preparing and reviewing the manuscript. Airle Miranda de Souza participated in reviewing the manuscript. Victor Augusto Cavaleiro Corrêa guided the research, participating in the analysis, discussion and interpretation of data, in addition to preparing and reviewing the manuscript. All authors approved the final version of the text.

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