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Perceptions of people with diabetes mellitus about the disease and its complications

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Abstract— *Objective: to verify the perceptions of people with diabetes mellitus about the disease and its complications in a treatment center for diabetics in the city of Belém, State of Pará. Method: descriptive, exploratory study with a qualitative approach, developed in a non-governmental organization in Belém , State of Pará, Brazil, from September to October 2018. The sample consisted of five users attended at the non-governmental organization*

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"Casa do Diabético", through semi-structured interview. Semi-structured interviews were used as a data collection technique, having as an instrument for collection an interview script prepared with open questions, and for analysis, the methodological framework proposed by Bardin.Results: it was shown that people with diabetes mellitus react and faced the disease in multiple ways, some needing psychological support, others in a more positive way, accept the limitations imposed by the disease. Despite the way of coping, everyone tried to adapt to the lifestyle changes necessary to achieve better health conditions. Regardless of the way of coping, the speeches allowed to verify the awareness about the importance of changing eating habits, the practice of physical exercises, as well as the correct use of medications or insulin therapy, aiming at the control of blood glucose, thus avoiding the possible complications arising disease.Conclusion: it is extremely important that nursing professionals dedicate themselves to providing the correct care to people living with diabetes mellitus, performing a continuous process with regard to health education actions, encouraging good health practices, changes in style of life and self-care.

***Keywords*—Diabetes mellitus. Self-care. Nursing care.**

I. INTRODUCTION

Diabetes Mellitus (DM) is part of a group of metabolic diseases characterized by hyperglycemia, motivated by complications or errors in insulin secretion and / or its action. Hyperglycemia presents peculiar symptoms that involve polyuria, polydipsia, weight loss, polyphagia and blurred vision, in addition to acute complications that can lead to life-threatening, such as: diabetic ketoacidosis and non-ketotic hyperosmolar hyperosmolar syndrome. Without adequate control and therapy, chronic hyperglycemia can lead to micro and macrovascular damage associated with dysfunction and failure of various organs such as eyes, kidneys, nerves, heart and blood vessels, directly impacting quality of life (QOL) [1].

Diabetes is classified into types I and II, the first is characterized by the absolute deficiency of insulin secretion caused by the destruction of pancreatic beta cells in the islets of langerhans, of an autoimmune or idiopathic order, which is indicated through pharmacological treatment. insulin therapy. Type II, on the other hand, is characterized by chronic hyperglycemia, resulting from varying degrees of decreased secretion and insulin resistance[2].

According to data from the International Diabetes Federation, the prevalence of DM reaches approximately 8.8% of the world population with a projection of 380 million people for the year 2025. In addition, the Brazilian Diabetes Society (SBD) estimates that about 26 millions of people have the pathology, and Brazil has about 13.7 million diagnosed Brazilians, placing the country in fourth place in the ranking of the 10 countries with the highest number of people with DM. It is important to consider that approximately 5.7 million Brazilians have the disease without diagnosis[3].

In view of the chronic nature, the forms of palliative follow-up and the need for changes in lifestyle and reconfiguration of activities of daily living that favor a good pathological prognosis, it is considered that the efficacy of treatment for both diabetes control and its complications they do not depend exclusively on professional intervention. The knowledge of the patient about his pathological condition, the incentive and encouragement to the main care and the participation of the family, are fundamental to encourage more regular care and better coping with the disease. Therefore, for the promotion and maintenance of QOL, as well as the prevention of subsequent injuries, it is necessary to have acceptance and awareness about the disease and effective coping with complications[4].

In this sense, health education emerges as an effective tool and mechanism in training for self-care, a scenario in which patients need to be active actors in the control of the condition, where the professional relationship between patients works as a means for the development of the individual's confidence. in their own capacities, maximizing available resources and providing patients with the knowledge, skills, attitudes and responsibilities capable of effecting changes in postures, capable of strengthening the coping process and improving health[5].

In view of the above, the following research questions emerged: what is the perception of people with DM about the disease, its complications and limitations? What are the feelings of individuals regarding the diagnosis of the disease? What is the importance attached to nursing care for self-care and glycemic control from the perspective of the person with DM?

Thus, this study aimed to verify the perceptions of people with diabetes mellitus about the disease and its complications in a treatment center for diabetics in the city of Belém, State of Pará, Brazil.

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II. METHOD

Descriptive, exploratory study with a qualitative approach, carried out in a non-governmental organization "Casa do Diabético", located in the metropolitan region of Belém, State of Pará, Brazil, from September to October 2018.

The study population consisted of five users who agreed to sign the Informed Consent Form (ICF), which was made explicit individually. The participants were identified with the following names: "P 1", "P 2", "P 3 ..." respectively, where "P" represents "Person" and the number the order in which they were interviewed, with the objective of preserve the anonymity and confidentiality of information.

The sampling closure occurred according to the saturation sampling method. In this, the researcher closes the group when, after the information collected with a certain number of individuals, new interviews start to present a number of repetitions in their content[6].

The inclusion criteria of the participants were: people diagnosed with DM I and II, of both genders, aged between eighteen and eighty years, whose drug treatment was insulin, oral antidiabetic and / or associations of these, and who perform consultations, examinations and treatment in the organization.

Users diagnosed with Diabetes Insipidus, Diabetes Mellitus Gestacional (DMG) and people with limitations in spoken communication were excluded from the study and who had interrupted treatment in the last 12 months.

Data collection was carried out on the premises of the Casa do Diabético, through semi-structured interviews recorded in audio and as an instrument an interview script, with five open questions prepared by the researchers.

The content of the interviews was transcribed in an original way, preserving the expressions used by the participants. However, to use them as a unit of analysis, orthographic corrections were made, excluding language vices, exchange or absence of letters, but maintaining the linguistic vices that have meaning in the context of speech.

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The categories were previously delimited due to the thematic axes of the interview script, being confirmed after analysis and construction of the data.

The project was analyzed and approved by the Research Ethics Committee CEP of the University of the Amazon (UNAMA), CAAE: 94975218.0.0000.5173, with opinion number 2.825.061. Resolutions no. 466/2012 and 510/16 of the National Health Council (CNS) and the National Research Ethics Commission (CONEP).

III. RESULTS

The corpus of the study made it possible to organize the content into three empirical categories: Perceptions and feelings related to the diagnosis of the disease, possible complications and limitations; Understanding about changes in lifestyle after diagnosis and Understanding and meaning attributed to nursing care; the categories being grouped later according to the theme extracted from the responses.

FIRST CATEGORY - PERCEPTIONS AND FEELINGS RELATED TO THE DIAGNOSIS OF THE DISEASE, POSSIBLE COMPLICATIONS AND LIMITATIONS

In the first category, all users revealed their trajectory of health care, from the moment of diagnosis, to the impact on everyday life, in relation to complications and limitations. The testimonies obtained allowed us to perceive the change in the mood state, with feelings ranging from the feeling of sadness and depression, to the acceptance and effective coping with the therapeutic regime, as can be seen in the statements:

"[...] I felt like depression, I couldn't sleep, I woke up thoughtful, then when I took diabetes tests, I took the medication, I got better, then I got back to normal". (P1)

"[...] Normal, my life remains the same, it hasn't changed anything, neither psychologically nor emotionally, everything is normal, of course I started policing myself about what I ate, I started taking my medicines". (P2)

"[...] At first I felt a little sad, because there is no cure, but after talking to my doctor and the nurse, they told me that it has no cure, but if you control it, you can live normally , so from then on it didn't shake me anymore ". (P3)

In this study, all respondents were aware that the complications arising from DM are real and understood that they needed to adhere to the care and treatment plan, in addition to making lifestyle changes, so that these complications were avoided. It was possible to observe

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that some of the patients needed psychological assistance due to their states of melancholy. After a better understanding of the disease in different aspects and its form of control, the patients got used to it and showed acceptance regarding the diagnosis, as can be seen in the following statements:

“Look, in my case, I accepted, my father was already diabetic, we were already researching; and the first time I came here to see me, the doctor always said that because my father was diabetic, I already had the seed inside me, so I already hoped that one hour this would happen ”. (P4)

“I felt really bad, I went to the psychologist, and I didn't accept it, I didn't want to accept it, until one day my brother died of diabetes! And I said that if one day I had this disease, it was risky to shoot myself in the head, because I wouldn't accept it ”. (P5)

When asked about their feelings about the disease, 90% of the interviewees affirmed the absence of difficulty in living with the diagnosis; moreover, it was found that, among these, there is no understanding of a direct association between mood changes and feelings experienced with the disease. However, it was noticed that at certain times, patients feel frustrated, mainly because they worry about the future and the possibility of serious complications.

It was evident that the interviewees are aware of the possible complications and limitations that DM can cause, knowledge acquired from educational actions carried out by the multidisciplinary team, as can be seen in the statements:

"The person feels weak, does not sleep at night, eats a lot, does not leave the house, pee a lot". (P1)

“It is a tr eacherous disease! (Silence) Either we take care of ourselves or she breaks up with us, because she is something from the inside out, she is acting and we think everything is fine, but it is not, now I am having this awareness, later the first lecture, after the second today ”. (P2)

"There are several complications, as long as you don't take care of her, you can have it, but if you take care of it, you won't have it." (P3)

"Limitations are like you say, if you don't get treated, you can lose one of the limbs, like my father who lost one of his legs." (P4)

“From what I've been through, lately it has given me pain in my legs, weaknesses, I felt very bad”. (P5)

SECOND CATEGORY - UNDERSTANDING OF LIFESTYLE CHANGES AFTER DIAGNOSIS

With regard to changes in lifestyle in view of the risks of developing DM, whether due to diet or hereditary factors, the participants' awareness of the need for changes in lifestyle and healthy habits to control glycemia is noted, thus providing better QOL. Some already had good habits, others are sensitized to improve from the recognition of this need, as noted in the speeches:

"[...] Change the diet, do physical activity and take the right medicine". (P1)

"[...] Normal, I am aware that I have to change, exercise, I was extremely sedentary, I know that I have to change the issues of eating habits, because until then, I ate everything!". (P2)

“[...] When changing my lifestyle, I don't feel much difference, because it is necessary to do it, then it has to be done! But sometimes we feel the need to eat something, but we cannot, then we have to conform, there is no use regretting it ”. (P3)

"[...] Food is essential, when things got more serious, glucose was over the limits, I cut the drink, I never smoked, because it is a cause of complication, and I keep food as regularly as I can". (P4)

"[...] Now, I'm walking, taking insulin, exercising, regulating food". (P5)

It was evident from the speeches that there are significant and real changes in the lifestyle of the participants, and that these were essential to effectively control blood glucose, generating an increase in QOL. It was found that such changes occurred gradually, based on the understanding that, in order to improve the clinical condition, it is of utmost importance to assume healthy habits, such as good nutrition, practice physical activities, correct medication dosage, as observed in the statements:

"[...] Change was precisely the question of food, and now a month ago I started an exercise, a walk". (P2)

"[...] The daily routine for sure, I had a very heavy diet, today I have a moderate diet, trying to maintain the pattern of eating food every 3 hours, so as not to have very low blood glucose". (P4)

"[...] I started to work less, eat on time and other things, I went to the nutritionist, who gave me some recipes, I stopped eating what is not to eat, today I feel good about it". (P5)

Despite the difficulty, all participants seem to understand the need to change their lifestyle, despite all the obstacles to be faced, aiming to have control of the disease, as reported below:

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"[...] I found it a little strange, a little difficult to adapt to the change, but it was necessary to change, I was forced to change". (P1)

"[...] The food that can no longer eat what I could, today is half and exercise! Before I didn't do it, then I felt the need to do it, but the rest is going well! [...] ". (P3)

THIRD CATEGORY - UNDERSTANDING AND MEANING ASSIGNED TO NURSING CARE

In this category, reports about the meanings attributed to the nursing care offered at the institution where they do health monitoring are described. The professionals were praised by the interviewees, although some did not express so many words, there was an absence of dissatisfaction regarding the care offered by nursing professionals. Despite the speeches not being explicit about the real care provided by these professionals, there is a consensus that the nursing team works properly and the praise of their importance in the process of caring for people with DM was notorious, as was observed in the following statements:

"[...] They treat me well". (P1)

"[...] Very good, the staff is very attentive, very human, it's not that automatic thing, they talk to you, try to understand you". (P2, (P3)

"[...] Here is 100%". (P4)

"[...] Very good, calm! Only they treat me well, have an education, they all have it "

"[...] "All are good". (P5)

IV. DISCUSSION

The findings of this study related to the first empirical category evidenced, reveal that the perceptions about a disease are never the same for different people, thus occurring manifestations, understandings and reactions unique to each case. Some people manage to overcome the challenge and maintain a good relationship with the disease, which allows them to have a healthy and harmonious life. However, others see the disease as a burden, failing to develop a good relationship of well-being and QOL.

In the meantime, this research is in line with another study in which it showed that of the 32 participants in their research, 68%, managed to live in an acceptable way with the diagnosis, while the other 32% had difficulties or psychosocial shocks in the face of pathology[8].

Regarding the understanding of patients about the limitations generated by diabetes, Rodrigues9 evidences that the low perception presented by 45 of the total of 78 participants in his analysis, led to a low adherence to the treatment imposed for diabetes, thus corroborating with the present study, demonstrating that the perception of complications of diabetes strengthens in the patient the need for treatment and coping with the disease.

As for the data on lifestyle changes after diagnosis, we observed that this component behaved as a fundamental characteristic for improving QOL and therapeutic success. This result corroborates with a survey carried out with 106 young people between 15 and 17 years old, where strategies were applied with individual guidance on the importance of changing lifestyle, promoting physical activity, changing eating patterns, guidance for parents and other family members. After six months of study, improvements in beta cell function were identified, improving insulin resistance and DM2 prevention. In addition to the decrease in C-reactive protein levels and a significant reduction in waist circumference[10].

In contrast, a qualitative, exploratory and descriptive study involving eleven people with diabetes, two male and nine female, aged between 42 and 80 years in the city of Ijuí / RS, made it possible to identify that diabetics experience changes of their daily lives for stability of the disease, however they express some indignation regarding the prescribed diet, accumulating some resistance and not fulfilling what is recommended. Other factors reported by the interviewees include changes on their own in the dosage of the prescribed medication, lack of follow-up of the rotation of insulin application and absence of physical activity[11].

The maintenance of satisfactory metabolic control guarantees the diabetic a reduction in the risk of these complications in addition to an increase in QOL, preventing the occurrence of microvascular and macrovascular complications. For this to occur, it is necessary that these individuals have access to quality health services, in addition to the patient's own contribution to maintaining and carrying out the therapeutic conducts planned by the multidisciplinary team.

It is important to note that monitoring through nursing consultations contributes to the control of DM and excellence in care, as it allows a continuous assessment of the patient's real needs. Nursing consultation is a private activity of nurses, as determined by the Federal Nursing Council (COFEN) through Law No. 7,498, of June 25, 1986[12].

The treatment of DM requires some precautions such as improved nutrition, physical activity, self-monitoring

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of capillary glycemia, insulin management, storage of inputs, correct insulin application technique, rotation of application sites, handling of syringes and needles , care with homogenization, subcutaneous fold, correct disposal of inputs, among others[13].

Within this importance of care mentioned above, the nursing process stands out, which is a planned series of actions that aim to execute the purpose of nursing, achieve pre-defined goals and thus maintain the most satisfactory degree of well-being of the client, and if that state changes, provide the totality and quality of nursing care that this situation requires to direct it back to well-being; if this cannot be fully achieved, the nursing process must collaborate for the client's QOL by maximizing resources in order to achieve the highest levels of health. . In this context, many patients recognize the importance of nursing in the process, and this has become more noticeable over time, allowing to change that view that only the medical professional has the responsibility and competence to take care of the patients' health[14].

In this study, one of the patients reported that nursing care is as important as that of the doctor, making the perception of reality concrete, which fosters the reflection that more and more nurses are present in the routine of providing patient care. with DM demonstrating its scientific value.

V. CONCLUSION

The objective of verifying the perceptions of people with diabetes mellitus about the disease and its complications was achieved according to the data presented.

We believe that living with a chronic disease means facing numerous constant challenges, since it requires knowledge about the disease and changes in daily habits. In the case of people with DM, it is necessary to know their perception about the disease in order to improve coping and avoid complications.

The results showed that knowledge about DM and complications is strongly associated with the person's own experiences with the disease or acquired through contact with close people affected by some complication.

We found that the participants did not have the necessary information to be able to make their choices on how to control DM, to monitor the evolution of this disease and the possibility of early detection of complications before monitoring at the institution.

We have evidenced that the acquisition of knowledge about the cause, symptoms, duration of treatment, consequences and limitations on DM are essential for adherence to the therapy used aiming at the metabolic control with increased QOL.

We consider it extremely important that nursing professionals dedicate themselves to providing quality care to people living with DM, carrying out health education practices, related to the knowledge of the disease, encouraging good health practices and self-care, also providing humanized assistance, which generates better quality in health production and greater user satisfaction, leading patients to become informed about diabetes, its complications and care, making them autonomous and emancipated.

We reinforce the need for health professionals to develop educational activities considering the individual experiences, beliefs and values of people with DM. It is important to highlight that this role of educator should not be restricted to the “traditional” model of knowledge transmission, where the nurse assumes the role of transmitting concepts and guidelines. This needs to build a committed posture to understand the context in which people with DM are inserted, the popular knowledge, the difficulties experienced and how each information is learned. This education must be based on a mutual exchange of knowledge and experiences, in this way, specific and personal doubts can be more easily understood and dealt with integrally and individually.

The findings reveal the difficulty of people with DM to change old eating habits and permanently accept a restricted diet, as they often feel frustrated for not being able to effectively control the desire to eat something they cannot.

We consider it pertinent to point out some limitations of this study, such as the reduced number of participants, compared to the total population of people diagnosed with diabetes monitored at the Casa do Diabético. This limitation places some obstacles to the generalization of the research results, in addition to all the people who participated in the study being linked to health centers, so we understand that they had the opportunity to receive some guidance, differently from those who have diabetes and are not linked health services.

Finally, we believe it is essential to institute investigations and methodological practice in the field in question as a way to optimize and consolidate knowledge during academic training, and educational intervention studies focused on health education in the context of people with DM, which may be the subject of other studies.

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