DIALOGUING ABOUT THE EXPERIENCES WITH DIABETES MELLITUS: SUBSIDY FOR EDUCATIONAL NURSING CARE

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ABSTRACT
Convergent care research aimed at describing the knowledge and practices of diabetic clients in outpatient care about living with Diabetes Mellitus (DM) and discussing the contributions of this knowledge and practices in educational nursing care. The study included 11 clients who met the inclusion criteria: clients with type 1 and/or type 2 DM, assisted at the outpatient clinic, with medical records at the institution, of both sexes, and those over 18 years of age. Individual interviews were conducted. Thematic content analysis was used. The results showed that the client’s knowledge and practices are presented in a fragmented way and as a result of knowledge acquired through experience. The knowledge and practices of diabetic clients were mobilized and valued through dialogue/reflection. This process was based on the exchange of popular and professional knowledge, on the discovery and (re)construction of knowledge and made it possible its application in educational nursing care for these clients.

Keywords: Health Education; Diabetes Mellitus; Nursing.

RESUMO
Pesquisa convergente-assistencial que objetivou descrever os saberes e práticas de clientes diabéticos em atendimento ambulatorial sobre a vivência com o diabetes mellitus (DM) e discutir as contribuições desses saberes e práticas nos cuidados educativos de enfermagem. Participaram do estudo 11 clientes que atenderam aos critérios de inclusão: clientes com DM tipo 1 e/ou 2, assistidos no ambulatório, com prontuário na instituição, de ambos os sexos e maiores de 18 anos. Realizaram-se entrevistas individuais. Utilizou-se a análise temática de conteúdo. Encontrou-se que tais saberes e práticas se apresentam de forma fragmentada e como resultado do conhecimento adquirido pela experiência vivida. Os saberes e práticas de clientes diabéticos foram mobilizados e valorizados a partir do diálogo/reflexão. Esse processo foi baseado no intercâmbio dos saberes popular e profissional, na descoberta e reconstrução do conhecimento e possibilitou sua aplicação no cuidado educativo de enfermagem a esses clientes.

Palavras-chave: Educação em Saúde; Diabetes Mellitus; Enfermagem.

RESUMEN
Investigación convergente-asistencial con miras a describir los saberes y prácticas de clientes diabéticos en atención ambulatoria sobre la vivencia con diabetes mellitus (DM) y discutir su contribución a los cuidados educativos de enfermería. En el estudio participaron 11 clientes que cumplieron con los siguientes criterios de inclusión: clientes con DM tipo 1 y/o 2, atendidos en el ambulatorio, con expediente clínico en la institución, de ambos sexos y mayores de 18 años. Se realizaron entrevistas individuales. Se utilizó el análisis temático de contenido. Los resultados mostraron que tales saberes y prácticas se presentan de forma fragmentada y que son resultado del conocimiento adquirido por la experiencia vivida. Dichos saberes y prácticas adquirieron valor a través del diálogo/reflexión. Este proceso se basó en el intercambio del saber popular y profesional, en el descubrimiento y reconstrucción del conocimiento y permitió que se aplicase en cuidados educativos de enfermería para estos clientes.

Palabras clave: Educación en Salud; Diabetes Mellitus; Enfermería.

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INTRODUCTION

The global distribution of diabetes mellitus (DM) reveals an ongoing epidemic. In 2002, the indices were 173 million diabetic adults, projected to reach 300 million in 2030 and 471 million in 2035.

Between 2006 and 2011, the prevalence of DM in Brazil increased from 5.3% to 5.6% in the population aged over 18 years. Women had a higher percentage of this disease, accounting for 6% of the population, although there was an increase among men from 4.4% in 2006 to 5.2% in 2011. Regarding age, data showed an increase in the number of cases with increasing age in the population: 21.6% of Brazilians over 65 years of age in contrast to 0.6% of Brazilians aged 18 to 24 are diabetic.

In Europe and the United States, the increase in the prevalence of DM is particularly evident in the more advanced age groups as a result of higher life expectancy, whereas in developing countries DM affects all age groups. The prevalence is three-fold higher in the 45 to 64 age group, and two-fold higher in the age groups of 20 to 44 years and over 65 years. Women had a higher percentage of this disease, accounting for 11.3%. Risk factors related to dietary habits and lifestyle of the population are associated with this increase in the global burden of DM cases. The disease appears among the fourth and eighth position in the list of leading causes of death in developed countries.

The importance of DM comes from its increasing prevalence and association with other diseases such as dyslipidemia, arterial hypertension and endothelial dysfunction. This health problem is considered an ambulatory care sensitive condition. This is to say that evidence shows that management in primary care avoids hospitalizations and deaths from cardiovascular and cerebrovascular complications.

It is noteworthy that the treatment of acute and chronic complications generates a considerable increase in the expenses of health systems. In Brazil, a study by the World Health Organization (WHO) showed that government costs with care for DM vary from 2.5 to 15% of annual health budgets and lost production costs can exceed by up to five times the direct costs of health care.

In the Sistema Único de Saúde (SUS), an annual cost of R$ 40.3 million is estimated, of which 91% is due to hospital admissions. This figure is possibly underestimated because it is patients treated for other obesity-related diseases also have diabetes.

Furthermore, symptoms of depression such as depressed mood, decreased interest, loss of energy, and difficulty to concentrate are quite common among diabetic patients and are associated with decreased self-care. Another aspect to be considered is the low adherence to preventive measures and treatment, a fact that leads to a greater number of complications.

Given the above, the realization of the present study is justified by the fact of addressing a disease with global impact - the significant increase in the prevalence of DM and its complications. Thus, the study aims to describe the knowledge and practices of diabetic clients in outpatient care about the experience of living with DM and discuss the contributions of these knowledge and practices to educational nursing care.

METHODOLOGY

The present field research adopted a qualitative approach, known specifically as convergent care research (CCR). This approach is geared towards the humanist commitment of the researcher to study and operate in a health care practice based on the perspectives of professionals and/or users involved in the context of the research.

The scenario selected for the study was the outpatient clinic for diabetic clients of a university hospital of the federal public network in Rio de Janeiro. The clientele includes people diagnosed with diabetes, recently or not, who started insulin treatment and who were referred by the assistant physician.

The role and dynamism of nurses working in this clinic stood out. The group consultation is guided by the topics presented by the clients. Furthermore, guidelines on insulin use for first-time clients are prioritized. The guidelines cover different types of insulin, handling, aspirated dose, storage, administration and possible complications.

It is worth mentioning that, after the first consultation, the client continues to attend the group indefinitely, following the schedule according to the nurse’s evaluation.

The study included 11 clients - six women and five men - who met the inclusion criteria: clients with type 1 and/or type 2 DM, assisted at the outpatient clinic, with medical record in the institution, of both sexes, and over 18 years of age.

Clients were identified by the letter C (Client) followed by an Arabic number that corresponded to the order of the interview. This guarantees the anonymity of the participants.

Of the 11 participants, one was in the age range between 18 and 29; one between 40 and 49 years; seven between 60 and 69 years; and two were aged 70 and over. The majority (63.64%) were in the age group between 60 and 69 years, corroborating data from the Ministry of Health on the increase in the number of DM cases as age advances in the population. 21.6% of Brazilians aged more than 65 years reported the disease, a much higher rate than that observed among people in the age group between 18 and 24 years, in which only 0.6% have diabetes.

To obtain the data, we used a semi-structured individual interview, a form for socio-cultural identification and discussion scripts for production of data.
Thematic content analysis was applied to analyze the discursive material, and the phase of categorization was carried out by thematic analysis. In this technique, the categories are not determined a priori, because they emerge from the speeches of the individuals.7

The project was submitted to the Brazil Platform and approved under Protocol 1,227. 894. The participants received information on the ethical aspects of the research, voluntary participation, guarantee of anonymity, possibility of withdrawal without damages, risks and benefits. They received a copy of the Informed Consent Form to sign.

RESULTS AND DISCUSSION

The diagnosis of a chronic disease brings profound changes in people's lives. In the case of DM, these changes are closely related to daily activities. Right after the diagnosis, there are feelings of anguish and despair before the perception of less control over the own life, which affects the power to act and think. This situation leads people to need comprehensive health care, involving the biological, cultural, social, economic, and psychological dimension, among others.2

In the study, the dialogue with the diabetic clients allowed the access to the knowledge and practices about the experience of living with DM based on the questions generating the debate. In a “problematizing” space, these issues foster dialogue and deepening of the discussion of the concrete existential situations of the subjects.8


The time of clinical course between the discovery of DM and the moment of data collection was, on average, six years. The reports of C1 and C9 show a common situation, the chance; the diagnosis occurred in situations of emergency, and not in a specific clinical investigation of DM:

It was when I had a cold; I went to do a show in a certain place, and suddenly I got a different temperature. Then I chilled, but I had to heal that very same day. As I’ve never been fond of laboratory drugs, I resorted to leaves, herbs. Then I was shown an herb, we took it; asked to make tea. I just had tea, in half an hour I started to ‘piss’, to urinate. Then I found that strange. I was very thirsty. Then I went to the health post of the city, then when I told the story, the doctor asked me to stick my finger and told me that I had diabetes (C1).

Look, I was very thirsty, I had a very dry mouth. Then my mother, who is a nursing assistant, told me to make a test because she thought I had diabetes because I drank a lot of water and nothing would quench my thirst. […] Then I did the exams that the doctor asked and the result was diabetes (C9).

At the time of the consultation, both reported having classic symptoms of diabetes, but did not associate them with this disease. Because it is a chronic condition, DM should be the focus of health promotion actions and widely disseminated prevention measures. These guidelines can not be standardized; they must encompass the autonomy and criticality of the individual and the family in the care process.

From that moment, it is necessary to start adapting the life habits to the limitations necessary for living with the chronicity of the disease. During the dialogue between researcher and clients, some feelings at the moment of the discovery of the diagnosis were detected, as follows:

I was very sad, because I really like sweets, until today I miss it very much. So it made me very sad, really sad (C6).

The participant C6 demonstrates the sadness in speech, because the disease influences the eating habits, mainly with respect to the ingestion of sweets. To the extent that the client get more familiar with DM, he learns that there are alternatives that satisfy well the desire to eat sweets. Sadness and discouragement are feelings that must be monitored because there is an important relationship between DM and depression. The multiprofessional service is very valuable. It is emphasized that the inclusion of psychologists and nutritionists is essential to help the client to deal with food control. This aspect is still understood from the point of view of imposed deprivation, “diet”, prohibitions and restrictions, and not as a need for alimentary reeducation.

According to the report of C10, the diagnosis of the disease did not cause any type of feeling. It is observed that the fact of having other members of the family with this disease allows the client to deal with it differently:

Oh, it was normal! I don’t know, because there were cases [of diabetes] in the family, since my grandmother, I think my grandmother’s mother, they already had it, so […] it was normal. It was nothing oh! It changed my life! [laughs] (C10).

Accepting the disease can be a more or less difficult process. The person with diabetes has to perception that he/she is someone who has somehow learned to live with the discomfort, uneasiness and pain generated by restrained habits, by the control imposed by the treatment of one of the most basic impulses of the human being, which is orality. Effective education
goes beyond the transmission of information. It causes change and/or the adoption of a behavior that incorporates the needs, goals and life experiences of the individual.9

Despite experiencing the same illness, each person expresses the feeling in a different way. Surprise and fright with the diagnosis were also reported:

Wow, girl […] I freaked out! (C5).

I almost fainted! (laughs) I got crazy, nutty (C4).

The understanding of the feelings and behaviors of the diabetic person can contribute to resize the model of health care with this clientele. Comprehensive care assumptions that include the dimensions of biological, psychological, social, and spiritual well-being, among others, are advocated in the primary health care model.9

In this sense, dialogue is a resource used in the relationship of care because it allows an exchange of information between professional and client, which will lead to reflection. Transformative dialogue leads the subject to abandon his passive and naive attitude and adopt an active, questioning position, seeking modifications and assuming a desire for change of reality.10

In order to problematize the person with diabetes, it is necessary that health professionals understand the personal questions and daily activities of the patients. They need to contextualize the clients’ reality with the necessary changes for a good control of diabetes and their need to live with the disease.11

**What is diabetes**

Access to general knowledge about the disease was fundamental to the later issues related to the fact of living with the symptoms of DM. Therefore, the questions “What is diabetes? Can you explain it to me?” guided this stage of the study.

Knowledge about their disease is the basis for the correct practice of self-care, as well as for a more effective participation in treatment. However, knowledge does not necessarily induce a change of behavior.12 For this to occur, an interaction between professional and client has to occur, with sharing of ideas, so as to make clients prone to change. At that moment, the sharing of knowledge about the disease between nurses and clients represents one of the concepts governed by CCR: dialogicity.

When answering the questions, the definition varied between the presence of sugar in the blood, non-functioning of the pancreas, and the possible complications, however, they did not define the disease. The clients had knowledge about the disease and were able to associate them with hyperglycemia, that is, the presence of sugar in the blood, as can be seen in the following statements:

I know. Is it sugar? Glucose that goes up. So, if you exagerate with sweets, the tendency of glucose is to rise, and I would exagerate very much in this point (C6).

I know it’s something that is in the blood, you have to avoid eating too much sweets […] C9.

Blood sugar? High blood glucose in the blood […] (C8).

Is the glucose test increased? I do not know above what level (C10).

A fragmented knowledge is present in the speeches of C5 and C9. The associations made by both to these specific issues come from guidance given in the outpatient clinic, but there is a dissociated understanding of the guidelines. They pick up the words “insulin” and “pancreas”, but they can not come up with a more complete answer about DM:

Look, diabetes, the way I know it, it’s my pancreas that does not work anymore, and that’s why I have to get the shots in the morning and at night, not to mention the medicine I take? (C5).

[…] insulin, in place of the pancreas, now I remember […] it is not dissolving as it was supposed to dissolve, then all this contributes to the disease (C9).

Complications and the chronicity of the disease were also reported by the participants:

I know that diabetes is a very treacherous disease. It can blind you, it can cripple you, it can take a piece of your foot, your […] everything? Because if the diabetes is high, it is dangerous […] if it is low it is dangerous as well. It has to be on its threshold, it has to be controlled (laughs) (C5).

The conception of health and the way each person faces illness are conceived based on personal experiences, and these are directly related to the beliefs and values formed throughout life.13 Health care professionals should not be limited to the clinical practice of DM. It is crucial to include also the clients’ popular knowledge, because it directly interferes with the care process.

**Types of DM**

Following the definition of the disease, the question “what types of diabetes?” was discussed. It can be seen in the following statements that clients relate the type of DM to age, that is, popular information:
The type 1 more common in children, is it? And type 2 is more common in adults. As far as I remember […] (C1).

Type 1 is born more for children, obese children, right? And type 2 is with people with most advanced age (C9).

Although the fact is shown in studies, that is, that type 1 DM is more common in children and young adults and type 2 DM in adults, the clients did not verbalize the issue of the absence or decreased action of insulin. The discussion with the clients about the types of DM provided a moment of reflection on the value of participation in the care process of the own health. The problematization of differences from one type to another caused the clients to make associations with their own symptoms and the therapeutic modality they follow.

Some reports referred to the etiology of hereditary or acquired DM and that types 1 and 2 would be the progression from one type to the other, as illustrated below:

Wait, I've heard […] there's one that the person already has […] genetics, is it? And the one you develop later (C6).

One is from birth and the other […] may not be from birth, it's hereditary… is that right? (C11).

My God! (pause). Look, what do I know about diabetes is that there is diabetes that is 1 and diabetes that is 2? And I think mine is already 2 (C4).

After the statements, DM type 1 and 2 were explained using clear language so they could understand the differences, as exemplified in the following section:

R: There are two types of diabetes, do you know that?

C7: Yes, type 1 and type 2.

R: And can you tell me a little bit about these types, the difference between them?

C7: No […] I know that type 1 is of children and 2 of adults.

R: Type 1 diabetes, as you said, is more common in children and young people and appears suddenly. And the person who has type 1 diabetes, her pancreas does not produce insulin […].

C7: Goodness!!
Cardiovascular disease is the most common cause of death and disability among people with diabetes. Cardiovascular diseases that follow diabetes include angina, myocardial infarction, stroke, peripheral arterial disease, and congestive heart failure. High blood pressure, high cholesterol, high blood glucose and other risk factors contribute to the increase of cardiovascular complications. 6

Complications of diabetes can be classified as acute, such as hypoglycemia, ketoacidosis and hyperosmolar coma; and chronic, such as diabetic retinopathy, nephropathy and neuropathy. 1

The report of hypoglycemia was present in the dialogues. Some of the clients went through the experience, but they were not aware of the cause to be able to avoid it, as portrayed in the following excerpt:

C8: Once my [blood glucose] fell, I had gone to the graveyard to pay a visit there at my son’s grave. When I’m leaving, I’m in the bus […] the good thing is that I was with my boy. Then I felt my sight darkening, darkening […] I said: ‘I’m feeling really bad’. I said, ‘Let’s drop here, get a cab and go to the health post’. Then I got off the bus, took a cab, and stopped at the health post. Do you know how high it was? It was 20 [mg/dL]. […] I do not know if it was because of the food I ate. I had a heart attack, right? I was eating food without salt […]

P: Or you had not eaten for a long time.

C8: Oh, too, taking too long to eat also causes this things right? Does it make it decrease?

P: Yes! You cannot stay long time without eating, because insulin is working, and it happens that the glucose goes down, more than normal. As you are not eating, glucose is being consumed, and this can lead to hypoglycemia, which is low glucose.

C8: It’s just like my fast, this one now. I was already starting to get dizzy that I’ve been like this since yesterday. It was 9 o’clock when I ate and did not eat anything anymore. Then when I took that glass of juice and ate that bread, I already felt […] blood already got some sugar […] (laughs).

It can be seen that from the knowledge acquired with the experience, the client associates the symptoms of hypoglycemia with fasting, since he had experienced similar symptoms. The knowledge acquired during the dialogue allowed the client to identify the possible cause of these symptoms and have a strategy to reverse the situation.

Thus, the interfaciality proposed by the CCR emerges when there is a change in practice.

C7: The low [glucose] happens like this: when it goes down, below 60, and reaches 40 [mg/dL], it gets bad, making the person faint, right? And I already fell […] I already fell twice. I fell once in the street […]

P: And you said that when glucose drops too much, which is hypoglycemia, a complication of diabetes too, and you know what you have to do when your glucose goes down like this?

C7: You have to eat candies, you know, sweets to make it go up. And it goes up, everything goes back to normal. But we also have to treat it; otherwise, if it rises too much, it is dangerous too.

P: Exactly. These cases require the intake of 15 grams of sugar, such as a 200 mL glass of soda or even a shallow spoonful of sugar.

In the speech of C7, it is evident the knowledge about the hypoglycemia when the client mentions the level and glucose below 60 mg/dL and the possible consequences. This is to show that the search for information and prior knowledge is an element that motivates the participation of the client. Thus, during the dialogue, the client had his/her autonomy respected.

It is important to emphasize the importance of proposals for practices that are necessary for education as a means of promoting the autonomy of the clients by respecting their culture, their empirical knowledge and their way of understanding the world around them. 15

It is worth emphasizing that this autonomy is only guaranteed if the educator takes into account the singularity and culture of the individuals and the environment in which they are socially inserted, placing them as participants in their care process. In this process, dialogue becomes a primordial tool, born from a critical matrix and generating criticality. It nurtures love, humility, hope, faith, trust. 17

The classic symptoms of diabetes are: polyuria, polyphagia, polydipsia and unexplained weight loss. 3 Some of these symptoms were emphatically mentioned by the participants:

C5: My daughter! I drink a lot of water.

P: This is a symptom of diabetes, you feel very thirsty, it’s called polydipsia.

C5: Oh yes! [astonishment].
P: Yes. As glucose levels are high in the blood of diabetic people, there is a loss of that glucose in the urine, and consequently the body loses water. And this causes your body to “ask for more water” and that is why you feel thirsty […] 

CS: I drink, and also pee.

P: Exactly, it’s another symptom. Lots of peeing.

CS: Dammit! Girls, I drink a lot of water […] but there’s also days when I sweat a lot. When it’s too hot, I sweat too much. But it is not diabetes, because when diabetes drops, I feel it. It’s the heat really, I sweat a lot, I melt! Because when I got sick from diabetes, it is a different sweat. Our pores get a lot of water, it would not stop, but there was no way. And the heat, when it is our sweat really, you feel that it is different. So more or less now I know. That neither she [the outpatient nurse] told me, I carry with me all the products inside the bag, it’s not for me to eat, it’s a need, an emergency. If I happen to feel bad, if before that happens, I’m feeling like something strange […] why you feel the symptoms? Oh, and you don’t have them, it gets complicated, because it is like this, in the blink of an eye.

P: Because now you already know that it is a possible complication of diabetes and you know what to do. Because when you felt bad, you did not know […]

CS: No, I was not aware of nothing at all.

It is noted that CS lived with classical symptoms of the disease but did not associate them with DM, showing surprise in the speech when clarified about the relationship between the symptoms and the chronicity of the disease.

The conversation with clients about the causes and clinical manifestations allows them to have subsidies for the early recognition of possible complications.

P: And besides high glucose, what other symptom of diabetes do you know, or have you ever felt any other symptom, or do you know of there are other symptoms?

C10: Oh, that’s when I […] exactly, I looked for the endocrinologist; I saw on my grandmother and my mother who also had diabetes. You feel like going to the bathroom all the time to pee, the urine foams lot, very thirsty, drinking lots of water every day… what else? […] I got up about five times a night to pee.

P: They are classic symptoms of diabetes.

C10 demonstrated knowledge of symptoms in addition to high blood glucose levels, based on the experiences of the mother and the grandmother. In common sense, the construction of knowledge takes place through associations. Thus, C10 associated the symptoms in the grandmother and mother with what he felt. This reflection led the client to decide to seek a medical specialist and confirmed the diagnosis of the disease.

Complications of the disease were evidenced in the following excerpts:

I know that diabetes is a very treacherous disease. It can blind you, it can cripple you, it can take a piece of your foot […] (C5).

It affects the vision and sometimes also the legs […] (C7).

Vision problem, that thing that they cut a part of the body too? (C8).

Amputation of feet, legs, fingers […] blindness […] and kidney problems, if you do not take care […] (C9).

The approach to the client with diabetes on the perception of complications is recommended by the Ministério da Saúde (BR) because preventing or minimizing the problems related to diabetes is one of the important aspects of the assistance provided.

Amputation and diabetic retinopathy are culturally known complications among people with diabetes. Annually, one million diabetic people in the world lose one part of the leg, translating into three amputations per minute. The prevalence of retinopathy in people with diabetes is 6.5%.1

Due to the relevance of the theme, the researcher highlighted during the dialogues that the situations reported are complications that can be completely prevented through care measures such as strict glycemic control, change in eating habits, practice of physical exercises and total abandonment of smoking and alcoholism, among other measures.

Eating habits, especially the consumption of sweets, appeared again in the reports of the participants:

C1: […] sometimes I would go to Rua da Alfândega to eat Arab sweets […] I was crazy about it, caramelized […] then I had to leave everything… almost everything. I sometimes still get out of control […] Sometimes we [referring to the daughter] even fight, have arguments, because I want to eat. Oh, you cannot eat! You really can’t! I say: “Sheila, it’s not that I cannot eat; the point is that I cannot eat every day”.

P: Because now you already know that it is a possible complication of diabetes and you know what to do. Because when you felt bad, you did not know […]

CS: No, I was not aware of nothing at all.
P: There is not a total restriction for the ingestion of sweets, but one should avoid consumption as much as possible, avoid eating every day or avoid eating high amounts.

The difficulty of following a sugar-free diet is common in people with DM, but adjusting to dietary restrictions is part of the treatment. Failure to adhere to diet happens because it is related to the acquired habits, strict schedules, the cultural value of food, the socioeconomic conditions, and the psychological issues involved.9

The articulation of scientific knowledge with common sense is fundamental to understand the need to consider the knowledge of each person for interventions regarding care for diabetes mellitus.

CONCLUSION

The knowledge and practices of diabetic clients in outpatient care about living with DM were exposed thanks to the opportunity given to them to express their ideas under the guidance of the dialogue/reflection.

The results showed that such knowledge and practices are fragmented, and as a result of knowledge acquired throughout the lived experience. The knowledge and practices of diabetic clients were mobilized and valued through dialogue/reflection. This process was based on the exchange of popular and professional knowledge and on the discovery and reconstruction of knowledge, and enabled its application in educational nursing care for this clientele.

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