

Social representations of diabetic foot for people with type 2 diabetes mellitus

REPRESENTAÇÕES SOCIAIS DO PÉ DIABÉTICO PARA PESSOAS COM DIABETES MELLITUS TIPO 2

REPRESENTACIONES SOCIALES DEL PIE DIABÉTICO PARA PERSONAS CON DIABETES MELLITUS TIPO 2

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ABSTRACT

This is a qualitative study with the purpose to understand the social representations of the *diabetic foot* for people with type 2 diabetes mellitus. Semi-structured interviews were held with ten people with diabetes mellitus, who participated in a support group. Two categories emerged from the content analysis: the *foot disease* with *perceived alterations* and *present threats*, and *feet care*, with *care as a concern with the future*, and *non-care as a feeling of guilt*. The results show that the subjects seek hopes of not developing foot disease or controlling the situation, influenced by the representations of alterations and threats. When non-care occurs, the feeling of guilt emerges, since the subjects knew about the necessary care but did not use it. The social representations contributed in the search for comprehension of how the subjects with diabetes mellitus build the knowledge that express their identity and guide their behavior, especially regarding the diabetic foot.

KEY WORDS

Diabetes mellitus.
Diabetic foot.
Social perception.

RESUMO

Trata-se de uma pesquisa qualitativa que objetivou compreender as representações sociais do *pé diabético* para pessoas com diabetes mellitus tipo 2. Foram realizadas entrevistas semi-estruturadas, com dez pessoas com diabetes mellitus que participavam de um grupo de convivência. Da análise de conteúdo emergiram duas categorias: a *doença do pé* com *alterações percebidas* e *ameaças presentes* e; o *cuidado com os pés*, com o *cuidado como preocupação com o futuro* e *não cuidado como sentimento de culpa*. Os resultados mostraram que movidos pelas representações de alterações e ameaças os sujeitos buscam no cuidado uma esperança de não desenvolver a doença do pé ou controlar a situação. Quando o não-cuidado ocorre, surge o sentimento de culpa por terem conhecimentos e não se cuidarem. As representações sociais contribuíram na busca da compreensão do modo como os sujeitos com diabetes mellitus constroem saberes que expressam sua identidade e guiam seus comportamentos, especialmente vinculado ao pé diabético.

DESCRIPTORIOS

Diabetes mellitus.
Pé diabético.
Percepção social.

RESUMEN

Se trata de una investigación cualitativa que tuvo como objetivo comprender las representaciones sociales de *pies diabético* para personas con diabetes mellitus tipo 2. Fueron realizadas entrevistas semi-estructuradas, con diez personas con diabetes mellitus que participaban de un grupo de convivencia. Del análisis de contenido emergieron dos categorías: la *enfermedad del pie* con *alteraciones percibidas* y *amenazas presentes*; y el *cuidado con los pies*, con el *cuidado como preocupación con el futuro* y *no cuidado como sentimiento de culpa*. Los resultados mostraron que movidos por las representaciones de alteraciones y amenazas los sujetos buscan en el cuidado una esperanza de no desarrollar la enfermedad del pie o de controlar la situación. Cuando ocurre el no cuidado surge el sentimiento de culpa por tener los conocimientos y no utilizarlos. Las representaciones sociales contribuyeron en la búsqueda de la comprensión del modo como los sujetos con diabetes mellitus construyen conocimientos que expresan su identidad y guían sus comportamientos, especialmente vinculado al pie diabético.

DESCRIPTORIOS

Diabetes mellitus.
Pie diabético.
Percepción social.

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INTRODUCTION

Diabetes mellitus (DM) is a challenging public health problem. It is a chronic disorder with high morbidity and mortality rates that affects a large share of the population and is caused by environmental and hereditary factors. In Brazil, it is estimated that there are five million people with DM, nearly half of these (46.5%) unaware of the diagnosis. It is estimated that, by 2020, there may be 11 million, due to population ageing, obesity, lifestyle, sedentarism and changes in the dietary patterns. The prevalence in the urban population aged 30-69 is 7.6%, similar to levels in developed countries⁽¹⁻⁴⁾.

DM and its associated vascular complications represent the fourth main cause of death in the United States. Over half of lower extremity amputations are due to this disease⁽⁴⁾.

People with DM have been constant victims of lower limb amputations, due to the evolution of the disease. The Ministry of Health notes that people with DM are 15 times as likely to have an amputation as non-diabetics, corresponding to 50% of non-traumatic amputations⁽⁵⁻⁶⁾.

Diabetic foot is one of the most devastating chronic complications of DM, due to a large number of cases that evolve to amputation. This term is used to characterize injuries that occur on the feet of people with DM, as a consequence of the combination of motor-sensitive and chronic peripheral autonomic neuropathies, peripheral vascular disease, biomechanical alterations that lead to abnormal plantar pressure and infection, which may be present and aggravate the case even further⁽⁶⁻⁷⁾.

The socioeconomic impact of the *diabetic foot* is significant, including expenses with treatment, prolonged and recurrent hospitalizations, physical and social disabilities such as loss of work and productivity. For the individual, it reflects in their personal life, affecting their self-image, self-esteem, their role in the family and in society. If physical limitations are present, social isolation and depression may occur.

During our care experiences for people with DM, we observed inadequate behaviors for the prevention of the *diabetic foot*. This perception caused some disquieting feelings, raising questions about how we could develop educational proposals that would promote people's reflection about their situation in order to develop the conscious ability to act and decide about their own care.

Chronic diseases like DM bring limitations and new incumbencies to the people who develop them. These diseases are usually not accepted or overcome because of the lack of knowledge about how to cope with them⁽⁸⁾.

The lack of proposals for preventing such chronic complications, with the development of healthcare education

supported in the concrete reality of the individuals, reflects in the high statistical rates of lower limb complications and amputations, influencing the quality of life of people with DM. One of the main factors of this chain of undesirable consequences, however, is the difference between people's knowledge about living with the disease and the technical-scientific knowledge of healthcare professionals, because they lack the comprehension of the meaning the chronic disease has for these people. Most of the times, they do not understand how diabetic patients perceive their disease and how the care procedures become a part of their daily routine. Therefore, to overcome the barriers that exist between people with chronic diseases and healthcare professionals, it is not enough to invest only in developing more knowledge about the disease, but it is necessary to include the comprehension of what it is like to live with this disease in order to create proposals of healthcare education focused on people, instead of the diseases.

With these perceptions and reflections, we decided to investigate the meaning of the *diabetic foot* for people with diabetes mellitus type 2, trying to identify how they represent the *diabetic foot* complication. Acquiring more knowledge about how people experience DM and, more specifically, how they represent the *diabetic foot*, is a fundamental factor to implement strategies of DM education that consider the human being in all of its complexity and diversity.

Dialogic education that privileges the subject's autonomy is established when there is a satisfactory communication between DM professionals and healthcare professionals. It is necessary to establish a respectful relationship, where cultural, social and emotional factors are considered, as well as the experiences and the knowledge that will permeate the teaching/learning process.

With these considerations in mind, we developed the present study, with a view to identifying the social representations of people with diabetes mellitus type 2 who received care about the *diabetic foot* in a reference service for chronic diseases.

The objective of all the representations was to familiarize the patients with something they are not familiar with, i.e. to represent socially all objects and situations of everyday conversations, so that they are accessible to everyone, or communicable. The dynamics used in the relationships is familiarization, where objects, people and events are perceived and understood in relation to previous encounters and paradigms. As a result, memory prevails over deduction, past over present, response over stimulus and images over reality⁽⁹⁾.

The representations are characterized by human interactions. When we find things or situations and become familiar with them, they are present and still influence hu-

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man behaviors. At the same time, they influence their experiences and social life.

In the present study, these representations occurred due to previous contact with people with the *diabetic foot* complication, which influenced the meaning elaborated about this complication. These representations were created in the social communication that became a reality for the members of the social group, having a decisive impact in their choices, in the way they raise their children and care for their health⁽⁹⁾. Therefore, the representations about the *diabetic foot* will either influence the performance of foot care for prevention and/or care of this complication or not.

The DM group, the social group and individual experiences, the information conveyed by the media, the healthcare services and others are registered in the memory of these people, consisting of the *figurative core*⁽⁹⁾. Figurative core or structural scheme is the nucleus of the representation, because it determines the meaning and organization of the representation. The figurative core has both a generating and organizing function, through which it attributes sense and determines the connecting links between the elements of the representation⁽¹⁰⁾.

These ideas and images, built in the daily events of the relationships, are records of past conclusions stored in our memory. Whenever we are faced with unfamiliar situations in our consensual universes, we use two mechanisms of a thinking process (anchoring and objectivation) to integrate them in our mental and physical world, which makes them familiar. In this process, we attempt to anchor foreign ideas, such as the *diabetic foot*, reducing them to common categories and images and bringing them into a familiar context. Later, we objectify these ideas, transferring what is in the mind to the physical environment, assuming a reality.

Objectivation and anchoring are the specific ways in which the representations establish mediations, making the symbolic production of a community almost material, and regarding the concreteness of the social representations in social life.

METHOD

The present study is a qualitative research that resulted from the articulation between nursing practice at a care service for DM patients and a proposal to implement a support group, with the purpose of building knowledge from the identification of the social representations of the *diabetic foot* for people with type 2DM.

The research was performed at a referral service for chronic diseases in Florianópolis – SC, which offers secondary-complexity outpatient clinical services in several specialties.

The research subjects were people with type 2DM, diagnosed for five years (or more), who take part in the support group and agreed to participate in the research. The choice for type 2DM is related to the higher incidence of

this type of population with diabetes, with a higher frequency in the search for nursing care at the institution where the study was held.

Support groups aim at personal growth, covering several dimensions of the process of living, using strategies that are appropriate for social development, healthcare education and problem solving, among others⁽¹¹⁾.

Data collection was accomplished with the triangulation of methods and techniques, which were used in the support group meetings and individual interviews. The collected data were recorded on cassettes and transcribed with the written consent of the participants.

The group meetings had an approximate duration of 60 minutes, with the development of a healthcare education proposal regarding the patients' experiences, whose core theme was diabetic foot complications. These meetings were named: 1) *Acknowledgement and revelation*; 2) *Seeking self-knowledge* and 3) *Building care*.

Group dynamics were held, which made it possible for everyone to participate, with the purpose of approximating the group reality as closely as possible, trying to develop the themes in a practical way, with an accessible language and discussion of real situations, identified in the daily routine of these people. During the meetings, we tried to apprehend the social representation of the *diabetic foot* for these people.

After the period when the support group was held, a semi-structured interview was performed with each member of the group in order to continue with the data collection, totaling 10 interviews at the end of the process.

The set of data collected in the support group and the individual interviews were analyzed, using thematic content analysis. Categorization sought to identify the social representations related to the *diabetic foot*, through anchoring and objectivation, following the three methodological stages: pre-analysis, exploration of material and treatment of the obtained results and interpretation⁽¹²⁾.

Considering the ethical aspects of research involving human beings, we attempted to guarantee that the rights of the citizens were protected, complying with resolution 196/96 of the National Health Council / Ministry of Health. The study population was invited to participate in the research, receiving all the necessary information about the proposal. A document was elaborated to formalize their consent, guaranteeing respect, secrecy and freedom of participation, and the ability to leave the study at any moment, without repercussions for the healthcare the patient receives at the institution. The study proposal was approved by the Review Board of Universidade Federal de Santa Catarina, file #091/2004.

The participants received fictitious names in order to preserve their anonymity and distinguish their characteristics and testimonies.

In this study, the group consisted of ten people with diabetes. Six of them were female and four were male, aged 53-77. The time with diabetes varied between seven and 41 years.

SOCIAL REPRESENTATION OF THE *DIABETIC FOOT*

During the stage of data analysis, two categories related to the study theme were identified in the subjects' discourse. The first was named *foot disease*, covering two sub-categories: perception of changes in the feet and present threats; and the second category was foot care, with the following subcategories: care as a concern for the future and non-care as guilt.

Foot disease

In the testimonies of the subjects, the representation of value attributed to the feet as support, body safety and fundamental for locomotion was evident. The social representation of walking is anchored in a relationship of independence and autonomy, consensually manifested by the respondents.

When asked about the body part that worried them most when thinking about DM, all of them mentioned their feet. The representation of the feet, objectified as a concern, is anchored in the perception of risk of developing the diabetic foot and its consequences.

These concerns increase as the patients identify changes and discomfort in their feet. As such, people with DM classify their feet as either sick or healthy, according to their paradigms, selected according to their representations.

The concept of health is not universal and consensual so as to be generalized, depending on the social representations the population builds about the disease and health⁽¹³⁾. Since health and disease are specific representations of a given social group, which is influenced by its culture, experience and everyday relations, the designation of the feet as healthy or sick also occurs.

The representation of the healthy foot is an image that expresses social thinking, anchored in the maintenance of its natural function: walking.

In the respondents' testimonies, diabetic foot complications were objectified as the *foot disease*. As such, this terminology was used to represent the research theme.

With this representation, two subcategories were highlighted, being expressed more often in the interviews: perception of alterations in the feet and the threat of the *foot disease*.

- Perception of alterations in the feet

Feet have shapes and characteristics that are consensually considered *normal*. Any alteration may be an indica-

tion that something is not right, especially for people with a chronic condition like diabetes mellitus, which represents a high rate of complications in the feet. About 10% to 20% of people with diabetes will develop injuries in the lower limbs⁽¹⁴⁾.

This information is constantly publicized by communication means, reaching the consensual universe where they are re-interpreted and represented. Therefore, the physical and sensorial alterations are commonly considered as warning signs.

The alterations noticed by the patients were classified as: pain, paresthesias, drying, deformities and numbness, manifestations of the neuropathy; circulatory alterations, injuries and infection. Pain was the representation made evident most often, since it was one of the first signs that something is not right with the feet. This unpleasant feeling affects the quality of life of people with DM, who start to live a daily routine of discomfort⁽⁶⁾.

In the representation of the perception of alterations, we noticed an influence of biomedical knowledge, which strengthens the physical characteristics of the *foot disease*. However, we noticed that there is a plethora of feelings behind such manifestations, which provide meaning to the current events. This meaning is full of life experiences, built in daily routine, in the relations with the whole social environment, which comprises the reality of the subjects.

- The threat of the foot disease

The *foot disease* is represented as a threat to the group, that of losing a foot (amputation) and everything it represents, in addition to death.

The fact of having DM is perceived by many people as an implicit threat of developing the well-known complications this disease can cause. *The diabetes*, as the subjects call it, is a *silent disease*, *dangerous disease*, *damned*.

The representation of the disease is the opposite of what is good – something unpleasant, which affects the being and cripples him, revealing something inadequate from within. Therefore, the disease is seen as evil in our culture. DM is considered a disease, with emphasis on care, revealing concerns with the complications of the disease, considered treacherous⁽¹³⁾.

This disease is sometimes unnoticed by the patients. Other times, it is seen as a situation of constant fear, especially when it is related to the risk of complications or discomfort due to its complications.

Foot care

Care represents a primordial survival action for every living being, especially humans. They have a close relationship with our experiences of receiving and giving care. Therefore, the meaning attributed is influenced by the cultural and social environment the subject is inserted in. The

way individuals take care of their own health is not universal, expressing the conditions of life and the strategies they use to maintain their well-being, yielding a plethora of representations, from the interpretation of scientific knowledge to popular healthcare practices⁽¹³⁾.

For the study subjects, DM was represented as a stimulus for care. The awareness of the importance of care is based on the common sense that being a person with this disease changes life, since they need to reorganize their daily routine. This condition demands care so that the patients could live well.

The testimonies of the subjects reflect a new stage in the process of living, with new incumbencies that were unnecessary until now. The necessity of maximum care is related with the scientific and practical knowledge the subjects have about DM, developed during their day-to-day, acquired from the media, healthcare services, contact with other people or in situations that are registered in memory and surface in the objectification of this disease.

- Care as a concern for the future

Concerns about the consequences of the *foot disease* give a specific meaning to the word care. The subjects become aware that, in a situation of having a chronic condition like DM, which *cannot be cured*, there is still something they can do about it.

Motivated by their own concerns and fears, the subjects seek to cope with the situation through several perspectives of care. The efficiency of their healthcare actions depends on the conscious and unconscious motivations of the subjects, with their subjectivities and potentialities⁽¹⁵⁾.

Direct care with the feet was objectified by washing and drying, applying creams, looking at or examining them very carefully, exercising/moving the feet, wearing adequate shoes that would not hurt them/avoiding walking barefoot/avoiding wearing slippers, not having pedicures, not stepping, clipping their nails in a straight pattern.

These care procedures translate the technical-scientific perspectives found in several healthcare sources, which are stressed to subjects who seek professional care, who in turn incorporate them in their discourse. Performing these care procedures is not restricted to expressing that they know its importance, but includes the awareness that turns these images into reality, anchored in the concepts existing in the minds of the social subjects.

Injuries are considered a warning sign that the situation may escalate. The subjects emphasize preventive care, since they see the injury as the first step towards a possibly greater loss.

In the presence of injuries, the main care procedure performed was the use of creams and topical medication. We noticed the representation of the medicalization culture. Society, according to biomedical reasoning, highly re-

gards the use of medication to achieve the cure of certain diseases, transforming medicine into a prescriptive routine. Medication is usually regarded highly, and the search for medications to solve everyday health problems is a common practice in the daily routine of the population.

Care was also seen in the look of professional and family help. When they perceived that something was amiss, the subjects sought help, clarifications and professional evaluation.

The evaluation and orientation of healthcare professionals are considered important. Technical-scientific knowledge emerges as a reference that is attributed to these professionals⁽¹⁶⁾. In the face of unknown situations, the subjects seek technical support to make them familiar and feel safer. The discourse of the healthcare professionals is not far from the common sense representations, since technicians influence the lives of the subject strongly⁽¹⁶⁾.

Family support was manifested through help when the subject presented difficulties in the maintenance of care, especially due to physical limitations (mobility and sight).

For the subjects, care is related with knowledge. In unfamiliar situations, such as DM and the *diabetic foot*, the subjects sought technical-scientific knowledge in healthcare services and common knowledge in their daily routine, so as to elaborate meanings about what is happening to them. The search for this comprehension can be understood as a form of care. In this knowledge, the subjects search for support for self-knowledge in this new perspective of living with the chronic condition.

We noticed that, when care is represented as a concern about the future, such as fears of the threats embedded in the *foot disease* becoming real, this propels the subjects to search a new perspective in their several conceptions. This cannot be imposed or transferred – it simply happens, when it is incorporated in their daily routine through awareness. It is not enough to simply acquire technical and scientific knowledge to care for oneself. It is necessary to know the emotions, so that the subjects can be aware of feelings, their own body and the care process⁽¹³⁾.

- Non-care as guilt

The representation of care as an obligation places the responsibility to maintain foot health on the subject. It can induce the thought that they may become responsible for the *foot disease* as they do not maintain care. At first, the act causes guilt, which is present in memory. The feeling of guilt is a consequence of a law, under which people are ruled and inscribed in their symbolic dimension, real guilt that afflicts us because of our flaws and daily actions⁽¹⁷⁾.

With the social valuation of body care, aesthetics and integrity, the deformity and injuries in the feet emerge, shocking social aesthetic standards. We noticed that, among the subjects, those who did not present deformities and/or wounds in their feet represented these alterations,

present in their colleagues, as laxity and carelessness. Therefore, society itself, with its own prejudices, labels these individuals as guilty.

As such, the social stigmas related to DM arise, with constant evaluations and judgments about the behavior of the subjects. When they need care and they do not perform it, it occurs because they are *lax, do not like themselves, do not have willpower*. With this, jargons are created to refer to non-care. These people are often reprimanded by the healthcare professionals themselves, who scold them when they do not follow what had been prescribed, sometimes even to the point of denying treatment if they do not *comply with the plan of treatment*. These *threats* make the subject feel even guiltier with the situation. As if the physical and emotional suffering of the foot disease were not enough, there is also the feeling of guilt. The induction of the feeling of guilt affects the self-esteem of the subjects who, in this condition and without many perspectives, may end up seeing no reason to take care of themselves. Guilt is a type of affection that does not lie, it articulates with the subject's truth, pointing to negative feelings of man inserted in civilization⁽¹⁸⁾. The subject feels guilty for breaking the standards society considers correct, associating their lifestyle habits with the development of the disease⁽¹⁰⁾.

Developing wounds was related with inadequate foot care, which could have been *avoided*. The subjects represented guilt associated with laxity, carelessness, lack and delays, considering that the progression of the disease was a consequence of their actions.

The perception that they *could have taken better care* was present in their discourse. However, in view of a whole situation of life involving cultural, social and economic factors, moral values and pleasure, we do not usually do what is *considered correct and good*, even knowing about it. The subjects/societies are very complex; their actions cannot be evaluated or judged outside the context and moment they occur in, because they involve the subjective relationships that give meaning to their behaviors.

Guilt for non-care was also represented as being linked to the lack of knowledge/orientation about the chronic condition, making the choice of healthcare actions to live with DM difficult.

Life experience and sharing this experience with social subjects is essential for a healthy life. Sometimes, even if they have knowledge, people do not take care of themselves. *Something else* becomes necessary in order to cause a change in behavior, which goes through a process of awareness. In the study subjects, we noticed that their concerns increased when the alterations related to the *foot disease* were already present. By then, they related the situation with non-care, and the consequent feeling of guilt motivated them to attempt to revert the prognosis.

The representation of non-care as guilt is anchored in the social value of care. As the subjects built knowledge

about the *foot disease*, with either technical-scientific information, contact with other subjects or other influences of their social environment, they also elaborate the representation of the necessary care. Then, when the practice of non-care is maintained, guilt arises by knowing what can be done, but not doing it. Therefore, we see the feeling of guilt as a result of the awareness of non-care.

FINAL CONSIDERATIONS

In the day-to-day relations of the consensual universe, people with DM elaborate and represent an image about the *diabetic foot* that is anchored in the memory of past experiences. A great concern about the feet was evident in the patients, related to the presence of DM. In the common sense, the *diabetic foot* is represented as the *foot disease*, which is considered a *disease* as it limits the natural capacity of the foot in locomotion. Therefore, the *healthy foot* is perceived by the maintenance of its function.

The alterations noticed in the feet arose in the objectivation of the *diabetic foot*, as an indication of abnormality. These representations manifest an influence of scientific knowledge, interpreted in the consensual universe of the subjects.

We noticed that, even when they describe their feet as *sick*, the subjects see differences between their feet and the *diabetic foot* of the reified universe, which they associate to the maintenance of the function of walking. This different perception of subjects' feet contributes to maintain hope that this threat will not become real.

Behind these changes, which are easily visualized and felt, the subjects expressed deep feelings involving the *foot disease*, which are related with the threats of amputation and a greater threat of death.

The representation of the *foot disease* propels the subjects to activities of care, in the sense of preserving life and facing fear, with the hope of care as prevention. Care was evident in concerns about the future.

Non-care arose as a representation of guilt, related to the development of the *foot disease* due to lack of care. In the representation of care as essential to cope with the *foot disease* and distance resulting threats, non-care makes the subjects suffer, grieve for not doing anything to fight the situation. Therefore, non-care, propelled by the feeling of guilt, can transform into care.

The visualization of the representation of the *foot disease* seeks a reflection about the importance of valuing social subjects, as thinking human beings, with their own paradigms that influence interpretations and attitudes about care, according to their view of reality. In education about DM, we can only attain teaching/learning if we consider this paradigm.

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