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AURORA DE AFONSO COSTA  
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## Perception of people suffering from diabetes regarding the disease and the reasons for hospital readmission: a descriptive study

Simone Cristina Baggio<sup>1</sup>, Catarina Aparecida Sales<sup>1</sup>, Sonia Silva Marcon<sup>1</sup>, Aliny Lima Santos<sup>1</sup>

<sup>1</sup>State University of Maringá

### ABSTRACT

**Aim:** To identify how people suffering from diabetes, rehospitalized due to uncontrolled glucose, perceived the disease, and the reasons that led to hospitalization.

**Method:** This is a descriptive study of a qualitative nature, performed with seven people suffering from diabetes who were hospitalized at least twice within a 12-months period. Data were collected in 2010 through semi-structured interviews and were submitted to thematic content analysis.

**Results:** The following categories have emerged: Experiencing the disease: 'we cannot do anything'; recognizing the possibility of complications: 'We can lose organs, lose everything...' and; the causes of hospitalization: 'When I realized, I was already in a bad condition'.

**Discussion:** The complexity, limitations and feelings that permeate living with the disease; the deficiency of knowledge regarding it; denouncing the failure of the health services.

**Conclusion:** Health professionals need to change their approach to people suffering from diabetes, making them capable of encouraging more effective self-care for controlling the disease.

**Descriptors:** Nursing, Diabetes Mellitus; Knowledge.

## INTRODUCTION

Type 2 Diabetes Mellitus (T2DM) is a chronic non-communicable disease related to excess weight and physical inactivity<sup>(1)</sup>. In Brazil, it is a serious public health problem. In 2011, 12.4 million people were affected, and it is expected that this number will reach 19.6 million people by 2030<sup>(2)</sup>. In addition, it is one of the four leading causes of death in the country, and is the main cause of blindness. It is also strongly associated with coronary heart disease, kidney diseases and lower limb amputation<sup>(3)</sup>.

Due to the growing number of people affected by T2DM, the complexity of living with this disease, and its potential to develop functional disability and early retirement, it is a frequent reason for concern in health services<sup>(4)</sup>.

The diagnosis of T2DM is directly associated with the need for several changes in the lives of those who are affected by it. These changes are related to daily life activities, as they involve diet reorganization and increased physical activity. Feelings of distress, anxiety and fear in terms of this new reality are also frequently present<sup>(5)</sup>.

When a chronic disease appears, it becomes necessary for the person involved to obtain knowledge in terms of its etiology, course, treatment, possible complications and necessary care in order to cope with it. This knowledge will lead to better acceptance, handling and experience regarding the disease, and will also lead to the adoption of self-care<sup>(6)</sup>. Consequently, in the specific case of DM, this may lead patients to a better metabolic control, the prevention of acute and chronic complications, and a better quality of life<sup>(5)</sup>.

This is because the complications, acute or chronic, resulting from T2DM are directly related to the individual's lifestyle, the way he experiences the disease, and the meaning that it has in his life. Concern in terms of the control of

the glycemic levels is of paramount importance, because persistent hyperglycemia culminates in pathological processes that can often lead to recurrences, including hospitalization<sup>(6)</sup>. In this context, nurses have an important role to play, namely, to develop the skills required by diabetes through self-care educational practices, in order to promote a healthy state on the part of the patient<sup>(4)</sup>. The nurse should educate people with diabetes and their families, and make them aware of the importance of particular daily practices that favor DM control, leading to a better degree of coping with the condition of the chronically ill. Thus, the professional allows the patient to be responsible for his own treatment which, in turn, will be reflected in the decreased morbidity and mortality that may arise from complications<sup>(5)</sup>.

Therefore, in view of the magnitude of this disease in our society, and the importance for patients and their families in being prepared to deal with the disease in their daily lives, to identify what the patient knows about the disease is critical to the control of glycemic levels. This fact enables professionals to identify important issues that need to be addressed in the care of these people. Note that, although this issue has already been addressed in many studies, there are still gaps that reflect the actions. This justifies this study, whose aim is to identify the knowledge that people with diabetes, who were re-hospitalized due to a loss of glycemic control, have with regard to the disease, and the reasons that led to hospitalization.

## METHOD

This is a descriptive study of a qualitative nature, conducted in a medium-sized city in the northwest of Paraná. The research subjects were people with T2DM who, in a 12-month period,

needed two or more hospitalizations – stays in the hospital for more than 24 hours – due to a loss of glycemic control. This criterion was used for considering that these people may be facing difficulties in terms of coping with the disease.

To locate the informants of the study a survey was conducted in three hospitals in the city with regard to all hospitalizations in the years 2008 and 2009. Patients who presented codes E10 (non-insulin-dependent) and E11 (insulin-dependent) of the International Classification of Disease (ICD-10)<sup>(7)</sup> as a primary diagnosis, were identified.

In the period in question we identified 101 hospitalizations in terms of the mentioned codes. Of these, 88 referred to individuals living in the city and 13 of them had been hospitalized two or more times at an interval of 12 months. It was these who were included in the study. However, when trying to contact them in order to invite them to participate in the study, it was found that three of them had died, two had moved from their cities, and one was totally dependent on care, with a significant cognitive impairment that prevented him from communicating. All the contacted individuals agreed to take part in the study, totaling seven subjects with T2DM.

Data were collected from May to July 2010. This was done in the participants' homes, through previously scheduled semi-structured interviews. These interviews had an average duration of 30 minutes and were recorded after consent had been given. We used a semi-structured script comprised of two parts: the first dealt with socio-demographic characteristics and the second consisted of five questions that addressed the experience of the respondent in terms of the DM, their knowledge of the disease, and the reasons attributed to the need for hospitalization.

The interviews were transcribed verbatim and submitted to analysis in terms of their the-

matic content<sup>(8)</sup>. This involves a set of techniques that allow inferences from the content objective of the statements obtained. The analysis is composed of three phases: pre-analysis, material exploration and data processing<sup>(9)</sup>. Pre-analysis is the process of organizing the documents in which the initial reading, the choice of the reports, the formulation of hypotheses, the choice of the indexes, and the development of indicators to support the interpretation, occurred. The exploration stage of the material consisted of finding groups and associations that responded to the study's objectives, from which some categories emerged. This phase involved the treatment of the results in turn, including the moment in which the inferences and the interpretation of the results were performed<sup>(9)</sup>.

The development of the study was in accordance with the criteria of Resolution 196/96 of the National Health Council and this project was approved by the Permanent Committee on Ethics in Research Involving Human Beings of the State University of Maringá (Opinion No. 670/2009). All participants signed two copies of the Informed Consent Form (ICF). To ensure the anonymity of the respondents, their statements were identified by the letters "S" for sick, followed by a number indicating the order of the interviews, and the letters M or F to indicate male or female and another number concerning the age of the participant (e.g. S5M48)

## RESULTS

Of the seven people with diabetes included in the study, four were males aged between 47 and 71 years, and three were women aged between 18 and 36 years. Regarding the level of education, two were illiterate and the others had four to 11 years of schooling. With regard to occupation, three were retired, two had no

occupation, one was a babysitter and another was a tractor driver.

Regarding the duration of the disease, it was found that it ranged from two to 21 years from diagnosis. Everyone was insulin-dependent, and six used other drugs for various problems such as circulatory problems (three individuals); chronic renal failure; diabetic foot; gastroesophageal reflux (one individual) and; anemia (one individual). Only two women aged 18 and 22 presented no other associated diseases.

It should be noted that in the 12 month period of the study, each of these individuals were hospitalized twice due to a loss of glycemic control. Hospitalizations for other causes were not investigated.

### *Experiencing the disease: 'we cannot do anything...'*

When presenting their conceptions about diabetes, the participants demonstrated that they were aware of the importance of the aspects experienced, that is, they made reference to the conditions related to the manifestation of the disease in their daily lives and their implications, marked by restrictions and limitations.

[...] uncontrollable disease that impairs the organism ... It is annoying! (S3F18)

[...] This is something that complicates our lives a lot. (S6M48)

[...] This is an annoying disease that won't let us do anything. (S4M47)

Others made reference to physiological aspects.

[...] It's the sugar in the blood. (S2M53)

It was also observed that the evolution of the disease and the appearance of organic impairments make people have a very negative conception of the disease.

[...] it's a disease that has no cure. One may even die of it, right? And you die without seeing or feeling anything. (S6M48)

Some people even compare it to a cancer:

[...] diabetes is worse than cancer ... It's something that gobbles you. I'm already lost because of this crap. (S7F36)

[...] Diabetes is a white cancer... It is a new cancer that appeared in people's lives, that hurts and slaughters people... (S2M53)

With regard to pathogenesis, some people recognize the existence of factors that can contribute to its development, in which case we may highlight heredity and factors related to lifestyle. Its manifestations concern the representations and the meanings they attach to the disease which, in turn, is related to the impact it has on their daily lives.

[...] it appears because of the family, of the heritability... (S5F22)

My grandfather has got it and so did my grandmother and aunt as well. (S3F18)

[...] he'd drink too much; he drank rum, ca-chaça... Then the disease appeared. (S2M53)

I used to eat many sweets [...]. After I ate them excessively, I harmed myself. (S6M48)

[...] the everyday rush, stress, these things ... I think it's emotional. (S7F36)

Physiological problems were also mentioned, but in these cases the patient seems to create his own explanations with regard to the pathological process.

The pancreas stopped working [...] the pancreas has dried up. (S7F36)

Finally, it is disturbing to note that one of the participants, although diagnosed with T2DM for more than five years, still claims not to know anything about the disease.

I know nothing about diabetes [...] I don't understand anything. (S1M71)

### *Recognizing the possibility of complications: 'We can lose organs, lose everything...'*

The appearance of chronic conditions such as renal failure and the consequent need for dialysis, the impairment of visual acuity, neuropathies, among others, are recognized by the study participants as complications resulting from T2DM.

[...] lose vision, kidneys ... Lose the movement of the feet ... my feet are already limp. One can lose organs, lose everything ... (S7F36)

It may blind you, you may lose an organ, a kidney ... It makes you weak, anemic and it may even make you sexually impotent as well. (S6M48)

You can go blind and have to undergo hemodialysis, because your kidney gets dried up. (S3F18)

In some cases, including the knowledge they had about the complications associated

with diabetes, their understanding was not only conceptual, but was also directly related to their own experiences in terms of the disease.

[...] I feel nothing in my feet ... You can cut a finger off and I will not feel it. (S6M46)

I had six abortions; small sores become something horrible, they don't heal [...] anything turns into a terrible infection [...] They had to take out all my teeth because of a gum infection. (S7F36).

### *Hospitalization causes: 'When I realized I was already in a bad condition'*

When investigating the aspects that were crucial to hospitalization, it is observed that some referred to the increase in blood glucose levels and to clinical manifestations that show this increase, but they did not mention the factors that can cause such an increase. Only one interviewee linked hyperglycemia to the infection.

Both times I was hospitalized were because my diabetes had altered a lot. (S6M48)

[...] I went to the hospital because the diabetes rose too much ... I felt leg pain, malaise and could not eat anything because I vomited a lot. Both times I was hospitalized were for the same thing. (S2M53)

Once I was admitted with a cough and fever of 40 degrees and the diabetes rose. The other time I had phlebitis in the leg because of an infection. The glycemia rose too much; it was above 600 and I had to be hospitalized (S7F36).

In the rare cases in which factors that could have caused the elevation of blood glucose levels were mentioned, there was carelessness, especially in relation to food, and also due to changes in the respondent's emotional state.

If I get nervous it climbs [...] this sharp pain that I feel, that no one finds out, makes me nervous, then it goes up. Just as it happened when my mother was hospitalized with early infarction: my diabetes rose too much. (S5F22).

It's because I didn't take care of myself ... I used to eat too much, because the diabetes makes you very hungry and I ate something all the time... it was just because of the food ... Anything I eat makes it go up [...] I was a bit rebellious, because I love yam, bread, pasta, wow ... I eat too much. (S3F18).

Finally, two patients said that there was no apparent cause for losing glycemic control.

[...] it happened naturally (S2M53)

*[...] when I realized it was already bad. I did nothing different, I got bad and had to be hospitalized because of diabetes... it reached 500... (S1M71)*

## DISCUSSION

The treatment of T2DM requires a series of changes in lifestyle. In care practice, the impact that T2DM has on the health of the population is often observed, as is the difficulty patients face in implementing changes in their lifestyle<sup>(10)</sup>.

Certainly, being well-oriented about the disease, its etiology, the possible complications, and the care needed to avoid such complica-

tions can stimulate the change of behavior of individuals. Moreover, the adoption of self-care practices favors autonomy, joint participation in decisions, and the adoption of positive attitudes. Knowledge empowers patients to become agents for transforming themselves and others<sup>(5)</sup>.

In the reports we received, it was observed that the knowledge about the disease and its causes is often simplistic and empirical, thus showing the presence of gaps in the guidelines offered by professionals. This fact could also be observed in a study conducted in the city of Porto, Portugal, which showed that a lack of awareness concerning the identity of diabetes was one of the aspects most frequently referred to by people with DM<sup>(11)</sup>.

However, it is important to note that having knowledge of the disease is not always a guarantee of behavior change, because, for this, there are necessary essential conditions that are independent of the people's will. In this context, economic, social, cultural and motivational factors as they impact on the individual and the community stand out, as does the implementation of public policies for health promotion<sup>(12)</sup>.

As for the causes of the disease's outbreak, we observe in the reports that the participants in the study refer to hereditary factors and lifestyle showing that, despite the fact that they do not know the etiology of the disease in very great detail, they correctly recognize the aspects that may be related to its appearance. This is relevant because, when identifying some lifestyle habits as responsible for the onset of the disease, they understand more easily the need to modify them to thereby prevent its aggravation<sup>(13)</sup>.

The way a person suffering from T2DM experiences the disease is directly related to economic, social, cultural and motivational factors as well as to the meanings that this person attributes to the disease<sup>(5)</sup>. It was noted in the reports that, for some participants, the disease features

degrading and insufferable aspects, and it is even compared to cancer, leading to important organic changes, exposing them to suffering and also to conflict. Negative feelings with regard to the disease can result in lower adherence to the essential care and, therefore, may lead to the early development of complications<sup>(14)</sup>.

Perceptions regarding a disease are never the same for every individual, as demonstrations, insights and reactions differ in each case. Some people can overcome challenges and maintain a good relationship with the disease, enabling them to lead a largely healthy and harmonious life. However, others see the disease as a major problem, as a weight, and fail to develop a good relationship with it<sup>(15)</sup>.

Faced with an illness situation, the individual needs to develop certain competences that will allow him to deal with the symptoms and limitations that this disease may cause in his daily life. Therefore, being informed about the disease is essential to the individual suffering from T2DM, to his family and to the caregiver to prevent complications, to perform the appropriate care regarding their condition, and to maintain metabolic control<sup>(5,16)</sup>. When such harmonious living with the disease, its treatment and its necessary restrictions do not occur, complications that make the individual's life even more traumatic, appear more frequently<sup>(13)</sup>.

Complications associated with T2DM are characterized as being slow and limiting, since they affect various organs and systems irreversibly<sup>(12)</sup>. In the testimonies we could observe that the participants generally are well informed about the possible complications of the disease. In reality, some of these complications, including neuropathy and difficulties in wound healing, are already being experienced by some of the respondents.

The consciousness expressed by patients regarding the damage caused by the disease

reinforces the importance of the work executed as a cornerstone in the treatment of diabetes, and makes them aware concerning the need for being more cautious and dedicated to the control of T2DM, changing their habits and lifestyle, aiming at the metabolic control<sup>(16)</sup>.

People who need emergency care or even hospitalization due to the loss of glycemic control, have a higher predisposition, albeit temporary, to change the lifestyle habits that are harmful to their health. In fact, situations of disease aggravation usually promote changes in the patient's life and contribute to a greater mobilization of their ability to deal with the diabetic condition<sup>(15)</sup>.

T2DM is seen as a major health problem, often associated with hospitalization, and it will often require rehospitalization in a short period of time due to nonadherence to the care of the disease, consequently resulting in inadequate metabolic control and other complications<sup>(17)</sup>. A study of the mortality and morbidity caused by DM indicates that the chronic complications of the disease appear as the main cause of death among diabetic patients<sup>(4)</sup>.

The complications, both acute and chronic, are associated with conditioning factors resulting from a lifestyle, that is, the way the individual controls glucose levels as part of his treatment.

In this context, being readily able to recognize early symptoms due to changes in blood glucose levels is essential for the patient, since it allows him to early act in order to regain control of the disease, thus avoiding the worsening of the symptoms. In the reports we received, it is clear that there is an association of hospitalization with increased glucose levels, possibly followed by clinical manifestations. Hyperglycemia is the primary triggering factor of the other complications of T2DM, in which case the development of macroangiopathies that compromise

the coronary arteries of the lower limbs and brain, in addition to the microangiopathies that specifically affect the retina, renal glomerulus and the peripheral nerves, is common<sup>(17)</sup>.

The increase in blood glucose levels may be related to several factors, such as a high consumption of foods rich in glucose, the incorrect use of oral antidiabetics, emotional aspects, among others<sup>(17)</sup>. In the reports generated by the present study, despite the fact that hospitalization is always associated with increased blood glucose levels, these have not always been associated with a causative agent. However, in some cases, the absence of self-care related to errors in eating, as well as emotional aspects, were indicated as responsible for hyperglycemia and, consequently, for hospitalization.

A study involving diabetic patients who had been hospitalized, showed that one of the greatest weaknesses in terms of self-care was related to nutrition, and the greatest difficulty pointed out by the participants was not to decrease the amount of fat in the diet, but to limit the intake of sugary foods<sup>(18)</sup>. Similarly, another study showed that, regardless of the time of the diagnosis, an individual who suffers from diabetes needs to have a balanced diet<sup>(10)</sup> and engage in constant physical activities<sup>(11)</sup>.

Moreover, a study of resilience on the part of patients who suffer from diabetes, hospitalized in an emergency service, showed that the highest rate of admission of diabetic patients is due to ineffective glycemic control associated with the lack of preparation of the patient and family for hospital discharge<sup>(16)</sup>. Therefore, the efficient control of the metabolic levels is essential for a balanced relationship with the disease, the prevention of complications and subsequent hospitalization<sup>(19)</sup> and also to reduce the cost of healthcare<sup>(20)</sup>.

Finally, another reason mentioned by the participants as the triggering factor for the incre-

ase in blood glucose levels, was the presence of an infectious process. Actually, the infection condition represents a well-known risk for diabetic patients, since the stress caused by the infection results in a massive production of catecholamine that inhibit insulin action. This relationship was observed in this study when S7F36 revealed that his T2DM was very high, that is, there was an extremely high concentration of circulating glucose (above 600mg/ml). This situation may trigger other serious abnormalities such as a hyperglycemic coma and diabetic ketoacidosis, which may result in severe aggravation and may endanger the patient's life.

Therefore, in order to prevent and/or mitigate the complications of T2DM, it is necessary to promote changes in the lifestyle of people with diabetes, by encouraging the adoption of healthy eating habits, physical exercise, control of blood glucose and blood pressure, and the reduction of body weight and lipid levels. Thus, it is essential that interventions aimed at people suffering from diabetes are established beyond the clinical care of the disease, and an investment in education be introduced, aimed at promoting self-care as an intervention tool<sup>(8)</sup>.

## CONCLUSION

The results of this study show those individuals with T2DM participating in this study, have limited knowledge about the disease, defining it in an empirical way. The participants have a general knowledge concerning the complications of the disease and have demonstrated awareness regarding its complexity and severity.

The lack of more concrete knowledge about the disease, including its causes and consequences, may indicate the need for greater diligence on the part of healthcare teams, especially nurses. These professionals are the ones

who are most closely involved in contact with individuals suffering from diabetes, drawing the care responsibility upon themselves, developing health education activities in a more effective and didactic way, and becoming the main point of contact for the individuals concerned.

In the planning of health education performed by nurses, it is essential to know or recognize the history of each diabetic individual, seeking to understand their experience and knowledge about the chronic disease, making it possible to develop specific healthcare in order to instrumentalize the individual so that he may become autonomous in terms of his own healthcare.

Although we have managed to obtain valuable testimonies from the respondents, it is important to point out the small number of study participants, as well as the fact that data collection took place in a single encounter, thus characterizing the point of view of the respondents at one point in time with regard to the phenomenon studied. These are therefore limitations to this study.

We conclude that there is a clear need for health professionals, particularly nurses, to act alongside people who suffer from diabetes in order to make them capable of making decisions and taking responsibility for the development of daily activities that are consistent with good control of the disease.

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