



## Analysis of the perception of autonomy and self-care among individuals living with diabetes

Análise da percepção sobre autonomia e autocuidado dos indivíduos que vivem com diabetes

Análisis de la percepción de autonomía y autocuidado entre individuos que viven con diabetes

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### ABSTRACT

**Objective:** To analyze the talk-in-interaction of individuals living with diabetes regarding questions about autonomy and self-care. **Methods:** This was a qualitative study with educational group sessions using a problematizing methodology with nine participants. **Results:** Five categories emerged: autonomy and self-care; food; diabetes complications; pharmacological treatment; and lifestyle habits. The results presented herein refer to the autonomy and self-care category. There was difficulty in adapting the guidelines given by the health team to the reality of individuals in their biopsychosocial context. A lack of access to health services and social and family support were also observed. **Conclusion:** The analysis of the participants' perceptions revealed difficulties in diabetes treatment related to each individual's daily life and access to treatment. Analyzing the demands and difficulties of individuals with diabetes, within their various realities, can help in building bridges between knowledge about the disease and changes in attitude toward its treatment, providing autonomy and self-care.

**Keywords:** Health education, Diabetes Mellitus, Personal Autonomy, Self-Care.

### RESUMO

**Objetivo:** Analisar as falas-em-interação dos indivíduos que vivem com diabetes a respeito de questões sobre autonomia e autocuidado. **Métodos:** Pesquisa qualitativa com grupos educativos utilizando metodologia problematizadora com nove participantes. **Resultados:** Emergiram cinco categorias: autonomia e autocuidado; dieta; complicações do diabetes; tratamento farmacológico; e hábitos de vida. Os resultados aqui apresentados referem-se à categoria autonomia e autocuidado. Houve dificuldade em adequar as orientações da equipe de saúde à realidade do indivíduo em seu contexto biopsicossocial. Além disso, observou-se falta de acessibilidade aos serviços de saúde e apoio social e familiar. **Conclusão:** A análise das percepções dos participantes revelou dificuldades no tratamento do diabetes relacionadas ao cotidiano de cada indivíduo e ao acesso ao tratamento. Analisar as demandas e dificuldades do indivíduo com diabetes, em suas diversas realidades, pode auxiliar na construção de pontes entre o conhecimento sobre a vivência com a doença e a mudança de atitude em relação ao seu tratamento, proporcionando autonomia e autocuidado.

**Palavras-chave:** Educação em saúde, Diabetes Mellitus, Autonomia Pessoal, Autocuidado.

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## RESUMEN

**Objetivo:** Analizar el diálogo-en-interacción de individuos que viven con diabetes sobre cuestiones de autonomía y autocuidado. **Métodos:** Este fue un estudio cualitativo con sesiones grupales educativas utilizando una metodología de problematización con nueve participantes. **Resultados:** Emergieron cinco categorías: autonomía y autocuidado; alimento; complicaciones de la diabetes; tratamiento farmacológico; y hábitos de vida. Los resultados aquí presentados se refieren a la categoría de autonomía y autocuidado. Hubo dificultad para adaptar las orientaciones dadas por el equipo de salud a la realidad de los individuos en su contexto biopsicosocial. También se observó falta de acceso a los servicios de salud y apoyo social y familiar. **Conclusión:** El análisis de las percepciones de los participantes reveló dificultades en el tratamiento de la diabetes relacionadas con el cotidiano de cada individuo y el acceso al tratamiento. Analizar las demandas y dificultades de las personas con diabetes, dentro de sus diversas realidades, puede ayudar a tender puentes entre el conocimiento sobre la enfermedad y los cambios de actitud frente a su tratamiento, proporcionando autonomía y autocuidado.

**Palabras clave:** Educación para la Salud, Diabetes Mellitus, Autonomía Personal, Cuidados Personales.

## INTRODUCTION

Diabetes mellitus (DM) is an important and growing public health problem (BRAZILIAN DIABETES SOCIETY, 2019). According to data from the International Diabetes Federation (IDF, 2021), the global prevalence of DM in 2021 was 537 million people, with a projection of reaching 783 million in 2045 (INTERNATIONAL DIABETES FEDERATION, 2021).

In Brazil, 9,1% of the population has the diagnosis, which corresponds to 14.5 million of persons according to Brazilian population in 2021, with progressive increase of cases since 2006. There was a reduction in the diagnosis of diabetes as the level of education increased (BRASIL, 2021; IBGE, 2021). Individuals living with DM require complex treatments, including behavioral and attitude changes; in this context, self-care is essential. The lack of understanding of the disease and its treatment partially explains the difficulty in achieving therapeutic goals. According to a study by Moreira et al., 73% of patients with type 2 DM in large cities in Brazil do not achieve adequate glycemic control (RIBEIRO CSA, et al., 2015).

Between the justifications found are the lack of accessibility to the new therapeutic arsenal by the users of the Single Health System and the necessity of larger knowledge about the disease and its treatment, providing changes of attitude from the individual face to his/her health condition. Such changes involve the literacy in health, which is the capacity to obtain, process and understand the necessary information for the decision making relative to self-care. That way, it is important that the healthcare team observe the main demands and difficulties of patients, utilizing a language adequate to the literacy grade during the orientations in the appointments (SANTOS LTM, 2017).

According to the American Association of Diabetes Educators (AADE), therapeutic education in DM should be based on 7 self-care behaviors: healthy eating, physical activity, monitoring of blood glucose levels, proper use of medication, problem solving, healthy coexistence with the disease and risk reduction (AMERICAN ASSOCIATION OF DIABETES EDUCATORS, 2009) In this sense, the American Diabetes Association (ADA) recommends that all patients with a diagnosis of DM have access to education and support for the self-management of care (POWERS MA, et al., 2020).

In addition, evidence shows that education should not be based exclusively on the transmission of knowledge, as it does not guarantee positive effects on self-care practices. For this reason, it is important that diabetes education be based on integrative practices, in which there is active participation of the patient, using his or her worldview (CYRINO AP, et al., 2009).

In line with these proposals, educational group sessions were held to understand the perceptions of patients with diabetes regarding the disease and the role of each individual in their treatment. This study aimed to analyze the talk-in-interaction of individuals living with diabetes regarding questions about autonomy and self-care.

## METHODS

### Scenario and sample

A qualitative study was developed from the analysis of educational group sessions lasting 90 minutes at two different times and was conducted by a multidisciplinary team composed of an endocrinology professor, an endocrinologist, a nutritionist and four undergraduate medical, pharmacy and nutrition students. This study was conducted with individuals with diabetes in outpatient follow-up at Hospital Universitário da Universidade Federal de Juiz de Fora (HU-UFJF). Regarding the selection of participants, among the 41 individuals included in a randomized clinical trial previously conducted by our group, 15 had time and financial means available to attend the educational group sessions (MIRANDA LSP, et al., 2022). For the qualitative research, the analysis of talk-in-interaction of the meeting with thematic autonomy and self-care was selected, in which 9 individuals participated in 2 group sessions. Individuals aged 18 to 64 years with type 2 DM who were receiving insulin therapy and had glycated hemoglobin outside the therapeutic target were included. The noninclusion criteria were type 1 or gestational DM, institutionalized patients or patients with chronic complications in advanced stages.

### Data collection procedures

The educational group sessions were structured based on the problematizing pedagogical methodology proposed by Paulo Freire; this methodology allows the construction of knowledge with the aid of experiences and the exchange of knowledge (FREIRE P, 1997). Sociodemographic questionnaires and the Short Test of Functional Health Literacy in Adults were applied, allowing better characterization of the sample (PARKER RM, et al., 1995; MARAGNO CAD, et al., 2019; BAKER DW, et al., 1999). The educational group sessions were designed to analyze the perceptions and experiences related to diabetes and the role of each individual in the treatment of the disease. Some questions were “What do you think the word self-care means?”; “What do you think diabetes is?”; and “What do you think about self-care in relation to diabetes?” Data were collected between May and December 2019. The meetings were held in the morning in a private room at HU-UFJF.

The participants were arranged in a circle to discuss the topic in question, and the sessions were mediated by a multidisciplinary team. The meetings were recorded, and the dialog was transcribed in full by members of the project team and subsequently checked again by the research team to ensure quality. The statements extracted were identified by the class number (1 or 2) followed by a letter, from 'a' to 'o', with the exception of the letter 'k', to ensure the anonymity of the participants. In the data analysis, of the 12 meetings (6 meetings in each group), 5 categories emerged: autonomy and self-care; food; diabetes complications; pharmacological treatment; and lifestyle habits. The results presented herein refer to the autonomy and self-care category.

### Data analysis and Ethical considerations

For the analysis of qualitative data, the content analysis technique proposed by Bardin was used, consisting of 3 stages: preanalysis, i.e., organization of the material available for analysis; exploration of the material, coding and categorization of the material and treatment of the results obtained; and interpretation, which can be performed through inference - controlled interpretation (BARDIN L, 1977). The data from the questionnaires were analyzed with special attention to the uniqueness of and the conditions that permeated the discourses. The project was approved by the Research Ethics Committee of HU-UFJF (number 2.615.760 CAAE no. 86845218.9.0000.5133). The interviewees agreed to participate by signing an informed consent form (ICF).

## RESULTS

Nine individuals with DM were included; most were female (66.6%), with a mean age of  $55 \pm 7.6$  years, and 44.4% had inadequate health literacy. In general, the individuals had a low education level; 44.4% had only an elementary education, and only 11.1% had received higher education. In addition, there was no perception of very good or excellent health, with the majority reporting reasonable (66.6%) or poor (11.1%)

health. Among the complications related to DM, 60% reported neuropathy, and 53.3% reported retinopathy, in addition to kidney diseases (20%) and foot disorders (13.3%). Table 1 shows the demographic data of the participants. For this article, the category "Autonomy and Self-care" was used because it is of fundamental importance in the care of individuals with DM.

**Table 1** - Sociodemographic variables.

Variables	Group (n=9)
<b>Gender</b>	
Female	6 (66.6%)
Male	3 (33.3%)
<b>Age</b>	55 ± 7.6 years
<b>Skin color/race</b>	
White	2 (22.2%)
Black	1 (11.1%)
Yellow	0 (0%)
Brown/mulatto	6 (66.6%)
Indigenous	0 (0%)
<b>Marital status</b>	
Married	7 (77.7%)
Single	1 (11.1%)
Widowed	1 (11.1%)
Separated	0 (0%)
<b>Family income</b>	
Up to 2 salaries	8 (88.8%)
3-5 salaries	1 (11.1%)
6-10 salaries	0 (0%)
More than 10 salaries	0 (0%)
<b>Education</b>	
Higher education	1 (11.1%)
High school	4 (44.4%)
5th to 8th grade	2 (22.2%)
1st to 4th grade	2 (22.2%)
<b>Health literacy</b>	
Inadequate	3 (33.3%)
Marginal	1 (11.1%)
Adequate	5 (55.5%)
<b>Self-rated health</b>	
Excellent	0 (0%)
Very good	0 (0%)
Good	1 (11.1%)
Fair	6 (66.6%)
Poor	1 (11.1%)
<b>Comorbidities</b>	
SAH	8 (88.8%)
Dyslipidemia	6 (66.6%)
CVDs	2 (22.2%)
Kidney diseases	2 (22.2%)
Retinopathy	4 (44.4%)
Neuropathy	6 (66.6%)
Foot disorders	2 (22.2%)
Other diseases	6 (66.6%)
<b>Smoking</b>	
Smoker	0 (0%)
Nonsmoker	6 (66.6%)
Ex-smoker	3 (33.3%)

**Note:** SAH: Systemic arterial hypertension; CVDs: Cardiovascular diseases. **Source:** Ferreira M, et al., 2023.

The nuclei of meaning of “Autonomy and Self-care” are summarized in **Chart 1**. In this study, the core meaning were represented by three categories, which are: understanding about autonomy and self-care and perception of diabetes; needs in diabetes self-care and barriers to the practice of autonomy and self-care in diabetes.

**Chart 1** - Core meanings of “Autonomy and Self-care” and their relationship with diabetes and respective recording units.

Core meaning	Recording unit
1. Understanding about autonomy and self-care and perception of diabetes.	Autonomy Self-care Diabetes
2. Needs in diabetes self-care.	Behaviors
3. Barriers to the practice of autonomy and self-care in diabetes.	Knowledge Emotional limitations Supplies Food Insulin Physical limitations Social/family support

Source: Ferreira M, et al., 2023.

### Participants’ understanding of autonomy and self-care

When asked about their understanding of autonomy and self-care, most participants showed an adequate understanding of these concepts. Regarding self-care, one of the participants reported:

1a: *taking care of ourselves.*

Autonomy is related to the capacity to make an independent rational choice. One participant defined the term “autonomy” and associated it with the environment in which one lives (Houska & Loučka, 2019).

2f: *Autonomy is doing what we have to do, you know. You have to have autonomy to do what you want. Many times we do not have autonomy; it depends on who lives around us.*

### Perception of diabetes

The participants’ feelings regarding the diagnosis of diabetes and their perceptions about the disease were evidenced throughout the study, as in the statement by one of the participants who reported anguish upon receiving the diagnosis and expressed a perception of the high lethality of the condition.

2j: *When I received the result, a thousand things go through your mind. The first thing is that you think you’re going to die anytime, like a time bomb.*

Although the new diagnosis originally generated negative thoughts and emotions, positive aspects regarding better body perception also emerged.

2j: *However, on the other hand, if you stop and think, you begin to discover your body. You start to discover your body, and you can work on it.*

### Needs in diabetes self-care: behavior

#### Food

The issue of food was a constant topic throughout the meetings. One participant shared the way she usually assembles a dish, balancing the amount of carbohydrates in meals. In addition, the participant shared with the group how difficult it was to implement this behavior.

*2f: I eat rice and beans, but I don't eat pasta. And, I don't eat angu. If I eat angu, I eat angu and beans with vegetables, but I don't eat rice or pasta. It's difficult, right?*

### **Adherence to treatment**

The difficulties that the treatment of diabetes imposes on individuals were widely debated throughout the discussions. The following statement by a participant was in response to a colleague who stated that she had already thought about abandoning treatment. The participant argued in favor of constant self-care in diabetes to avoid possible complications:

*2f: Yes, but can't not do it. No, you can't, because you think you are better, then you abandon it, and when you check again, you will see that you are much worse.*

### **Barriers to the practice of autonomy and self-care in diabetes**

#### **Food**

Several participants in the group reported challenges in the practice of autonomy and self-care in diabetes. Among these, food was a point cited by several participants. References to food challenges ranged from the erroneous perception of prohibited foods, such as pasta and sugar, to the tendency to deal with problems through food, for example, emotional eating. One participant noted this relationship with food and stated that it is an obstacle in her treatment.

*2f: However, it is so difficult.... For example, my difficulty is food. Food is passion. Passion for food. It would seem as if I've never seen food before, no joke. Yes, I feel passion.*

#### **Insulin**

Some patients described difficulty with injecting insulin, revealing technical barriers, despite reporting training in this regard, and psychological issues, reported by the participants as a situation that causes great "distress." Notably, the participants were knowledgeable of alternating between injection sites.

*2f: Another thing I have a serious problem with, that I cannot, I cannot. If I stand here for you, everything will be purple. I cannot manage to apply that insulin properly. It's amazing, I can't. It hurts me a lot. And so then, I loathe taking insulin. I really don't want to do it... In the morning, I open my eyes like this, then keep looking... I can't apply it here (points to the buttocks) or the arm, and so, I apply more in the belly. However, I change the places, right? But it is too difficult. This is my barrier for improving.*

These psychological barriers are also permeated by social constructions that may hinder treatment adherence. One participant's comment demonstrates how diverse the perception of insulin therapy for diabetes is.

*2g: I have an acquaintance, and she and her mother have diabetes. I met her on the street and asked, "do you use insulin?". I said "I do", and she said "insulin kills". (...) And she's not taking medicine or giving her mother medicine.*

### **Emotional/psychological limitations**

Several participants recognized the influence of emotions on self-care in diabetes, even considering emotions as a cause of the disease. Uncontrolled eating when anxious, focusing mainly on sweet foods, was also reported. One participant noted this challenge, recognizing, almost instantaneously, the possibility of future complications:

*1c: The day that I feel anxious, in my case, I tend to eat more and eat whatever I have in front of me. I do not want to know what it will do to me. But, I know I'm harming myself... this emotional side... this is how it rises.*

The feeling of sadness was also reported as a limitation to better self-care. This can be observed in a statement by a participant who even attributed the occurrence of episodes of sadness to immunity:

*2i: What about when your immunity becomes low and you go into your room and do not want to hear about anyone, see anyone?*

Given the challenges encountered for optimized management, giving up was considered.

*2g: I already want to quit (the treatment).*

### **Supplies**

Blood glucose monitoring and outpatient follow-up with medical specialists are essential tools for intensive glycemic control. As seen in the following statements, some participants reported a lack of material resources and availability of health services.

*2h: There are no (strips). (...) not even in the medical facilities.*

*2f: (...) there is no medicine, no medical appointment, no time slots, nothing. You have to ask them to give you an appointment. The federal government takes care of this need.*

### **Family/social support**

The environment in which individuals find themselves is often seen as a challenge for the practice of self-care in diabetes. Some participants described a lack of empathy from others, especially family members, as a barrier to self-care:

*2h: However, most do not accept it. "So, it is your problem."*

*2f: (...) no one gives support either, right? Nobody does. (...) at least in my family, no one gives you support. Like, "I'm not going to have this because I know she can't," no one does. (...) so this is why we sometimes are discouraged, for this reason. Because you cook, you have to do everything. Then, when the time comes, it is what you said: do you think you are able to take care of yourself? I am, but do I have the conditions and time to prepare my food separately? Then you say "no, but you have to eat healthy." And so then you put healthy food on the table and see if they will eat it.*

Others indicated this barrier through the stigmatizing view of health professionals, without extensive knowledge of the disease and its treatment and the lack of dialog among multidisciplinary team members:

*2j: When you go to the dentist for an exam and he discovers that you are diabetic, then, you start that fight; they say, "come back when your glucose is low".*

## **DISCUSSION**

The present study evaluated the perceptions and experiences of the participants of educational group sessions conducted using a problematizing methodology. Among the most frequent topics were difficulty adapting the guidelines given by the health team to the reality of each person, concern with the lack of access to health services and family and social support.

During the analysis of the participants' perceptions of diabetes, feelings such as anguish and fear and an association with imminent death were observed. Similar reactions have been described in the literature, as in the study by Silva et al., in which the participants of a qualitative study focused on reflexivity reported feelings of panic and shock associated with the diagnosis of DM (SILVA JA, et al., 2018). Sadness and anxiety are also present not only at diagnosis but throughout treatment. These reactions are associated with worse self-care and low adherence to treatment, especially if diabetes distress is present, a situation in which an individual presents intense suffering related to DM (PANDIT AU, et al., 2014; CHAN CKY, et al., 2020).

Autonomy, an important practice during the treatment of DM, was well defined by the participants, and there was emphasis on the fact that it depends on the conditions in which they live. Studies have shown that social support improves self-care practices and contributes to individual self-efficacy, with a direct impact on health and quality of life. Living with individuals with diabetes also allows sharing problems, exchanging experiences, and achieving better solutions. In addition, social support can neutralize the negative effects of low health literacy (CHAN CKY, et al., 2020; SOUZA JG, et al., 2020). In the present study, a lack of social support was also cited as a complicating factor for individuals with diabetes, leading to losses mainly in their adherence to diets and promotion of self-care.

Barriers were observed in the day-to-day lives of people with diabetes, for example, difficulties in the acquisition of supplies and medications, in addition to other limitations stemming from social and emotional issues. These difficulties have also been observed in Brazil (VERAS VS, et al., 2014) and in other countries; for example, a Chinese study (LE C et al., 2016) reported a lack of capillary blood glucose strips, negatively affecting self-management with a subsequent impact on treatment and consequently on glycemic control. In the present study, difficulties were observed in relation to diet, medication management and insulin injections, and such barriers led to thoughts related to the desire to abandon diabetes care. These findings are strongly influenced by social and emotional issues that are known to have an impact on therapeutic adherence.

This association was also evidenced in a cross-sectional study conducted in Rio de Janeiro, in which the participants who had better scores in the emotional domain of the SF-36 exhibited greater adherence to DM treatment (MARINHO FS, et al., 2018). Furthermore, a previous study showed that low adherence to a diet is related to a lack of time and the high cost of fresh foods compared to ultra-processed foods (BROWN SA, et al., 2015). Notably, our study was conducted in a developing country in the public health system, with individuals with a low income and low health literacy, which are factors that amplify the difficulties associated with diabetes treatment. Furthermore, in this study, a lack of access to health services was noted, a finding also described in another study in the state of Ceará, in which there was dissatisfaction of the population with diabetes regarding the wait time for consultations with a specialist and the scheduling of tests (MARINHO NBP, et al., 2018). Similar results are also reported for other Brazilian states and for other countries around the world (DA SILVA JVM, et al., 2015); MENDES F, et al., 2013).

As a strength of the study, the educational group sessions, with a duration of 90 minutes, allowed an accurate analysis of the demands and expectations of the participants. As most participants were using insulin, the group discussions included difficulties regarding its management. Because the sample was homogenous and included only patients who had not met their therapeutic goals, several issues associated with lack of glycemic control arose in the group discussions. The limitations in this study include the sample size and the fact that the participants were monitored in a secondary care center, not representing the main level of care through which people living with diabetes are monitored in Brazil. Finally, the analysis of the participants' statements revealed that there are gaps between the guidelines provided by health teams and reality of individuals with DM. Social and emotional impacts of diabetes directly influence the self-care of individuals. In addition, social and family support seem to contribute significantly to coping with the disease.

## CONCLUSION

The analysis of the participants' perceptions revealed difficulties in diabetes treatment related to each individual's daily life and access to treatment. Analyzing the demands and difficulties of individuals with diabetes, within their various realities, can help in building bridges between knowledge about the disease and changes in attitude toward its treatment, providing autonomy and self-care.

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