



DIABETIC FOOT: SOCIAL REPRESENTATIONS ABOUT THE EXPERIENCES OF PEOPLE WITH DIABETES MELLITUS

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ABSTRACT

Objective: to understand the social representations about the experiences of people with diabetic foot. **Method:** a qualitative study, based on the Theory of Social Representations, carried out with 28 participants, in reference services for the treatment of diabetic foot in São Luís, Maranhão, Brazil, from February to May 2019. Data collection took place through semi-structured interviews, a script to characterize the sociodemographic and clinical profile and a field diary. Content analysis was applied with the support of a qualitative data analysis software for categorization.

Results: the results made it possible to identify two categories: experiencing diabetic foot, with the respective subcategories, and social responses to diabetic foot. The first category includes the following subcategories: cognitive aspects, psycho-affective aspects, social aspects and morality. The social representations of diabetic foot were based on a painful daily experience, with reference to functional loss, dependence on others and difficulty performing activities that were previously usual.

Conclusion: the study made it possible to assert that diabetic foot is an object of social representation, showing how people build, connect and apply knowledge. The research constitutes a support tool for the care of people with diabetic foot, as it assists in the planning of interventions with impacts on the development of representations that generate positive health behaviors, from the perspective of foot self-monitoring.

DESCRIPTORS: Diabetic foot. Diabetes mellitus. Nursing care. Nursing. Social psychology.

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PÉ DIABÉTICO: REPRESENTAÇÕES SOCIAIS SOBRE AS VIVÊNCIAS DAS PESSOAS COM DIABETES MELLITUS

RESUMO

Objetivo: Compreender as representações sociais sobre as vivências das pessoas com a condição de pé diabético. **Método:** estudo qualitativo, fundamentado na Teoria das Representações Sociais, realizado com 28 participantes, em serviços de referência no tratamento de pé diabético, em São Luís, Maranhão, Brasil, de fevereiro a maio de 2019. A coleta dos dados ocorreu por meio de entrevistas semiestruturadas, roteiro para caracterização do perfil sociodemográfico e clínico e diário de campo. Aplicou-se análise de conteúdo com suporte do *software* de análise qualitativa de dados para categorização.

Resultados: Os resultados possibilitaram identificar duas categorias: vivenciando o pé diabético, com as respectivas subcategorias, e respostas sociais ante o pé diabético. Na primeira categoria, têm-se as subcategorias: aspectos cognitivos, aspectos psicoafetivos, aspectos sociais e moralidade. As representações sociais do pé diabético se sustentaram em vivência cotidiana penosa, com referência à perda funcional, dependência de terceiros e dificuldade de realizar atividades antes habituais.

Conclusão: o estudo possibilitou afirmar que o pé diabético é um objeto de representação social, demonstrando o modo como as pessoas constroem, conectam e aplicam conhecimentos. A investigação constitui ferramenta de apoio ao cuidado da pessoa com pé diabético, por auxiliar no planejamento de intervenções com impactos na elaboração de representações que gerem comportamentos positivos em saúde, na perspectiva da autovigilância dos pés.

DESCRITORES: Pé diabético. Diabetes mellitus. Cuidados de enfermagem. Enfermagem. Psicologia social.

PIE DIABÉTICO: REPRESENTACIONES SOCIALES SOBRE LA EXPERIENCIA DE PERSONAS CON DIABETES MELLITUS

RESUMEN

Objetivo: comprender las representaciones sociales sobre la experiencia de personas que padecen pie diabético. **Método:** estudio cualitativo, basado en la Teoría de las Representaciones Sociales, realizado con 28 participantes, en servicios de referencia en tratamiento del pie diabético, en São Luís, Maranhão, Brasil, de febrero a mayo de 2019. La recolección de datos se realizó a través de entrevistas semiestructuradas, guía para caracterizar el perfil sociodemográfico y clínico y diario de campo. El análisis de contenido se llevó a cabo con el soporte de un *software* de análisis de datos cualitativos para la categorización.

Resultados: los resultados permitieron identificar dos categorías: la experiencia de vivir con pie diabético, con sus respectivas subcategorías, y respuestas sociales al pie diabético. En la primera categoría, se encuentran las subcategorías: Aspectos cognitivos, Aspectos psicoafectivos, Aspectos sociales y moralidad. Las representaciones sociales del pie diabético se basaron en una experiencia cotidiana dolorosa, con referencia a la pérdida funcional, la dependencia de los demás y la dificultad para realizar actividades que antes eran habituales.

Conclusión: el estudio permitió afirmar que el pie diabético es un objeto de representación social y demuestra cómo las personas construyen, conectan y aplican conocimientos. La investigación se constituye en herramienta de apoyo para el cuidado de personas con pie diabético, puesto que contribuye en la planificación de intervenciones que impacten en el desarrollo de representaciones que generen conductas positivas de salud, desde la perspectiva del autocuidado de los pies.

DESCRIPTORES: Pie diabético. Diabetes mellitus. Cuidados de enfermería. Enfermería. Psicología social.

INTRODUCTION

The following are pointed out as worrying issues related to Diabetes Mellitus (DM): the high prevalence and the impact of arising complications, with emphasis on diabetic foot, which greatly affects the life of the affected person, both in the individual sphere and in the family and community spheres¹. Diabetic foot syndrome is defined as a complex pathophysiological condition, characterized by lesions that appear on the feet of people with DM as a response to a neuropathy (90% of the occurrences), peripheral vascular changes and foot deformities².

The premise that, to live and to deal with a chronic condition such as diabetic foot, it is fundamental that the patient has knowledge about the nature of the disease and is able to perform self-care, has encouraged scholars on the subject matter to identify effective strategies to promote grounded knowledge for subsequent assertive and practical decision-making based on the best scientific evidence available³. But which strategies can help to build adequate knowledge? How does this happen?

The recent literature has warned about the important relationship between health care self-management and the patient's experience and how living with the disease influences the formation of a body of knowledge that guides daily care⁴. Thus, understanding how the meaning of experiences is constructed and their impact on the health practices, considering the knowledge acquired in the historical, socioeconomic and political spheres, can contribute to an integral view of the complexity of the health-disease process.

A meta-synthesis, exploring the perceptions and experiences of people with DM about diabetic foot, identified that the participants of the survey included in the study presented fears, beliefs and interpretations that were different from the scientific community that significantly influenced foot self-care behaviors, which did not collaborate to preventing that comorbidity⁵. Thus, it is noticed that there is an imaginary and common sense theories about diabetic foot, turning it into an object of social representation for people with DM, being important for the scientific community to know the theories that so much influence behaviors from the perspective of foot self-monitoring. Therefore, it is justified to approach this object from the perspective of the Theory of Social Representations (TSR)⁶, as it is socially relevant, for pointing out cognitive resources present in the social relationships and structuring routine social practices.

Despite identifying such need for the health care of such population, it was verified in the literature that most of the research studies conducted address the disease with a biological and pathophysiological focus, with few studies with a main focus on the Social Representations (SRs), the meanings, culture and other aspects about the person with diabetic foot. This context suggests the need to expand research studies on the subject matter, in order to better understand the phenomenon^{7–14}.

By tracking the scientific literature on the topic, a study was found that sought to identify the elements that structure the SRs of diabetic foot among people with DM. Also in this perspective, the scientific community specializing in the subject matter pointed out the need for more research studies that explore the experiences of patients with diabetic foot, in order to enable people to reframe their own condition and the best way to take care of themselves, providing clues that there is a field to be explored¹⁵.

In this aspect, understanding the SRs about the experience with the diabetic foot, under the gaze and social dynamics of people living with this complication, will make it possible to understand elaborated knowledge, attitudes, meanings and values, as well as understand the feelings regarding the actions aimed at the feet. This research is in harmony with the evolution of the Nursing science, in view of the perspective of better understanding the individual's motivations and difficulties in relation

to diabetic foot, which sometimes result in carelessness associated with the health condition, and can thus favor changes in the treatment and care program of these social actors, during the length of this complication in their lives, assisting them in self-management and improving their quality of life.

In addition to that, the result of the study will also help to understand diabetic foot outside the biomedical model, since it will take away the focus from biology and pathophysiology to emphasize social and subjective aspects such as meanings, values, and affective and communication elements. Conceiving care based on the logic of the person to whom it is directed and paying attention to the psychosocial processes underlying foot self-vigilance behaviors can be an effective strategy to be used by nurses to prevent this and other complications in people with DM.

In this sense, this research sought to fill the gap in the field of SRs regarding experiences in the context of diabetic foot syndrome and to answer the following research problem: Which are the social representations of the experiences of people with diabetic foot? To answer this research question, the study aimed at understanding the social representations about the experiences of people with diabetic foot.

METHOD

To achieve the objective proposed, a methodological design was created, characterized by a qualitative, descriptive and exploratory study, based on Moscovici's TSR. The TSR is applied to facilitate the researcher's understanding of socially shared knowledge, addressing the interface of what is peculiar to the individual in the constant interrelationship with the social. For this reason, it allows for the organization of structured mental contents, based on a relevant social phenomenon, identified in images and shared with other members of the social group. The procedural aspect of the theory was applied, seeking to understand the origin and elaboration process⁶.

The TSR considers that SRs constitute interpretation schemes resulting from the interaction of some aspects, such as the individuals' belonging group, the way they interact and live and the social structure that surrounds them. Thus, the SRs are understood as such a way for deciphering reality, attributing meaning to the existence of groups and coordinating them around collective interests. They also make it possible to moderate social bonds and direct the behavior expressed by the person and their respective attitudes, with impacts on daily life⁶. Thus, research in SRs helps to understand how people assimilate the social context, striving to understand them and helping to solve problems of different natures. To ensure rigor of this study, the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist was followed.

The project was approved by the Committee of Ethics in Research with Human Beings and the participants signed the Free and Informed Consent Form, with guaranteed anonymity, in which the letter E ("Entrevistado" in Portuguese) was used, followed by an Arabic numeral to identify the interviewees.

The scenario consisted of three locations: (1) endocrinology and diabetes outpatient clinic; (2) a medical clinic ward of a university hospital; (3) a medical specialty and diagnosis center, considered a reference service for DM in Maranhão, Brazil, located in the capital, linked to the Unified Health System. All the study fields have specific care in the field of dermatology for diabetic foot and the Nursing team performs dressings on the lower limbs in people with DM.

Twenty-eight individuals with DM participated in the research, selected through non-probabilistic convenience sampling, considering their availability to participate and their presence in the locus during the data collection period. The inclusion criteria were as follows: DM diagnosis for more than five years, with diabetic foot; being 18 years of age or older; and being in sound psychological and communication conditions to answer the guiding questions of this study. Evaluation of these conditions was carried out through the Mini Mental State Exam¹⁶. It is noteworthy that determination of the diagnosis time

of five years is due to the knowledge that the meanings are engendered in the experimentation of coexistence¹⁷. Thus, participants with a longer diagnosis time were able to contribute, in a broader way, to the study proposal. People with part or the totality of the lower limbs amputated or having some clinical instability were excluded. Clinical instability is understood as any event that alters the person's hemodynamic state, characterized by malaise, with changes in blood pressure, heart rate and/or in the state of consciousness. During recruitment, 38 people were approached; however, 10 were excluded for having part of one of their lower limbs amputated, especially amputation of one or more toes or of half foot.

Recruitment of new participants was interrupted by theoretical data saturation, when it was found that new elements to support or deepen the study were no longer inferred from the researchers' interviews and observations. In order to maintain an ethical attitude and transparency regarding the sampling criteria and demonstrate the scientific rigor adopted, the technique was used in a systematic way^{18–19}.

To use the theoretical data saturation technique, collection and analysis occurred concurrently, allowing the researcher to distinguish the elements that emerged and those that were replicated. Eight procedural steps were followed to verify data saturation. In step one, the speech records were made available and transcribed, paying attention to intonation elements and phonic particularities. In step two, the content of the interviews was explored as they were being carried out. In step three, the themes and statements identified were compiled by handling the excerpts after identifying the paragraphs of the transcripts. In step four, the themes were gathered for each category, including excerpts from the relevant interviews that exemplify them. To perform step five, the data were coded. In step six, the themes were allocated in a table that allowed visualizing the analytical elements worked on. In step seven, theoretical saturation for each pre-category or formation of a new category was verified. Finally, in step eight, the point was visualized at which no new information was identified and considered relevant for theorizing¹⁸.

It was identified that, in interview number 25, all categories and subcategories were saturated, with no new elements appearing in the research. Thus, still following what was recommended by the technique, the researcher chose to conduct another three interviews, in order to confirm the saturation point, providing reliability to the method used.

Data collection was carried out only by the first author (nurse/master's/researcher/female) who had no prior contact with the participants and addressed the research scenarios at random, according to her availability. In outpatient care, the researcher initially approached and socialized with the participants in the waiting room, seeking to understand the care dynamics, through trivial conversations. This way of acting is advised when using the TSR as a theoretical framework¹⁷, as it is a valid and indispensable strategy to establish previous involvement with the group, in order to become familiar.

Subsequently, the researcher introduced herself, providing credentials, explaining the research objectives and inviting the person to participate in the study. Under condition of acceptance, data collection was carried out in a private room, respecting privacy. When the individuals were hospitalized, it was conducted at the bedside.

Data collection was carried out from February to May 2019, through semi-structured interviews, a script to characterize the sociodemographic and clinical profile and a field diary. The triggering question of the interview was as follows: What does it mean to you to live with diabetic foot? The interview questions allowed discussing internalized cultural content and experiences related to the experience with the comorbidity, which allowed access to the processes of construction of thought about the diabetic foot. The interviews lasted between 45 and 85 minutes and permission was requested to record them in audio. The participants' emotional reactions were also incorporated in the transcripts

and the interactions between the participant and the interviewer were considered based on the field diary records. The researcher's impressions were recorded in the field diary, immediately after the interviews, and the records were composed of descriptive field notes, addressing singular aspects or recommendations to be considered in the following interviews.

The first author transcribed the interviews in full, immediately after each approach, and the material was not returned to the participants for validation.

Resources of the content analysis techniques were applied²⁰. Thus, a pre-analysis (with exhaustive reading of the textual transcripts to identify the meanings), categorization, treatment and interpretation of the results achieved was carried out. The analysis categories emerged from the empirical data and articulation with the TSR.

In order to ensure quality of the categorization process and rigor of the method, the Web Qualitative Data Analysis (WebQDA) version 3.0 was used as a support for data organization, with shared collaboration. Files in the *word* format were imported into the program, whose analytical process took place interactively, online and in real time between the two researchers. With the documents saved in the program, the analysis process was initiated, carried out line by line, highlighting the text units to build the categories. The initial analysis was carried out by the first author and confirmed by the second author (nurse/teacher/PhD/researcher/female), independently, until consensus was reached. In this process, the first author identified four categories and the second, two. However, after reviewing and discussing the interview data between them, it was concluded that two of the categories identified by the first author were subcategories of the first analytical category. The coding and categorization process was carried out simultaneously, with the researchers being able to edit, view, interconnect and organize all the material.

The transcribed interviews were inserted as internal sources in the software and coded according to the empirical categories. Through the interpretive coding tool provided by WebQDA, the code tree system was used, which enabled the hierarchy in codes and subcodes, as needed, being possible to view the record units in a column of references that displays the excerpt of the text encoded. Subsequently, the synthesis of each category was conceived, delimiting the nuclei of meaning, grouping them by theme, thus making it possible to create two analytical categories and their respective subcategories. The themes and subthemes were named based on the extracted meanings²⁰.

RESULTS

Of the 28 (100%) study participants, 54% were male and 46% were female, aged from 33 to 92 years old (41% were between 60 and 69 years old). The mean schooling time in the group was 7.2 years and 67.5% lived with their spouses. The mean DM diagnosis time was 12 years: Type 1 DM corresponded to 8.7% and Type 2 DM was the most prevalent, with 91.3%.

Regarding the study setting, 25% of the participants were in an inpatient unit and the others in outpatient care. However, no differences were observed in relation to the social representations produced in the different scenarios.

The analysis of the narratives led the study to the understand that there is a central theme that expresses how the affected people represent the experience with diabetic foot: experiencing diabetic foot is painful and difficult. This representation is based on two main sets of categories: experiencing diabetic foot and social responses to diabetic foot. The first category includes the following subcategories: cognitive aspects, psycho-affective aspects, social aspects and morality, with presentation of some of the interviewees' statements to express and exemplify these categories and subcategories.

Category 1: Experiencing diabetic foot

From the *Experiencing diabetic foot* category, four subcategories emerged that highlight the person who experiences diabetic foot as a social actor, characterized by intrinsic cognitive attributes, psycho-affective reactions and social aspects that reveal the transformations in their social interactions arising from this condition. It is also constituted by subjective elements, such as the expression of moral values and beliefs. This category consisted of 177 units of analysis.

The first subcategory, called *Cognitive aspects*, consists of 32 units of analysis, with the contribution of 19 participants for its conformation, and reveals how the person apprehends the diabetic foot phenomenon in their experience, from the perspective of previous experiences and understandings. The cognitive aspects express the representation of social knowledge about this complication, elaborated and shared in the social context and retrieved when it arises. In this subcategory, re-elaboration of knowledge about the comorbidity by the participants was noticed, reproducing health information, assimilated prior to the beginning of the experience with diabetic foot, as evidenced by the following statement: [...] care has to be doubled, because diabetic foot causes a number of things, loss of limbs or loss of one's own foot, even losing the leg and causing much more, if you don't have the necessary care. Starting with diabetes itself. If you don't have a very strict control, it will bring about all of this. And to keep your feet without any problems, you have to be very careful with everything, starting with the foot treatment itself. Glucose was very high and that's what helped this happen in my foot (E1).

In the speeches, it was noticed that the knowledge and conceptions used to build common sense about the causes of diabetic foot presented particularities grounded in the rectified universe of knowledge. They talked in the group they belonged to, incorporated the information and, later, gave new meaning to this knowledge in their daily lives, justifying onset of the complication, as shown in the following excerpt: [...] I try to understand, but it comes at the end, I already understand that it's diabetes, I understand that it's because of diabetes, bad circulation, I understand that the foot was like this because of that (E2).

The second subcategory, *Psychoaffective aspects*, consists of 59 units of analysis and had the collaboration of 28 participants for its composition. The psycho-affective references manifested anchor the elaboration of the representational content and are essentially based on negative feelings towards diabetic foot. The statements by three participants were as follows: [...] *you can't wear a tall sandal with an ugly foot, swollen, then I get angry. I didn't do anything, I just cried. I lost patience, I lived on the edge* (E3); [...] *I felt depressed, a little desperate. I feel useless* (E1); [...] *comes the image that I'll never be the same again, because the wound that opened under my foot opened inside my heart too* (E4).

Indicative SRs for the potential emotional distress were been observed, as illustrated in the following narrative: [...] because it doesn't hurt inside of me [pauses] it hurts my soul [speaks with a lot of emotion and crying] (E5).

The Social aspects subcategory is responsible for the highest percentage of composition in the category analyzed, with 68 units of analysis and the contribution of 28 participants for its composition. The registration units evidenced different experiences of the participants in the social context, with narratives that revealed the limitation in previously usual activities, difficulties and repercussions in daily and practical life, as revealed below: [...] I live in dependence today. If I can't move around, how can I live? It stopped life because I can't move. So, everything I had to do is stopped, waiting for the feet to recover. I'm alive! But, it's not living life fully, working, enjoying, walking. Everything is very limited (E6); [...] first it was my walk, because I couldn't support my body with my foot. I started using crutches, now I'm in a wheelchair. It brought me problems, because I couldn't work anymore, because I can't stand up. I'm a bricklayer, I couldn't stand to make any move. So, diabetic foot brought me a lot of difficulty in my profession. I had to abandon, give up everything (E7).

The Morality subcategory, made up by 18 analysis units and with the contribution of 18 participants, contemplates the lines that pointed out the dichotomy between good and evil personified in the figures of God, Jesus and the Devil. From some units of analysis, divine control over the onset of diabetic foot and the evolution and satisfactory therapeutic result were inferred, in addition to highlighting the disease as a means of moral and/or spiritual evolution and punishment, due to inadequate behaviors in the past. The results showed that 91.7% of the people professed some religion, with Catholicism being the most cited, followed by Protestantism: [...] That wound in the foot perhaps it's God's will (E8); [...] but, my God told me that He tried me a lot for love, but I didn't want to obey, then pain came. I know the Devil was to blame a little bit, but this one here (pointing to the foot) it was God who let him do it to me for disobedience to Creation (E4); [...] and everything that happened to me comes from Jesus. Because for me, I think it was a test, a teaching. Maybe what I did back in time, happened. It set an example for me too. Because I've done a lot (E9).

Category 2: Social responses to diabetic foot

This category was made up from the contribution of 25 participants and comprises 48 units of analysis that, from the social and representational perspectives, evidenced the social coping of the person with diabetic foot and the reactions of the health professionals, the family nucleus and the third parties towards the disease. In this category, it was possible to understand that diabetic foot is not only a physical disease; it also has impacts on various aspects of people's lives, especially in social relationships, making them feel unwelcome by health professionals and rejected by others and often leading them to keep the condition a secret, as evidenced by the following excerpts: [...] because my foot is practically covered all the time. Nobody sees. They know I have a problem, but they don't see the wound (E10); [...] I feel rejected in some popular environments when I go out. Sometimes I get into something and people don't want to get into where I got into anymore. I feel like they look with rejection. My wife sells chicken and there are people who don't touch there anymore because of my wound, because they think it's contagious (E11); [...] every place that I arrived [referring to the health services] everyone said that my wound was bad, that it should have healed, no one came to comfort me, say good words, no. They just wanted to drag me further down. And then what happens? Diabetes goes up. I even had intestinal problems because of people's words [health professionals] that made me nervous (E12).

DISCUSSION

Research on diabetic foot, as an object of social representation, points to a painful daily experience as a representation for the participants, indicating the multidimensionality of this comorbidity that is based on a meaning that goes beyond merely physical distress, showing that this disease also consists of a psychological and even existential discontent, as it influences the way in which people perceive themselves in the world.

Having a functional foot that enables mobility and independence is part of a natural and expected process. On the other hand, the onset of diabetic foot is something unfamiliar that needs to be learned and integrated into knowledge and daily life, a function performed by the SRs⁶. In this sense, the participants conceived diabetic foot and made it palpable, creating an experience permeated by difficulties, adversities and complications, where loss and amputation were possible scenarios.

Knowing the social conditions in which knowledge is developed and the information sources that people use is fundamental in the process of developing knowledge and, consequently, in understanding production of the SRs, as it is at the origin of the information that lies the mediation between different forms of communication, representing, at the same time, the origin of knowledge

and the way in which people sustain communication⁶. In the representation created by most of the participants, there was knowledge about diabetic foot as an outcome of diabetes. This representation gave rise to self-care aimed at controlling the risk factors for DM. However, this knowledge about the disease process seemed limited. This result differs from those found in a qualitative meta-synthesis, which revealed that the patients' understanding was not in harmony with conventional biomedical understanding, in which many were unaware of the relationship between DM and foot complications⁵.

On the other hand, the finding that the understanding of the investigated group was reduced was in line with a previous study, in which patients with foot ulcers in a rehabilitation hospital exhibited a basic understanding of the causal factors²¹. The social arrangement of a given object derives from the way in which information about it is acquired, fragmenting the universe into areas in which the messages move freely or with difficulties⁶. Thus, there is reflection on the extent to which this representation for the participants can impact on the management and modification of the risks for developing foot injuries and on the quality of Information that patients have received, since the content of this knowledge is a strong element in conception of the SRs.

The statements also pointed to the existence of an SR that gained contours due to negative feelings, through the expressions "fear, worries, crying, nervousness, sadness and anger", focusing on the psycho-affective aspects involved in this condition. Given this representation, there are clues that the psycho-affective dimension contained in this SR object directs the discourse of people who live with diabetic foot, placing these negative emotions in a central position.

These negative feelings, with a strong emotional charge, permeate the SRs of the studied group, revealing the potential harmful effect on the emotions of these individuals, which can impair the motivation to adhere to the treatment, as revealed in another research study²². In addition to that, when crystallized, these negative emotions can trigger depression and anxiety, requiring increasingly complex approaches. Such data are consistent with those obtained in another study, which showed that many participants expressed anger and frustration arising from dependence on others as a result of ulceration, also pointing out that negative feelings or signs of depression were common and often accompanied by lack of energy and motivation⁵.

The participants represented diabetic foot as an arduous experience, referring to the limitations imposed and dependence on others, sometimes leading them to experience feelings of sadness, irritation, worry and the impression of not leading a full life. The mention of these barriers presents the SR anchoring process, so that these aspects that involve the representational field of the group are important and generate meanings, when they are related to limitations and dependence. It is emphasized that anchoring is the process of integrating new knowledge and concepts with previous and culturally internalized values and ideas, attributing meaning to the object⁶. These same aspects expressed by the participants were also pointed out in a study which evidenced that the restrictions determined by diabetic foot and dependence on someone for activities previously carried out autonomously constituted the greatest difficulty faced by these individuals, with the feeling of loss of control over their own lives, arousing irritation and a sensation of vulnerability²³.

The perception of a painful experience arises from impaired function and independence. This fact was represented as a facilitator for the incapacity or impairment in walking (the most commonly mentioned functional impact) and absence from work activities. Most of the participants claimed to have interrupted their work because of the physical limitation imposed by diabetic foot, in addition to the need for dressing/treatment, with frequent visits to the health services, which frequently leads to premature retirement. This result is consistent with what was found in a previous study that identified that chronic diseases and their respective treatments are characterized by symptoms that negatively affect individual performance at work²⁴. Another survey carried out with aged Europeans pointed out

that the fact of having diabetes increased the chance of those people being afraid that the condition would limit work activities before retirement and decreased the probability of performing formal voluntary work²⁵.

Impaired gait was commonly described as a limiting factor that causes harms in various life areas, altering the ability to socialize and generating mood changes. Some individuals described the indication to use some kind of mobility aid such as crutches, canes and/or wheelchairs, signaling the social isolation associated with these objects and the repercussions on self-image and the way they perceive themselves in the world. The reference to orthopedic devices showed the SR anchoring process, that is, the way in which aspects involving the representational field of these individuals about diabetic foot affect them and have meaning when they are related to mobility aids. Also regarding the impaired gait reported by the participants, another study corroborates this finding with the verification that people with diabetic foot presented psychosocial distress in view of the biomechanical challenges imposed by the injury, which require the development of complex strategies to address these issues²⁶.

Most of the participants reported professing some religion and this aspect seemed to have repercussions in the content of the statements, in which understandings were observed that diabetic foot was determined by a divine entity, as one of the important meanings of the representation. These elaborations integrated the consensual universe and transversalized the speeches and social beliefs over the years, strengthening the SR characteristic, by guiding the interpretations and meanings that people conceive in relation to the relevant social objects. Some analysis units showed more prescriptive elements of behaviors, indicating an attitude of acceptance and understanding of the onset of diabetic foot and revealing a person guided by a deep relationship with the sacred and the transcendental that, in some way, gives meaning beyond what can be objectively understood.

The representation of diabetic foot as a way of purifying past inappropriate behaviors and/or transgressions of morally determined principles was also observed, motivating the belief that diabetic foot is a punishment, followed by moral evolution. This finding is compatible with a study which identified that most of the participants considered that living with a chronic wound was a punishment, indicating that some religious beliefs can bring guilt, doubts and anxiety, with impacts on adherence to the treatment²⁷.

The care provided to human beings in the face of the demands arising from the moral sphere cannot be limited to a technical approach, as beliefs and symbolic constructions exert an impact on decision-making from the self-care perspective. Thus, an intervention plan that has support as its essence and makes sense of the reality in which the diabetic person is inserted is necessary, alleviating the feeling of impotence in the face of difficulties and pain, in addition to strengthening the relationships between health professionals and individuals, with positive results and greater satisfaction with the care provided.

The arduous experience as a manifest representational content is also linked to the prejudice perceived by the participants, leading some to adopt, as a strategy not to feel rejected, concealment of diabetic foot, in order to avoid embarrassment due to the appearance and odor of the wound, in a clear example of when the SRs guide the actions. Some narratives revealed that the action of limiting this condition to the private space is intended to avoid negative reactions from others. When discussing the problem that patients with chronic diseases face when exposing the diagnosis, a research study revealed that the patients face the possibility of losing autonomy and acceptance, facing a real risk of being stigmatized, which evidences that some are unable to deal with the reactions of other people and end up emotionally out of control²⁸.

The perception of prejudice seems to be an element of the SR silent zone, as the participants spoke about the prejudice of others and not of themselves. However, as observed in participant E3's report, she herself characterized her own foot as "ugly", bringing up a sense of something strange and repugnant. The silent zone is a fragment of the representation, structured from elements not spoken by the people during the interviews, as it is considered inappropriate content and which may go against the moral values in force in society⁶.

The participants also presented the SR of diabetic foot as a communicable disease, through contact with objects in common use as a basis for social distancing from people with this comorbidity, evidencing the prescriptive function of acting in the SRs⁶. This representation and way of acting warn about the need for nurses to act so that social knowledge is closer to scientific knowledge, in order to clarify mistaken ideas and minimize avoidable distress.

In the participants' statements, the perception of non-acceptance of all the real demands by the health professionals and the need to be motivated during the consultations were also noticed. They often felt that the professionals did not value the repercussions of diabetic foot in their lives, paying little attention to their concerns, imprinting distance in the care relationships and showing superficiality in meeting the countless dimensions of these people's needs.

The negative reputation of the public health service professionals is a cognitive phenomenon and is structured based on a combination of information and personal experiences. In this scenario, a series of adverse events, including rude treatment by nurses, collaborate to form this image of the health professionals, leading the patient to experience a situation of institutional vulnerability, as evidenced in participant E12's speech. These arrangements show that the group imposes representations of inefficient care on the professionals working in public health services and that it reproduces unfair social organizations through a power relation. The cultural structure, socially disseminated values and guidelines that are outlined by the social framework and power relations are examples of the trans-subjective level of the SRs⁶.

These data also open space for debate on the ethical dimension of care, especially with regard to the social commitment inherent in the care practices and attention to the solidarity and integrality of people with diabetic foot. This observation was consistent with a previous paper⁵ which showed that individuals, due to difficulties, sought comfort from health professionals and considered communication very ineffective, having the perception that health providers did not seem to care in a holistic way, compromising the relationship or failing to provide emotional support. In that study, observance of these issues seemed to encourage passivity in the health care interactions, exerting a negative impact on the participants' role as self-managers of their condition. Another research study²⁸ showed reports of positive health experiences, when the professionals showed interest in physical and emotional well-being, being widely praised for the supportive relationship. Many patients emphasized the fundamental role of empathy, understanding and the open communication channel in the health care spaces.

The representational conception brought about by this research consists of elements that involve the experience of the person with diabetic foot, allowing to outline the daily experience with this complication. The contents identified make it possible to assert that this is an SR, as there are elements that determine its elaboration by social actors, namely the information, the action and the representation field⁶.

Recognition of the SRs on the experiences of people with diabetic foot contributes to understanding the phenomenon from the point of view of people who experience it, helping to provide innovative care and implementation of more advanced Nursing, through a patient-centered approach.

Other studies propose looking at the person with DM individually, as a respected partner in their care, in which the development of a realistic care plan would have a greater chance of success, when this partnership relationship between nurse and client was in evidence^{29–30}.

The study made it possible to understand diabetic foot as a psychosocial phenomenon, in the way people build, connect and apply knowledge in self-care, advancing in knowledge. Therefore, it becomes imperative to have a Nursing workforce that is sensitive to socially developed knowledge about diabetic foot and its repercussions, so that it is possible to implement a collaborative, innovative and person-centered care model that, in the practice, provides care that supports the mobilization of internal resources, allowing conscious decision-making, greater engagement with the treatment and making it autonomous in self-management, thus enabling the achievement of positive health outcomes and contributing to the advancement of Nursing as a science and profession.

As a limitation, we consider the fact that the research was restricted to participants seen in the health services; it is not clear whether the representations documented would extend to other empirical scenarios, such as the home or other community environments. However, this analysis provides *insights* for researchers who plan and implement actions in services aimed at the care of these patients.

CONCLUSION

From the perspective of the TSR theoretical-methodological contribution, contents and aspects that made up the SRs of the experience of people with diabetic foot were recognized, relative to knowledge, actions and feelings. In this organization, it was identified that the SRs about living with diabetic foot arise based on an arduous, painful life and surrounded by a negative emotional charge, sustained by functional loss, dependence on others and difficulty performing activities that were previously usual. It was also observed that living with diabetic foot is a complex and multidimensional phenomenon that generates SRs in the cognitive, psycho-affective, moral and social dimensions, which create a network of meanings that contribute to elaboration of the SR.

Thus, the study may be a tool to support the care of people with diabetic foot, especially with regard to the barriers imposed, in the management of the psychosocial factors and symbolic constructions about comorbidity, with a unique opportunity to elaborate representations that generate conscious attitudes and that aim at effectively supporting self-management, from the perspective of foot self-vigilance, contributing to excellence in care.

REFERENCES

- Chastain CA, Klopfenstein N, Serezani CH, Aronoff DM. A clinical review of diabetic foot infections. Clin Podiatr Med Surg [Internet]. 2019 Jul [cited 2021 Apr 13];36(3):381-95. Available from: https://doi.org/10.1016/j.cpm.2019.02.004
- Bus SA, Lavery LA, Monteiro-Soares M, Rasmussen A, Raspovic A, Sacoo ICN, et al. Guidelines on the prevention of foot ulcers in persons with diabetes (IWGDF 2019 update). Diabetes Metab Res Rev [Internet]. 2020 Mar [cited 2021 Aug 16];36 Suppl 1:e3269. Available from: https://doi. org/10.1002/dmrr.3269
- 3. Ma JQ. National health information and its role in prevention and control of chronic diseases: framework design of person-centered and whole life recycle surveillance system for chronic diseases. Zhonghua Yu Fang Yi Xue Za Zhi [Internet]. 2020 Apr 6 [cited 2021 Aug 16];54(4):378-84. Available from: https://doi.org/10.3760/cma.j.cn112150-20191223-00950
- 4. Manzaneque NN, Pérez-Arechaederra D, Montalbán JMC. Side effects and practices to improve management of type 2 diabetes mellitus from the viewpoint of patient experience and health care management. A narrative review. Endocrinol Diabetes Nutr (Engl Ed) [Internet]. 2019 Dec [cited 2021 Aug 16];66(10):596-610. Available from: https://doi.org/10.1016/j.endinu.2019.05.010
- 5. Coffey L, Mahon C, Gallagher P. Perceptions and experiences of diabetic foot ulceration and foot care in people with diabetes: a qualitative meta-synthesis. Int Wound J [Internet]. 2019 Feb [cited 2021 Apr 13];16(1):183-210. Available from: https://doi.org/10.1111/iwj.13010
- 6. Moscovici S. Representações sociais: investigações em psicologia social. Petrópolis, RJ (BR): Vozes; 2015. 408 p.
- 7. Coelho MS, da Silva DMGV, Padilha MIS. Social representations of diabetic foot for people with type 2 diabetes mellitus. Rev Esc Enferm USP [Internet]. 2009 Mar [cited 2021 Apr 13];43(1):65-71. Available from: https://doi.org/10.1590/s0080-62342009000100008
- 8. Kim EJ, Han K-S. Factors related to self-care behaviours among patients with diabetic foot ulcers. J Clin Nurs [Internet]. 2020 May [cited 2021 Sep 3];29(9-10):1712-22. Available from: https://doi.org/10.1111/jocn.15215
- Carlesso GP, Gonçalves MHB, Moreschi Júnior D. Evaluation of diabetic patients' knowledge about preventive care of the diabetic foot, in Maringá, PR, Brazil. J Vasc Bras [Internet]. 2017 Apr-Jun [cited 2021 Sep 3];16(2):113-8. Available from: https://doi.org/10.1590/1677-5449.006416
- 10. Schoen DE, Glance DG, Thompson SC. Clinical decision support software for diabetic foot risk stratification: development and formative evaluation. J Foot Ankle Res [Internet]. 2015 Dec 12 [cited 2021 Apr 13];8:73. Available from: https://doi.org/10.1186/s13047-015-0128-z
- 11. Zhang P, Lu J, Jing Y, Tang S, Zhu D, Bi Y. Global epidemiology of diabetic foot ulceration: a systematic review and meta-analysis. Ann Med [Internet]. 2016 Nov 3 [cited 2021 Apr 13];49(2):106-16. Available from: https://doi.org/10.1080/07853890.2016.1231932
- 12. Ghotaslou R, Memar MY, Alizadeh N. Classification, microbiology and treatment of diabetic foot infections. J Wound Care [Internet]. 2018 Jul 2 [cited 2021 Apr 13];27(7):434-41. Available from: https://doi.org/10.12968/jowc.2018.27.7.434
- 13. Kurečič M, Rijavec T, Hribernik S, Lapanje A, Kleinschek KS, Maver U. Novel electrospun fibers with incorporated commensal bacteria for potential preventive treatment of the diabetic foot. Nanomedicine (Lond) [Internet]. 2018 Jul 20 [cited 2021 Apr 13];13(13):1583-94. Available from: https://doi.org/10.2217/nnm-2018-0014
- 14. Sothornwit J, Srisawasdi G, Suwannakin A, Sriwijitkamol A. Decreased health-related quality of life in patients with diabetic foot problems. Diabetes Metab Syndr Obes [Internet]. 2018 Mar 7 [cited 2021 Apr 13];11:35-43. Available from: https://doi.org/10.2147/DMSO.S154304



- Lopes GSG, Rolim ILTP, Alves RS, Pessoa TRRF, Maia ER, Lopes MSV, et al. Social representations on diabetic foot: contributions to PHC in the Brazilian Northeast. Cien Saude Colet. 2021 May [cited 2021 Aug 16];26(5):1793-803. Available from: https://doi.org/10.1590/1413-81232021265.04702021
- Bertolucci PHF, Brucki SMD, Campacci SR, Juliano Y. O mini-exame do estado mental numa população geral: impacto da escolaridade. Arq Neuropsiquiatr [Internet]. 1994 [cited 2021 Aug 18];52(1):1-7. Available from: https://www.scielo.br/j/anp/a/Sv3WmxHYxDkkgmcN4kNfVTv/?lang=pt&format=pdf
- Sá CP. Social psychology studies: history, behavior, representations, and memory. Rio de Janeiro, RJ (BR): Eduerj; 2015. 458 p.
- Nascimento LCN, Souza TV, Oliveira ICDS, Moraes JRMM, Aguiar RCB, Silva LFD. Theoretical saturation in qualitative research: an experience report in interview with schoolchildren. Rev Bras Enferm [Internet]. 2018 Jan-Feb [cited 2021 Sep 3];71(1):228-33. Available from: https:// doi.org/10.1590/0034-7167-2016-0616
- Falqueto JMZ, Farias JS, Hoffmann VE. Saturação teórica em pesquisas qualitativas: relato de uma experiência de aplicação em estudo na área de administração. Rev Cienc Adm [Internet]. 2018 Dec [cited 2021 Apr 13];20(52):40-53. Available from: https://doi.org/10.5007/2175-8077.2018V20n52p40
- 20. Bardin L. Análise de conteúdo. Lisboa (PT): Edições 70; 2016. 288 p.
- 21. Barg FK, Cronholm PF, Easley EE, Davis T, Hampton M, Malay DS, et al. A qualitative study of the experience of lower extremity wounds and amputations among people with diabetes in Philadelphia. Wound Repair Regen [Internet]. 2017 Sep-Oct [cited 2021 Apr 13];25(5):864-70. Available from: https://doi.org/10.1111/wrr.12593
- 22. Khaledi M, Haghighatdoost F, Feizi A, Aminorroaya A. The prevalence of comorbid depression in patients with type 2 diabetes: an updated systematic review and meta-analysis on huge number of observational studies. Acta Diabetol [Internet]. 2019 Jun 1 [cited 2021 Sep 3];56(6):631-50. Available from: https://doi.org/10.1007/s00592-019-01295-9
- 23. Meriç M, Ergün G, Meriç C, Demirci İ, Azal Ö. It is not diabetic foot: it is my foot. J Wound Care [Internet]. 2019 Jan 2 [cited 2021 Apr 13];28(1):30-7. Available from: https://doi.org/10.12968/jowc.2019.28.1.30
- 24. Cabeceira HS, de Souza DMST, Juliano Y, Veiga DF. Work ability and productivity in patients with diabetic foot. Clinics (Sao Paulo) [Internet]. 2019 Mar 25 [cited 2021 Apr 13];74:e421. Available from: https://doi.org/10.6061/clinics/2019/e421
- Rodriguez-Sanchez B, Alessie RJM, Feenstra TL, Angelini V. The relationship between diabetes, diabetes-related complications and productive activities among older Europeans. Eur J Health Econ [Internet]. 2018 Jun [cited 2021 Apr 13];19(5):719-34. Available from: https://doi.org/10.1007/ s10198-017-0911-9
- 26. Vileikyte L, Crews RT, Reeves ND. Psychological and biomechanical aspects of patient adaptation to diabetic neuropathy and foot ulceration. Curr Diab Rep [Internet]. 2017 Sep 23 [cited 2021 Apr 13];17(11):109. Available from: https://doi.org/10.1007/s11892-017-0945-5
- 27. Suza DE, Eltrikanawati T, Tarigan R, Setiawan, Gunawan J. The lived experience of patients from an ethnic group in Indonesia undergoing diabetic foot ulcer treatment. Br J Nurs [Internet]. 2020 Mar 12 [cited 2021 Sep 3];29(5):S20-6. Available from: https://doi.org/10.12968/bjon.2020.29.5.S20
- Dibley L, Williams E, Young P. When family don't acknowledge: a hermeneutic study of the experience of kinship stigma in community-dwelling people with inflammatory bowel disease. Qual Health Res [Internet]. 2020 Jul 1 [cited 2021 Apr 13];30(8):1196-211. Available from: https:// doi.org/10.1177/1049732319831795



- 29. Trout KK, McCool WF, Homko CJ. Person-centered primary care and type 2 diabetes: beyond blood glucose control. J Midwifery Womens Health [Internet]. 2019 May-Jun [cited 2021 Apr 13];64(3):312-23. https://doi.org/10.1111/jmwh.12973
- 30. Muñiz GM, Gómez BA, Becerril LC, Solano GS. Lifestyle of the elderly person living with diabetes and characterization of nursing diagnoses. Texto Contexto Enferm [Internet]. 2019 [cited 2021 Apr 13];28:e20170552. Available from: https://doi.org/10.1590/1980-265x-tce-2017-0552

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