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Social representations on diabetic foot: contributions to PHC in the Brazilian Northeast

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Abstract *This study aimed to identify the structuring elements guiding the establishment of the social representations of diabetic foot among people with diabetes mellitus. This qualitative study is based on the Social Representations Theory and was conducted in a capital of the Brazilian Northeast. The free word association test and a roadmap were used to characterize the sociodemographic and clinical profile to collect data. The analysis was performed using openEVOC software. The constituent elements of the diabetic foot's social representation "cure" and "really bad", revealing that living with a diabetic foot is challenging, but there is hope for a cure, which is a driving force in the daily search for care. The "prevention" element emerged in the representational field, denoting a more critical view and a capacity to transform the identified core elements. We found that the representational structure is based on subjective, valuating, and attitudinal contents. This knowledge can contribute to the design of interventions in the provision of care and diabetic foot screening in PHC services.*

Key words *Diabetic foot, Social psychology, Diabetes mellitus*

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Introduction

Actions and services offered in Primary Health Care (PHC), mainly by the Family Health Strategy (ESF) teams to users with diabetes, can reduce the number of hospitalizations due to complications of this disease, including the diabetic foot. These actions aim to prevent or contain injuries, promoting timely access and comprehensive care for an intervention.

People with diabetes mellitus (DM) should be evaluated comprehensively and regularly to detect early changes increasing the risk of developing ulcers and other diabetic foot complications. To this end, flowcharts for PHC care and specialized health care are available, considering risk stratification, thus allowing the most efficient and effective use of teams' time and resources[1].

Diabetic foot is a generic term that refers to the variety of pathological conditions associated with neurological abnormalities and varying degrees of peripheral vascular disease in the lower limb that can affect DM patients' feet. It is a relevant public health problem in developed and developing countries due to its frequency and association with high mortality and healthcare costs. Managing diabetic feet is a daunting challenge[2-4] despite the existence of well-established guidelines globally.

However, a gap must be filled by scientific evidence supporting most of the routine clinical practice, which produces some care models susceptible to people's opinions and beliefs and can cooperate and justify the uneven distribution of this condition geographically. Regarding the population impact, a systematic review with large-scale meta-analysis identified that the overall prevalence of diabetic foot was 6,3%. As problematic as this data is the estimate that 25% of diabetics living in developing countries have had throughout their lives one foot injury whose prognosis is influenced by vascular disease and infection, both associated in more than 50% of lower limb amputations[4-7].

A previous study showed that the health-related quality of life indicator is markedly poor in people with diabetes, pointing out that the diabetic foot contributes to affected people experiencing severe restrictions in daily life. Social isolation stands out as a consequence of reduced mobility, the requirement for frequent clinical treatment and constant care, impacting the perception of negative feelings and a close relationship with higher levels of depression and worse psychosocial adaptation to the disease. These outcomes contribute to a unique setting for the design of representations. Thus, knowing diabetic foot's social representations can reveal how the daily experiences of people with DM are influenced by these social representations and how they elaborate beliefs, meanings, opinions, and attitudes focused on the care of their feet, increasing knowledge on the diabetic foot[8].

Other studies reveal that the lack of examination of the feet of people with diabetes and the lack of educational guidance and prevention actions presuppose an increased risk of injuries, especially in patients with greater social vulnerability[9-11]. Thus, the need for access to educational and preventive care practices, comprehensive care for patients with diabetes, the active search and longitudinal monitoring of these users, and the coordination of care for patients with DM in the care network point to the fundamental importance of PHC in the care and prevention of diabetic foot, enhanced in regions such as the Brazilian Northeast[9-11].

In general, social representations make something unfamiliar familiar through two socio-cognitive processes (anchoring and objectification), connecting new knowledge and concepts to previous values and ideas internalized in culture to build a context familiar to a social group. They emerge as cognitive elements, images, concepts, categories, and theories[12].

This study employed the complementary structural aspect to understand the structure and the central core of social representation based on the Central Core Theory of Social Representations proposed by Abric[13], a theoretical-methodological construct that aggregates the original theory – Social Representation Theory (SRT) by Moscovici[12]. The author hypothesizes that all social representations are organized around a central core that gives meaning to the representation and around a peripheral system that is the interface between the central core and the concrete reality[12,13].

In the health area, knowledge about social representation (SR) has broadened the understanding of the health-disease process, contributing to the development of bold approaches to therapeutic and educational practices, so crucial for managing comorbidities such as diabetic foot through more humanized and personalized behaviors, and approaching the context of people with diabetes[14,15].

We aim to identify the structuring elements that guide the establishment of diabetic foot SR among people with DM.

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Methods

Study type

This is a descriptive, qualitative research based on the Social Representation Theory (SRT) in the Central Core Theory approach. While not an objective of the study, some quantitative data on the participants were employed to support the discussions, reiterating the SRT view that the ideas, beliefs, and values are based on the identity of the groups they belong to.

Population and setting

The investigation was conducted from February to May 2019 at the endocrinology and diabetes clinic and wards of a university hospital and a center for medical specialties and diagnoses, both located in a capital of Northeastern Brazil. The locations selected for the study are municipal reference services for monitoring people with DM, including referrals of users through the PHC/ESF.

Participants were selected by non-probabilistic, convenience sampling, considering the availability to participate and present at the location at the time of data collection. The study participants met the following inclusion criteria: having a diagnosis of DM for more than five years, with a diabetic foot; being 18 years of age or older; and having psychological and communication conditions to answer the guiding question of this study. It is worth mentioning that the determination of the time of diagnosis of five years is due to the knowledge that meanings are engendered in the experience of living with the condition. Thus, participants with a longer diagnosis time contributed more broadly to the study proposal.

People with a current diagnosis of diabetic foot who had part or all of one of the lower limbs amputated or were clinically unstable at the time of the data collection approach were excluded from the study. We included in the sample only people without amputation to understand the SR from the perspective of those having a comorbidity with a high lower limb potential loss and what this means to these people. We also decided to explore the topic with people who have not yet experienced the amputation process because the qualitative studies identified in the literature have not made this differentiation.

A total of 110 people were approached during the recruitment of participants. However, ten were excluded for having partial amputation of one of the lower limbs, especially amputation of one or more toes or half-foot amputations.

Data collection

In outpatient care, initially, the researcher integrated with patients in the waiting room, interacting and seeking to understand care dynamics. Thus, she sought to socialize with them and participate in trivial conversations, aiming at an approximation. This procedure is advised when using SRT as a theoretical reference, as it is a valid and essential tactic to establish a previous involvement with the group with which we intend to develop the study to familiarize ourselves with the participants.

A pilot test was carried out to verify the reliability and adequacy of the collection instrument and the method for the study. The pre-test was conducted under the same circumstances as the research with 12 participants who were not part of the final sample and showed the reliability and operability of the instrument.

An instrument was used that contained a question for applying a free word association test (FWAT), and permission was requested for audio-recording. Finally, the roadmap was used to characterize the participant's sociodemographic and clinical profile. The FWAT is widely used in studies theoretically supported by SRT, as it allows the evidence of semantic elements of a particular group through evocations from inducing stimuli, facilitating the understanding of the representational structure. It is a projective technique that brings unconscious aspects to consciousness through manifestations of evocation behaviors[16].

FWAT was applied at the onset of data collection to prevent applying the roadmap to characterize participants from eliminating spontaneous responses. We used the following inducing sentence: Mention four words or images that come to your mind when you hear about a diabetic foot. Participants were then asked to indicate which of the terms mentioned was most important to them. Previous training assured the participant's understanding of the technique, using an inducing stimulus unrelated to the object of study. Data collection was started after verifying the effective understanding of the technique. The researcher's perceptions were recorded in a field diary immediately after applying the FWAT, and the records were descriptive, addressing clarifications on terms issued by the participants.

Data analysis and processing

The empirical data were ordered first in an Excel table and later processed in the OpenEVOC 0.85 software. This program supports the SR research process aligned with the SR Central Core Theory, identifying SR's central up to peripheral systems. The software considers the simple frequency and the mean order of appearance of the spontaneously evoked words that, when combined, give rise to the four quadrants framework that considers and sorts the evocations produced according to the relevance attributed by the research participants.

Ethical aspects

The Research Ethics Committee of the University Hospital of the Federal University of Maranhão approved the research project in 2018, in compliance with Resolution n° 466/2012 of the National Health Council. All participants received oral and written information about the study and the responsible researchers. All participants signed the Informed Consent Form, and anonymity was ensured.

Results

Knowing the profile of the study participants provides us with broader understanding of the representational elements of their ways of thinking. Of the 100 survey participants, 51% were male and 49% female, ranging from 33 to 92 years old (37% were between 60 and 69 years old). In the group, the mean number of schooling years was 7,9 years, and 62.5% lived with their spouses. The mean time of DM diagnosis was 14 years: type 1 and gestational diabetes corresponded to 6,25% each, and type 2 was the most prevalent, with 87,5%. It is noteworthy that the group of people with gestational diabetes approached corresponds to women who developed comorbidity during pregnancy, with persistent changes in blood glucose after delivery but who were not pregnant at the time of the research.

We aimed to elucidate the central and peripheral system from the structural analysis of the free word association with the abstraction of the diabetic foot SR structure or organization. The results showed that the participants elaborated 381 evocations with 110 different expressions or words. After issuing the evocations, the participants signaled the word they considered most important, which allowed knowing the representation's contents and organization or structure.

The words evoked only once were discarded when the quadrants were constructed, as their percentage was non-significant (13,65%). As a result, 86,35% of the total words emitted were used, making the analysis more robust and representative. Then, the mean frequency of evocations emerged, dividing the total words (329 thematic units of analysis) by the number of different words (110), obtaining a mean frequency of 3. The software automatically generated the value of 2,47 to obtain the mean evocation order. The four-square table emerges from the software, with the evocations of the inductive term diabetic foot. Thus, we could observe the organizational structure of the SR and the hierarchy of the elements underlying their mental contents (Chart 1).

The ten most mentioned expressions corresponded to 60,5% of the total and were care (42), amputation (33), cure (29), fear (24), concern (16), incurable (12), really bad (12), diabetes (11), takes time to heal (11), and diet (9). The word care emerged from the statements with a meaning of self-care and its fundamental role in diabetic foot prevention.

According to SRT's structural approach, the expressions that appear in the upper left quadrant characterize the probable central core of the representation since they were promptly evoked (lower mean evocation order) and have a high frequency. The central core is the most stable and resistant to changes in the SR and articulates historical, sociological, and ideological issues, marked by the collective memory of the group of belonging and the system of rules to which it refers[17]. The underlying elements of the referred quadrant were cure (with the sense of desire/hope to recover soon) and really bad (as a synonym for something painful), indicating that the hypothesis of the diabetic foot SR centrality is anchored in subjective and evaluative content. In the evocations, the hope of a cure was powerfully present and sometimes the only source of strength for someone to continue the treatment.

The group of male participants with type 2 DM and aged between 60 and 69 years old has a special relationship with the two evocations cure and really bad, bringing an understanding that these characteristics lead them to perceive more promptly the negative impact of the diabetic foot on daily life, producing their narrative in this line of argument.

On the other hand, the peripheral system consists of the primordial complement of the

central system, in which central elements are regulated and adapted to the real situations experienced by individuals. The first periphery includes the terms that corroborate the central elements, with the words with the highest frequencies, albeit evoked later on[17]. In this investigation, the upper right quadrant gathered the following words: care, amputation, fear, concern, incurable and diabetes.

The term care has an attitudinal dimension related to the practice of caring for oneself, showing the idea of responsibility for own health; that is, care as a daily construction and dependent on the individual. In the first periphery, we find words that refer to the subjective dimension of SR, wrapped in concern about the condition and fear. Participants expressed fear of injury, infection, using a wheelchair, and losing their foot.

In the second periphery (located in the lower right quadrant), we observe terms less frequently mentioned and evoked more extemporaneously, which are relevant in the representational field for bringing elements related to daily practices, translating the knowledge of individuals, and guiding their behavior[17]. This quadrant was formed by the expressions/words: takes time to heal, wound, dressing, diet, sadness, difficulties, pain, limitation, medicine, worst disease, complication, suffering, desperate, addiction, hydration, nervous, difficult gait" and lack of care. In this periphery, ideas, and meanings related to the negative impacts of the diabetic foot condition and the more instrumental care or lack of care, emerged.

In this second periphery, we then perceive words that translate how the participants imple-

Chart 1. Evocations of social representations to the inductive term "diabetic foot" obtained from the OpenEVOC 0.85 software. Maranhão, 2019.

++ Frequency ≥3/ Evocation order < 2,47			**+ - Frequency ≥3/ Evocation order≥ 2,47**		
1º Quadrant: Central elements			**2º Quadrant: 1st periphery**		
9,01%	Cure	1,83	12,42%	Care	2,1
3,73%	Really bad	1,75	10,25%	Amputation	2,33
			6,83%	Fear	2,32
			4,97%	Concern	2,13
			3,73%	Incurable	2,17
			3,42%	Diabetes	2,09
- + Frequency < 3/ Evocation order < 2,47			**- - Frequency < 3/ Evocation order ≥ 2,47**		
3º Quadrant: Contrast zone			**4º Quadrant: 2nd periphery**		
0,62%	Prevention	1,5	2,8%	Takes time to heal	2,33
			2,8%	Wound	2,33
			2,8%	Dressing	3,11
			2,8%	Diet	3,44
			2,48%	Sadness	3
			1,86%	Difficulties	2,17
			1,86%	Pain	3
			1,86%	Limitation	3,17
			1,86%	Medicine	3,17
			1,55%	Worst disease	2,2
			1,55%	Complication	2,6
			1,24%	Suffering	2
			0,93%	Desperate	2
			0,93%	Dependence	2,33
			0,93%	Hydration	2,67
			0,93%	Nervous	2,67
			0,93%	Difficult gait	3
			0,93%	Lack of care	3,33

Source: The authors (2019).

ment foot care, setting up an attitudinal dimension. Elements that show a subjective (suffering, sadness, difficulties, pain, limitation, desperate, and worst disease) and relational dimension (dependence) also appear.

The lower left quadrant (contrast zone) contains low-frequency elements and quickly evoked, which bring aspects that reinforce the terms found in the central core[17]. This quadrant includes the prevention element.

Discussion

The cluster of words and expressions evoked for the inductive stimulus diabetic foot and its arrangement in the quadrants indicate that the SR of the studied group is firmly anchored in a feeling of hope for improving the condition, negative feelings, and recognizing the importance of self-care. Understanding that the diabetic foot is related to a chronic condition and, to a lesser or greater degree, is characterized as a physical limitation factor affecting the psychological and social sphere resonates in the elements that appear in the central and peripheral system of the quadrants.

Considering that the central core behaves as the most stable part of the representation, it evidences the collective thinking and provides elements that underpin the social group's identity[13,17], in the analysis of the revealed central core, namely cure and really bad, we can infer that the assigned meaning provides an initial impression of a certain opposition between these evocations, evidencing an antagonistic perception of the individual who experiences the diabetic foot. However, these data generate clues about the daily difficulties experienced by people to control comorbidity and, concomitantly, the awareness acquired by participants after the diabetic foot is affected regarding the importance of self-care, both directed at foot care and other aspects of their lives, highlighting a positive aspect linked to this comorbidity.

The central element of most significant evidence is cure, with a link to hope for the mitigation of the diabetic foot condition. While many are already used to self-managing diabetes, people living with this complication need a narrative of hope and positive thinking to remain engaged with self-care. Scholars suggest that, in caring for people with life-limiting conditions, health professionals should help them find the path of hope centered on healing, providing a more realistic emotional foundation with physical, emotional, and spiritual relief[18].

Living with the diabetic foot is a challenge and is permeated by negative nuances, as shown by the participants of this study through the second really bad core element. People with DM believe that daily life includes efforts to harmonize various commitments to the management of diabetes and its complications. In this context, there is an additional pressure on the well-being of these people, evidenced by the impaired quality of life, early retirement, or increased unemployment and stress related to work or social relationships[19,20].

According to the principles of SRT's structural approach[13], the contrast zone located in the lower left quadrant consists of elements with low frequency and low evocation order, which are, however, important to the participants. In this research, the prevention element is found in the contrast zone; that is, it reinforces and dialogues with the central core and, concomitantly, portrays a certain tension regarding the inductive term diabetic foot. Prevention is connected to the cure and really bad elements, showing a particular awareness that that action can ensure a more peaceful life and prevent the diabetic foot, thus excluding the need for a cure. Therefore, prevention denotes a more critical view directed at the diabetic foot condition and can transform the identified core elements.

The evocation prevention indicates the meaning of the diabetic foot in the conception of the studied group and may be connected with the collective memory built during the treatment of diabetes, in which the health team stresses the importance of self-care to avoid complications. However, it makes us think that perhaps some prevention approaches have been insufficient to prevent complications. A study carried out in India suggests that, for effective prevention of chronic diseases, such as diabetic foot, the approaches implemented should include the target audience in the entire process of developing educational practices. Ideally, these strategies should be culturally adapted to generate innovative solutions[21].

Thus, more effective care can be directed by changing practices at different care levels in the health network, especially in PHC, from the identification of aspects related to diabetic foot prevention actions, such as the assessment of risk patients' feet, thus identifying more vulnerable individuals, anticipating and reducing subsequent complications[9].

The elements in the first periphery in the upper right quadrant (Chart 1) show how the group with diabetic foot adapts to daily situations. The words care, incurable, and diabetes express individuals aware of their chronic condition and the constant need for self-care, but who live daily with fear and concern, knowing that it is a comorbidity that can develop into undesirable and devastating complications such as limb amputation.

The most significant complication of the diabetic foot incurs amputations, generating high costs to the Unified Health System, a concern revealed by the respondents. A study carried out by researchers at the University of Goiás, State University of Rio de Janeiro, and the Federal University of Rio Grande do Sul from 2014 and 2017 showed that, of the total estimated annual medical costs for Brazil, based on 2014, 85% of the costs were related to the treatment of patients with a neuro-ischemic foot with ulcers[22].

The most relevant term in the upper right quadrant was care, emerging from the statements with a sense of self-care, evidencing the participants' awareness about the fundamental role of self-managing the diabetes-diabetic foot dyad. DM is a complex disease requiring effective self-management. Scholars claim that the greater the autonomy of patients, the better the self-management, and the greater the self-efficacy of people with diabetes. Thus, the health team should urgently develop proactive communication with people with a diabetic foot or who are at risk to develop it in order to stimulate the sense of autonomy and promote better self-management of the diabetic foot condition, increasing this approach with behavioral agreements that respect people's preferences and support them in adopting self-care[23,24].

The evocations limitation, dependence, and difficult gait are connected and denote the SR's imagery dimension[12] vis-à-vis the explored object. These evocations point to negative aspects, with repercussions on the daily life of the explored group. Usually, the appearance of the diabetic foot brings limitations, with the need for adjustments for life to continue flowing, such as, for example, the use of mobility aid and the need for support from third parties for care previously self-performed. The emergence of these evocations in the second periphery appears to be anchored in the socially disseminated idea that the diabetic foot's appearance is associated with the inevitable use of orthopedic devices and a necessarily impaired gait[25].

Experiencing chronic comorbidity is a multidimensional, dynamic, complex, and cyclical process that requires the elaboration of some attributes, such as acceptance, coping, self-management, among others, which, depending on how these properties act, may emerge different ways of living, from refusal to a new normal. Understanding how these problems are processed is essential for the health team at different care levels, as it can contribute to person-centered care and a broader and more uniform analysis of what it is like to live with diabetic foot, serving as a guide for the development of appropriate interventions to facilitate this process and mitigate negative impacts[26].

This study found that the mean time of diagnosis of DM was 14 years and the participants reported fear, especially of foot amputation. Research conducted in the US found that patients with diabetic foot were more afraid of amputation than death, and one of the variables with the most significant association with fear was the duration of DM ≥ 10 years, which is in line with this study. Research has shown that patients with chronic leg wounds experience negative feelings associated with higher levels of depression and anxiety that generate psychological stress that is difficult to manage over time. Knowing the fears of people with diabetic foot provides clues to the health team on how they experience comorbidity daily and contribute to earlier interventions to prevent more psychological severe changes[27,28].

The findings of this study are essential to support the monitoring of people living with diabetes in PHC, as specialized support services for the treatment of diabetic foot may be scarce or non-existent in small municipalities. The elements of suffering, desperate, and sadness raise a debate about the experience with the diabetic foot, perceived by the group, explored as a distressing experience based on the verification of the limitations imposed by the comorbidity affecting social, work, and psychological life. Suffering arises from the limitations since a significant mobilization of energy is necessary to address these issues daily, which can generate psychological wear and tear.

The perceived health status that comes with the evocation induced by the research provides patients with a greater awareness of their condition, reinforcing their health education and, consequently, self-care. Since individuals or their relatives perform the daily care for the treatment of diabetes, participatory educational methodologies assist in this perspective[1].

Research findings indicate that the diabetic foot brings substantial losses to psychological and emotional functioning, with different meanings to the social, cognitive, and individual realms, and requires health professionals' humanization, specific skills, and abilities to design plural interventions addressing the psychological suffering faced by people with this complication[29].

According to the fundamentals of SRT's structural perspective, the peripheral system is associated with substantial experience, encompasses transition elements, and renews the central core[17]. This process leverages change in social reality, generating inputs supporting conscious behavioral choices and better decision-making by people with a diabetic foot or at risk for developing it.

Study limitations

This study has some limitations. The method of analysis chosen was the OpenEVOC program, which focuses on identifying SR's structural elements. However, further research employing the discourse analysis may contribute to a better understanding of the diabetic foot as a psychosocial event or conducting methodological triangulation studies. Another limitation is data collection in health services, which may have generated some discomfort in the participants, and we cannot affirm whether the SR's constituent elements on diabetic foot would be the same in other settings, thus being an opportunity gap for future studies.

Although these limitations have been identified, we believe that this study is helpful for health professionals who develop activities with people with a diabetic foot or at risk of developing it in different points of the care network, especially primary care, because it brings about new knowledge of the explored phenomenon from the psychosocial perspective.

Final considerations

The theoretical-methodological approach sorted evocations in the four quadrants, identifying the structuring elements guiding the establishment of the diabetic foot's SR among people with DM. The results add to the current knowledge of the diabetic foot SR's constituent elements in the central core, which are "cure" and "really bad", revealing that living with a diabetic foot is challenging at an individual level. However, there is a hope of a cure that is a driving force in the daily search for care, an element underlying the first periphery, corroborating the central core. In turn, daily care is intrinsic to the primary level of health care, anchored in the PHC principles, which must be prepared formatively and operationally to prevent and care for patients with diabetes comprehensively.

In this sense, this can be a prosperous area for developing educational programs that encourage responsibility for people's self-care, supply psychosocial demands, and increase the perception of social support of people with a diabetic foot or those at risk for developing it. In parallel, it is also necessary to create training programs for health professionals to prepare them better to address psychosocial issues brought up by this target audience and plan and implement interventions sensitive to a socio-cultural understanding and how people interact socially, further qualifying health services, especially those related to PHC, strengthening coordinated and comprehensive care for people with diabetes.

SR's dynamism allows understanding how these mental structures guide the beliefs, opinions, and behaviors of these people, thus contributing to the design of more specific and innovative interventions to stimulate autonomy, emotional and psychological support and sustaining the adoption of healthy behaviors that lead to feet health's positive results. Health professionals should urgently create opportunities within the primary and specialized care spaces to facilitate qualified listening, exploring people's beliefs and perceptions about their diabetic foot experience so that their interventions can sensitize them, challenge them to reflect on possible mistaken beliefs, and lead them to reframe their condition, positively impacting their self-care and influencing them to make efficient behavioral choices.

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Collaborators

GSG Lopes participated in the conception, design, analysis, and interpretation of data, writing, and critical review of the paper; ILTP Rolim participated in the conception, design, analysis, and interpretation of data, writing of the paper, and, as a research advisor, participated as a reviewer of all preparatory stages of the paper; RS Alves participated in the writing and critical review of the paper; TRRF Pessoa participated in the writing and critical review of the paper; ER Maia participated in the writing and critical review of the paper; MSV Lopes participated in the writing and critical review of the paper; APP Morais participated in the writing and critical review of the paper; RCS Queiroz participated in the writing and critical review of the paper. All participated in the approval of the version to be published.

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