

METABOLIC SYNDROME: EXPERIENCES IN RELATION TO HEALTHCARE

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ABSTRACT

Objective: to interpret the experiences of people with metabolic syndrome in relation to healthcare.

Method: this is qualitative research using Grounded Theory as a method and Symbolic Interactionism as a framework for analysis. It was carried out at a Basic Health Unit in the city of Marília/SP, Brazil, with 24 interviews in three sample groups (patients, family members and healthcare professionals), from February 9, 2022 to January 16, 2023.

Results: a total of 734 codes were identified and grouped into categories and subcategories, with the central phenomenon being “(Not) Taking Care of Health”, which is characterized as a dualistic process that encompasses both neglect and care. Aspects relating to neglecting health include the categories: “Considering not having health problems”; “Having difficulties understanding and resisting following care”; and “Lack of adherence to treatment”. In the aspect of taking care of the health, there are the categories: “Understanding that they have metabolic syndrome”; “Receiving guidance”; and “Counting on support”.

Conclusion: the experience of people with metabolic syndrome permeates the biological, psychological, social and spiritual spheres, as they deal with their health problems according to the social interaction maintained with themselves and other people. Therefore, meaningful communication and bonding with healthcare team are the main tools for adherence to treatment.

DESCRIPTORS: Metabolic syndrome. Health promotion. Lifestyle. Noncommunicable diseases. Primary health care.

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SÍNDROME METABÓLICA: VIVÊNCIAS EM RELAÇÃO AO CUIDADO COM A SAÚDE

RESUMO

Objetivo: interpretar as vivências de pessoas com síndrome metabólica no que se refere ao cuidado com a saúde.

Método: pesquisa qualitativa utilizando como método a Teoria Fundamentada nos Dados e como referencial para análise o Interacionismo Simbólico. Foi realizada em uma Unidade Básica de Saúde do município de Marília/SP, Brasil, com 24 entrevistas em três grupos amostrais (pacientes, familiares e profissionais da saúde), no período de nove de fevereiro de 2022 a 16 de janeiro de 2023.

Resultados: identificaram-se 734 códigos que foram agrupados, chegando-se às categorias e subcategorias, tendo como fenômeno central “(Des) Cuidando da saúde”, que se caracteriza como processo dualista que perpassa tanto pelo descuidando quanto pelo cuidando. Os aspectos referentes ao descuidando da saúde incluem as categorias: “Considerando não ter problemas de saúde”; “Tendo dificuldades de compreensão e resistência para seguir os cuidados”; e “Faltando adesão ao tratamento”. No aspecto cuidando da saúde, encontram-se as categorias: “Compreendendo que possuem síndrome metabólica”; “Recebendo orientações”; e “Contando com apoio”.

Conclusão: a vivência das pessoas com síndrome metabólica perpassa pelas esferas biológica, psicológica, social e espiritual, pois eles lidam com seus problemas de saúde de acordo com a interação social mantida consigo próprio e com as demais pessoas. Portanto, a comunicação significativa e o vínculo com a equipe de saúde são as principais ferramentas de adesão ao tratamento.

DESCRITORES: Síndrome metabólica. Promoção da saúde. Estilo de vida. Doenças não transmissíveis. Atenção primária à saúde.

SÍNDROME METABÓLICA: EXPERIENCIAS EN RELACIÓN CON EL CUIDADO DE LA SALUD

RESUMEN

Objetivo: interpretar las experiencias de las personas con síndrome metabólico en relación con la atención sanitaria.

Método: investigación cualitativa utilizando la Teoría Fundamentada como método y el Interaccionismo Simbólico como referencia de análisis. Se realizó en una Unidad Básica de Salud de la ciudad de Marília/SP, Brasil, con 24 entrevistas en tres grupos muestra (pacientes, familiares y profesionales de la salud), del 9 de febrero de 2022 al 16 de enero de 2023.

Resultados: se identificaron 734 códigos que se agruparon en categorías y subcategorías, siendo el fenómeno central el “(Des) Cuidado con la Salud”, que se caracteriza por ser un proceso dualista que abarca tanto el abandono como el cuidado. Los aspectos relacionados con el abandono de la salud incluyen las categorías: “Considerar no tener problemas de salud”; “Tener dificultades para comprender y resistirse a seguir los cuidados”; y “Falta de adherencia al tratamiento”. En el aspecto de cuidar su salud, existen las categorías: “Entendiendo que tienen síndrome metabólico”; “Recibir orientación”; y “Confiar en el apoyo”.

Conclusión: la experiencia de las personas con síndrome metabólico permea los ámbitos biológico, psicológico, social y espiritual, ya que abordan sus problemas de salud de acuerdo con la interacción social que mantienen consigo mismos y con otras personas. Por lo tanto, la comunicación significativa y el vínculo con el equipo de salud son las principales herramientas para la adherencia al tratamiento.

DESCRITORES: Síndrome metabólico. Promoción de la salud. Estilo de vida. Enfermedades no transmisibles. Atención primaria de salud.

INTRODUCTION

As a result of the socioeconomic and demographic changes that have been occurring in Brazil and around the world, there has been a change in the population's lifestyle habits, which has become increasingly sedentary both at work and at leisure, changing their eating pattern, giving preference to industrialized foods composed of excess fat, mainly of animal origin, carbohydrates, sodium, and insufficient fiber intake¹. Such factors contribute to increased obesity, favoring changes in neuroendocrine mechanisms, including metabolic syndrome (MS)².

MS is characterized by a set of health conditions, such as the presence of hypertension (HP), abdominal obesity, dyslipidemia and changes in glucose metabolism, causing complex metabolic changes in the body, which triples the risk of developing cardiovascular diseases (CVD), increases the chances of developing type 2 Diabetes Mellitus (2DM) five times and doubles the risk of premature death, regardless of the causes².

In Brazil, its prevalence is estimated to be 38.4%, reaching more than 60% of individuals over 60 years of age. However, there is a lack of reliable estimates of the prevalence of MS, since it is necessary to confirm, through biochemical and anthropometric data, with national representativeness, which is not observed among the majority of studies, in addition to the existence of different criteria for defining MS, making it difficult to compare the populations studied².

Mortality from chronic noncommunicable diseases (NCD) in Western countries has decreased drastically in recent decades as a result of better prevention, diagnosis and treatment; however, in developing countries, it still represents major challenges for public health, and CVDs represent the main cause of death and disability in Brazil, causing more than 38 million deaths/year worldwide³.

In the Strategic Actions Plan for Tackle Chronic Diseases and Noncommunicable Diseases in Brazil 2021–2030, the need to understand the population's behavior and the aspects that can impact health at all stages of life is valued. Therefore, policies that encourage the population to adopt and maintain healthy behaviors are emphasized by creating conducive and accessible environments so that the population learns to choose correctly⁴.

To meet such needs, Primary Health Care (PHC) is considered a privileged place for developing individual and collective health actions involving the promotion, protection, rehabilitation and prevention of health problems. Such actions have a positive impact on individuals' health and autonomy and on the determinants and conditions of collective health, being able to prevent NCD risk factors from taking hold⁵.

MS treatment consists of improving lifestyle, considering changing eating habits, taking into account the quality and quantity of food consumed, aiming at weight loss associated with regular physical exercise. To this end, multidisciplinary interventions, both individual and in groups, can be used and demonstrate a reduction in MS parameters in studies⁶.

It appears that many people with MS face difficulties in following health guidelines because they do not fully understand their condition and how it should be addressed. There are also cultural and social factors that favor or hinder the implementation of the necessary actions⁷.

Due to the relevance of the topic in the context of public health, the difficulties encountered by people with MS in following the indicated treatment and the high risk of complications, this investigation starts with the following question: How do people with MS experience care for their health? Therefore, we aimed to interpret the experiences of people with MS with regard to healthcare.

METHOD

This is qualitative research using Grounded Theory (GT) as its method and Symbolic Interactionism as a framework for analysis. It was carried out at a Basic Health Unit (BHU) in a medium-sized municipality in the countryside of São Paulo, which has approximately 220 thousand inhabitants⁸. Its development was based on the criteria required by the COnsolidated criteria for REporting Qualitative research (COREQ)⁹.

GT seeks to generate explanations through the creation of grounded theories about a given phenomenon. It values the simultaneous data collection and analysis, favoring the understanding of experiences and meanings that individuals are experiencing in a given context with a focus on human interactions, behavior, perceptions and thoughts in relation to the situation they are experiencing^{8,10}. For this study, the Straussian approach was used, which allows the researcher to compare the information that emerged with the literature during the data collection and analysis process¹⁰.

Symbolic Interactionism, proposed by Herbert Blumer and adapted by Joel Charon, describes individual and collective human action and allows us to understand how people define reality and how they act on their definitions and beliefs. It focuses on the nature of interactions, the dynamics of social activities and the meaning of events for people, in the context in which they are inserted and in the actions carried out¹¹.

Three premises underlie Symbolic Interactionism: human beings act in relation to things according to the meaning they have for them; the meaning of things arises from social interaction or lack thereof; the meaning can be modified by a person's interpretation of experiences¹¹.

Furthermore, Symbolic Interactionism understands senses and meanings as a social product. Thus, this framework makes it possible to understand the meanings attributed and interactions that occur in the experiences of people with MS in the healthcare process¹¹.

The selected BHU has a population of approximately 18,000 inhabitants. It has a team of 32 professionals with high school or higher education from different categories.

The population of this study was made up of people diagnosed with MS living in the coverage area of the selected BHU. Inclusion criteria comprised having a diagnosis of MS according to the criteria established by the National Cholesterol Education Program's Adult Treatment Panel III (NCEP-ATP III), which consists of people who present at least three of the following conditions: men with abdominal circumference (AC) measurement ≥ 102 cm and women with AC ≥ 88 cm; triglycerides (TGL) ≥ 150 mg/dL; HDL cholesterol < 40 mg/dL in men or < 50 mg/dL in women; systolic blood pressure ≥ 130 mm/Hg and diastolic blood pressure ≥ 85 mm/Hg; and fasting blood glucose > 110 mg/dL¹²; presenting preserved cognitive capacity. Minors under 18 years old were excluded.

To identify people with MS, medical records of patients using ciprofibrate, provided by the Specialized Component of Pharmaceutical Assistance, were selected for analysis of laboratory tests and anthropometric data, checking whether users met the MS diagnostic criteria according to the NCEP-ATP III¹².

After identifying participants, a professional from the unit's team contacted them, informed them about the research and asked for authorization to provide the researcher with their telephone number.

Data collection took place from February 9, 2022 to January 16, 2023, after scheduling by telephone, in a room at the health unit or at participants' homes, depending on individual preference. The interviews were carried out by the first author, who is a male nurse, resident in emergency care, with a graduate degree in cardiology and works as a nurse in the hemodynamics sector and is studying for a master's degree. To do this, he received training and supervision from researchers experienced in the technique.

The interviews lasted from 21 to 45 minutes and took place privately, with only the author and the participant present. The speeches were recorded and later transcribed in full, guaranteeing interviewee confidentiality. There were no pilot testing, field notes, or repeat interviews.

The first sample group consisted of 15 people with MS (CP). Other sample groups were included to deepen knowledge and fill gaps that emerged during the interviews: the second sample group was composed of five family members (FA); and the third was composed of four PHC (PS) professionals of their reference.

Two people with MS, three family members and one healthcare professional refused, due to lack of interest or availability to participate.

The interviews were closed as soon as data saturation was achieved, and were discussed between the first three authors. There was no transcription returned to participants; however, information was analyzed by two professionals experienced in the methodology and with experience in the topic covered, considering that there was consistency of data and clarity in the main and secondary topics.

The interview script characterized participants in terms of sociodemographic and socioeconomic data (age, sex, marital status, skin color, education, work and income), also containing open-ended questions related to their experience, perception, knowledge, attitude regarding their problems health and what the consequences of these are on their daily life. From the medical records, the latest results of laboratory tests were collected (fasting blood glucose, HDL cholesterol, TGL), such as weight, height, Body Mass Index (BMI), blood pressure measurement, CA and medications for continuous use.

For interviews with professionals and family members, the interview script was adapted, maintaining the aim of identifying the experiences of people with MS in relation to healthcare. The characterization of family members included data regarding age, sex, kinship, education, skin color, work and income. Age, sex, skin color, training time and time working in PHC were collected from healthcare professionals.

Data were coded by the first three authors using Straussian GT as a method, with the first analytical step being open coding in which data is examined in detail, word by word and line by line, asking exhaustive questions, with the purpose of conceptualizing ideas and/or meanings expressed by participants, allowing us to understand what each data represents¹⁰.

In the second stage – axial coding –, data are regrouped according to their relationships and connections, developing more comprehensive explanations about the phenomena investigated through the classification, separation and synthesis of these codes, making them more targeted, selective and conceptual. This step enables better analytical understanding to categorize the data in an incisive and complete way, through an inductive and deductive movement, allowing the identification of patterns and relationships between the data, helping to build a deeper and more complete understanding^{8,10}.

Furthermore, in this second stage, coding paradigm (paradigmatic model) is used, formed by conditions, actions-interactions and consequences, which help to systematically order the data and identify relationships between the categories and the central phenomenon/category. “Conditions” refer to reasons or explanations, i.e., why/how people respond to problematic situations.

“Actions/interactions” are meanings attributed by them to the problematic events/situations experienced and how they manage/achieve their objective^{8,10}.

“Consequences” are the results of actions/interactions (physical, psychological, social). Selective coding selects the most relevant categories and integrates the data into a more comprehensive theory^{8,10}.

The research was approved by the Research Ethics Committee of the proposing institution and the Municipal Research Assessment Council of the Municipal Secretariat. Participants were informed about the purpose/procedure and signed the Informed Consent Form, respecting the principles of Resolution 510/2016 of the Brazilian National Health Council.

RESULTS

The age of people with MS ranges from 47 to 78 years (mean of 66.73): eight are female; 10 are married; nine identify themselves as white; 10 receive between one and five minimum wages; eight do not carry out work outside the home; and 10 have completed/incomplete elementary school. Mean diagnosis time of 13 years. Regarding health conditions, everyone has high blood pressure levels, use polypharmacy (mean of six medications/day), and three have normal BMI. As for laboratory tests, mean fasting blood glucose was 189 mg/dl, mean TGL was 481.6, mean HDL was 42, and mean CA was 103.6 cm.

In the second sample group, four are children and a spouse, with ages ranging from 34 to 72 years (mean of 45.4), four are female, identify themselves as white, receive between one and 5 minimum wages, have complete/incomplete high school, and three carry out work activities outside the home. Among the PS, their age ranges from 31 to 57 years, all female, identify as white, graduated between three years and 33 years and work in the area between five months and 33 years.

In the analysis, 734 grouped codes were identified, arriving at categories/subcategories and their connections. Experiences are characterized as a process that involves both carelessness, with numerous risk factors, and care, identifying the central phenomenon “(Not) Taking Care of Health”, as seen in Chart 1.

Chart 1 – Distribution of categories and subcategories “(Not) Taking Care of health”. Marília, SP, Brazil, 2023.

(NOT) TAKING CARE OF HEALTH PHENOMENON		
	Category	Subcategory
Not taking care of health	Assuming they have no health problems	<ul style="list-style-type: none"> • Reporting no symptoms • Denying the presence of diseases • Considering they have a normal life
	Having difficulties understanding and resisting care	<ul style="list-style-type: none"> • Disbelieving in necessary care • Having difficulties accessing healthcare • Considering that they take a lot of medications • Lacking meaningful guidance
	Lack of adherence to treatment	<ul style="list-style-type: none"> • Using medications irregularly • Abandoning treatment after improvement in laboratory tests • Having difficulty changing lifestyle habits
Taking care of health	Category	Subcategory
	Understanding that they have metabolic syndrome	<ul style="list-style-type: none"> • Recognizing the presence of disease • Recognizing the presence of complications • Identifying factors harmful to health • Making correct use of medications
	Receiving guidance	<ul style="list-style-type: none"> • Receiving nutritional guidance • Being guided to perform physical activity • Having guidance on medication use
	Counting on support	<ul style="list-style-type: none"> • Exercising faith • Feeling support from family members

Category 1 – “Assuming they have no health problems”

As participants have no symptoms and can lead a life without limitations, both they and their families do not consider MS to be a health problem, despite numerous changes in laboratory tests and using polypharmacy, which is also recognized by healthcare professionals as a limiting factor for awareness and investments in healthcare.

[...] and I'm normal, I'm not tired, I don't have palpitations, my house is in order, I go to my son's house and clean his house, so, for me, I'm a very healthy person (PC01). [...] but what problem are you talking about? Because for me she has nothing. It's busy all day here. [...] she wants to take care of everything (FA03). [...] it suggests that many people don't care about cholesterol, triglycerides, and altered blood sugar levels. For them, it is a natural thing (PF 03).

Category 2 – “Having difficulties understanding and resisting following care”

Difficulties are reported in following the prescribed care, due to disbelief in the necessary care, difficulty in accessing health services, considering that they take too many medications and that there is a lack of meaningful guidance. They disbelieve that care is effective, as they consider the habits they have maintained throughout their lives to be adequate, which do not impose restrictions. Furthermore, there is recognition that these changes are not easy, thus giving the idea that they do not significantly understand that these actions help prevent complications.

[...] he gave me a list, I took the list and threw it away. [...] I think that if I follow these guidelines, I will really die. I'm fine living the way I live, eating what I want and drinking what I want (PC07). [...] it is difficult to change some lifestyle habits [...] so I realize that they have difficulty understanding and even resist changing their lifestyle (PS01).

Regarding the lack of access, participants claim difficulties in scheduling appointments, laboratory tests and obtaining medications, in addition to considering the service provided by professionals to be inconsistent. Those who are able resort to doctors and private tests, if not, they give up treatment. It is also observed that they do not always undergo periodic appointments, and in this case, they continue treatment by repeating prescription.

[...] we never manage to make an appointment, [...] they don't even look at our face and give us these medications that are useless; they just leave us worse off than they were when we got there [...] and I decided to attend an appointment privately (PC11). [...] the prescription is a year old, but I go to the pharmacy and buy it (PC09). [...] polypharmacy is also considered a difficulty in following care due to the side effects presented. Furthermore, they do not believe in the need to use all prescribed medications, considering it to be an exaggeration. [...] I didn't feel well, we monitor our bodies and know when something is wrong [...] (PC 03).

[...] take a handful in the morning, one in the afternoon and one at night. Then I think, “God, why so much medication?” (FA 04).

People with MS point out lack of guidance to correctly follow what was prescribed, as appointments are carried out superficially: they hand out the prescription, advise how to lose weight and check blood pressure. Furthermore, they find it difficult to follow the instructions, and healthcare professionals consider that patients are resistant to following treatment.

[...] no, no one said anything [...] they just gave me the prescription and told me to measure my blood pressure [...] and said that I had to lose weight (PC 04). [...] they tell us things that are very difficult to follow. If I cook without fat or salt, my husband fights with me, it becomes difficult to prepare food separately (PC 15). [...] we even detailed a lot of easier paths for them, considering their financial condition, considering their social condition, but they are very resistant to following (PS 03).

Category 3 – “Lack of adherence to treatment”

There is also a lack of adherence to treatment in relation to irregular use of medications and abandonment after improvement in laboratory tests. Correctly following the diet and performing physical activity are important recommendations to prevent the progression of diseases and their complications.

Prescribing multiple medications, in addition to side effects, causes more difficulties for patients, favoring their suspension or irregular use. Instead of seeking guidance from the PS, patients act according to their wishes.

[...] sometimes I don't take it right, I end up forgetting, the time even sometimes goes by a little because I forget (PC2). [...] as I had diabetes, I took medication [...], she asked me to take it twice a day, but if it's high, I take it early, midday and in the afternoon (PC 08).

[...] it is common for patients to suspend drug treatment and opt for using natural medicines, believing that they are safer or less harmful to their health. [...] I think there's a lot of rubbish that we put into our bodies, so, at first, I wanted to try to lower it without this medication, just with the natural medicine that I make, and it's damn good (PC 14).

[...] patients tend to abandon treatment when they see an improvement in the results of laboratory tests, considering that they have already been cured. [...] they started using the cholesterol medication, then they take the test and see that it has improved, [...] they start to stop taking the medication (PF 01).

Regarding physical activity, numerous factors contribute to lack of adherence, such as physical limitations, laziness and lack of will. The same occurs in relation to food intake, as they claim not to find the necessary support from family members and difficulty in changing the habit of eating large amounts of food.

[...] (laughs) you know how it is, right? You get lazy, you have to feel like going for a walk (P03). [...] when I walked, I felt good, then I stopped because I started to not see (PC 08). [...] that's the problem, it's difficult at home, my wife makes dinner for everyone and I think they can go a month without drinking water if they have soda (PC04).

[...] for me, it's painful, because I like to eat large portions; when I abuse it, I take two cholesterol medications, I don't know if it helps, but it won't get in the way, right? (PC12).

Category 4 – “Understanding that they have metabolic syndrome” and its subcategories

When a person with MS recognizes the presence of the disease, its complications and factors harmful to their health, they end up understanding that, if they do not implement the actions, they may run serious risks. This way, they can motivate themselves to follow medical recommendations and adopt a healthy lifestyle.

[...] I just know that I have high blood pressure and cholesterol, I take medication, and if by chance a vein gets blocked it's dangerous to kill me [...] we hear that unregulated blood pressure causes these things, stroke, so I try to take care of that doesn't happen to me [...] I take my medications correctly, I try to walk every day [...] I eat a lot of fruit [...] (PC06).

It is also identified that participants value adherence to medication treatment considering that its use is good for their health. Faced with physical difficulties and the availability of access to some medications, they develop strategies to ensure continuity of treatment, and sometimes it is necessary to return to health services for adjustment in the case of side effects.

[...] because of my eye problem, what I can't see, the girls look at me, help me, I take it every day, I don't miss a day, always at the right time (PC08). [...] in relation to adverse effects, they seek to adapt to a change when they feel bad with the medication, but they do use medication (PS02).

Category 5 – “Receiving guidance”

Participants also state that health services provided significant information, both individually and as a group, encouraging them to make changes in their lifestyle habits, including a balanced diet, physical activity and medication use.

[...] they tell us to have a very regular diet, not to eat pasta [...] they told me to go on a diet and I walk; I never forget the conversations they had with me [...] there were some group activities and some individual ones, but always about food and exercise (PC 13).

Category 6 – “Counting on support”

In search of support to face the challenges of living with a chronic illness, people rely on religion and help from family members.

Through religiosity, individuals are able to deal with the stress and anxiety associated with chronic illnesses, which can improve general well-being, aiming for health to take care of themselves and their family. Support from family members through support during appointments/tests and during leisure time was considered an incentive to adhere to healthy lifestyle habits and treatment.

[...] ah, I have a lot of problems, high blood pressure, cholesterol and diabetes, but with God's faith we overcome. I play my part by taking medication and controlling my mouth, but whatever is meant to be will be (PC 08). [...] my wife, who takes care of the food, used to cook with lard, but with these problems here she can't use this or that, so she helps me (PC 13).

Theoretical Model – “Experience of people with metabolic syndrome in relation to healthcare”

Experiences are characterized as a dualistic process that involves both carelessness with countless risk factors and care, which allowed us to reach the central phenomenon called “(Not) Taking Care of Health”. The lack of care for health was interpreted as follows: due to absence of symptoms and the ability to live without restrictions, people with MS do not consider this condition to be a disease.

They state that they have difficulty adhering to the necessary care because they disbelieve in its effectiveness, considering their lifestyle habits to be adequate, in which there are no dietary restrictions, no need for physical activity and use of medications.

The lack of access to health services proved to be an obstacle, as participants reported difficulties scheduling appointments/laboratory tests and obtaining medications. For them, professionals are not attentive during monitoring and do not consider their particularities in light of prescribed guidelines. Polypharmacy was interpreted as a complex condition due to side effects and the belief that the use of multiple medications is not necessary and is harmful. As a consequence, they do not adhere to regular physical activity and have difficulty following a diet.

In the action/interaction movement, it is possible to record that people with MS use the guidelines as a trigger for changes in lifestyle and adherence to medication treatment, and are driven by acceptance of the disease and its complications, sharing responsibilities in the creation and implementation of a care plan.

It is also clear that the health service has the potential to provide significant information and that religiosity and support from family members are essential to guarantee changes in lifestyle.

DISCUSSION

Participant characterization data, such as advanced age, female gender, obesity, low purchasing power and lower level of education, are similar to those found in other research. Studies indicate that Brazilians over 60 years old have a higher prevalence of MS^{2,13}, especially among women, due to decreased estrogen during menopause, in addition to the greater propensity to develop MS in response to stress and socioeconomic factors¹⁴.

Obesity also has a significant impact on public health, as visceral adiposity can trigger several metabolic changes that increase the risk of developing HP, preexisting medical conditions, CVD and 2DM, the main components of MS¹⁵. Referring to marital status, living with a partner can contribute to treatment adherence, sharing of responsibilities and healthier lifestyles¹⁶.

Regarding socioeconomic conditions, results from different studies are consistent in demonstrating higher prevalence of MS among people with lower income, lower educational level and worse occupation, being mainly related to low adherence to health guidelines due to financial difficulties in purchasing food healthy or pay for physical activities, health programs and medicines when these are not available in the public network^{15,17}.

When interpreting the experiences of people with MS, it is possible to identify that they do not recognize their current health condition as a disease, as it is a silent disease, presenting symptoms in the most advanced stages. Another possibility may be communication during follow-up in health services, and when they receive information in a non-significant or comprehensive way, they begin to believe/understand that they are not sick¹⁸.

From the perspective of Symbolic Interactionism, the way in which a person acts towards the world represents the materiality of the product of human knowledge that emerges from the communicative capacity established through interactions between people, in which they share experiences. Therefore, given the confirmation of diagnosis and the guidance that this disease has no cure and that it can lead to health problems if not controlled, requiring a drastic change in lifestyle, one cannot expect this change to occur immediately, relying only on quick guidance, as it is through experience that people become social beings^{18,19,20}.

Socioeconomic, cultural, environmental, political factors, age, sex and genetics can influence habits, both individually and collectively, forming a particular lifestyle based on social relationships that integrate living conditions, pressure from family members and society, which direct the perception of individuals in their way of living. It can thus be inferred that there are subjective and intersubjective factors that permeate social relations through interaction, having language/communication as mediation²⁰⁻²¹.

In relation to life experiences, traumatic events, health problems or significant changes in personal or professional life can influence the choice of actions, so it is important that the healthcare team has a broader view and understands that individuals' lifestyle interferes with much more than just individual choices, as the context in which they are inserted is influenced, and it is up to professionals to understand each person's reality in order to establish a care plan suited to individual characteristics²².

Therefore, when considering that human action is based on the meanings offered, it appears that, in the case of a person with MS, it is necessary to give new meaning to the way they live, with a view to promoting changes in habits, since meanings are modified through an interpretative process of relationships with new elements¹¹.

The inclusion of pedagogical approaches in professional health practice aims to teach care practices based on daily reports of problems, experiences and attitudes of a person and/or their family members. Through this exchange of knowledge, it is possible to establish a strong bond between the team and the person/family, in addition to promoting a change in daily practices aimed at promoting health, contributing to an increase in quality of life and the development of a healthier community²³. Thus, reciprocal influences are established on users' and healthcare professionals' actions, with possibilities for new meanings in the healthcare process.

The difficulty in accessing health services favors abandonment of treatment due to the lack of clear information about health problems, culminating in the worsening of the general condition and decompensation of the disease, as frequent monitoring and assessment of MS are fundamental to its control and prevention^{12,24}.

Daily management of MS is highly complex, as affected people need to deal with the administration of multiple medications and may face unwanted effects. These effects can lead to treatment interruption in individuals who do not have access or connection with the team²⁵⁻²⁶. Furthermore, patients do not always have clear information about the recommended treatment, which includes diet, physical activity and stress, and do not understand that changes are important for their health^{1,12}.

From the action/interaction movement, it is identified that, faced with the challenges encountered in adhering to treatment/lifestyle changes, there are those who use the guidelines as a trigger, adhering to healthy habits, in addition to using medications that help control symptoms and prevent injuries, creating a feeling of control over one's own life.

To follow treatment correctly, the participants in this study rely on faith, as it is considered a way of dealing with difficult situations. The relationship between faith and health is recognized for its positive effect on people's mental and physical health, and may be associated with greater psychological resilience and a lower incidence of depression and anxiety, as there is a desire to improve health associated with plans and new projects and the need to finish those that have been started²⁷.

Including the family in this process also represents an important condition, as it provides, in addition to emotional support, the organization of medications, encouragement to practice physical activity, promotion of healthy eating and the creation of a favorable environment for self-care²⁸.

The family can help identify possible signs of health problems and seek/monitor medical care when necessary. People with MS want to stay healthy due to the need to take care of their family or the fear of becoming dependent and needing a caregiver²⁸.

The research also showed that, by becoming aware of the health problem and its possible complications, care is followed correctly, as there is a significant difference in quality of life between people who adhere to drug treatment compared to those who do not²⁹. Thus, it can be seen that, when there is interaction, symbols are used, the self is directed, there is engagement in mental actions, decision-making and change of direction.

Finally, even though the study made it possible to reveal important aspects of healthcare for people with MS, some limitations were found that made it difficult to delve deeper into participants' reports, as they tend to provide brief answers focused on what they recognize as correct in MS care.

CONCLUSION

The development of this study allowed us to interpret the experiences of people with MS in relation to healthcare, highlighting the dualistic phenomenon “(Not) taking care of health”, showing that the experiences faced with the disease are covered in ambiguities that permeate both the care or carelessness with health, according to interactions that occur with oneself and others.

The research showed that people with MS disregard their health problems due to the lack of limitations to perform their roles and that they find it difficult to follow instructions, discrediting the need for such care. There are also difficulties in accessing health services and using polypharmacy, resulting in lack of adherence to treatment.

However, it was found that, depending on the interactions established with the healthcare team and family members, people incorporate the necessary care for treatment and prevention.

It is understood that experiences in relation to healthcare permeate the biological, psychological, social and spiritual spheres, requiring great commitment from those involved.

It is noteworthy that communication and bonds between users, family and team are the main tools for adherence to treatment and changes in lifestyle.

Therefore, it is vitally important that healthcare professionals invest in individualizing care, based on people’s real health needs.

Furthermore, it is concluded that advances in research are necessary in order to deepen the understanding of the factors that influence carelessness as well as the possibilities of intervention, especially aimed at preventing MS.

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NOTES

ORIGIN OF THE ARTICLE

This study is part of a dissertation entitled “*Síndrome Metabólica: vivências em relação ao cuidado com a saúde, apresentada ao Programa de Pós-Graduação em Ensino em Saúde*”, presented to the Graduate Program in Health Teaching – Professional Master’s Degree – at the *Faculdade de Medicina de Marília*, in 2023.

CONTRIBUTION OF AUTHORITY

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CONFLICT OF INTEREST

There is no conflict of interest.

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