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Original Article

Learning demands of diabetes self-management: a qualitative study with people who use insulin*

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Highlights: (1) Perceived severity of diabetes positively influences self-care. **(2)** Continued health education for people who use insulin is essential. **(3)** The importance of recognizing the benefits of insulin in adherence to treatment. **(4)** Emotional aspects in diabetes management should be considered in health education.

Objective: to understand the experiences with diabetes mellitus management of people who use insulin, in order to identify possible factors that may influence adherence to self-care and thus define their learning demands for diabetes self-management. **Method:** this is a qualitative study carried out using individual semi-structured interviews online. The interviews were recorded, transcribed and evaluated using Atlas.ti® software by means of Thematic Content Analysis, using the Health Beliefs Model as a theoretical framework. **Results:** 11 people living with diabetes and using insulin took part in the study. Four categories were identified: understanding diabetes, how to deal with diabetes, difficulties related to insulin use and emotional adaptation. **Conclusion:** the perception of the severity of the disease, its complications and the benefits of adhering to treatment positively influences adherence to self-care behaviors. Although the study participants have lived with diabetes for many years, they are not exempt from difficulties related to insulin use and disease management, reinforcing the importance of continuing health education. In this sense, the findings of this study guide important educational themes to be worked on by health professionals to promote autonomy in diabetes self-management.

Descriptors: Qualitative Research; Diabetes Mellitus; Insulin; Self-Management; Self Care; Health Education.

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Introduction

Insulin is one of the mainstays in the treatment of diabetes mellitus (DM) and its use requires great care, as it is considered a potentially dangerous drug due to its narrow therapeutic window(1). Studies carried out in Brazil have identified problems related to inadequate practices in the reuse of needles, storage of insulin, inadequate rotation at application sites, incorrect disposal of supplies and errors related to the technique of preparing and applying insulin(2-4).

Inadequate use of insulin, in turn, has consequences for the health and glycemic control of people living with DM, since it compromises the safety and effectiveness of the drug's use. In this context, health professionals play an important role in DM education, based on transmitting knowledge, developing skills, attitudes and behaviors that are essential for self-care(1). In order to plan educational interventions, it is necessary to understand personal questions, difficulties and limitations in coping with the disease and its treatment on a daily basis, thus contextualizing the reality of people with DM when faced with the changes necessary for good glycemic control and living with the disease(1).

DM education is a process that is not only the responsibility of health services and social institutions, but also of the target population, since they are primarily responsible for caring for the disease on a daily basis. Although the literature presents important points to be worked on in DM education(1,5-6), it is essential to consider the opinions and experiences of people who live with this condition daily, as well as the barriers and facilitations that can influence the performance of self-care, since they can be perceived differently by health professionals(1).

These experiences have been explored in some Brazilian studies, but from the perspective of certain groups such as adolescents(7-8), children(9), people with type 2 DM(10), rural population(11), family members of people living with DM(12) or focused on more specific topics, such as insulin use(13), diabetic foot(14) and psychological factors(15). In view of the above, the aim of this study was to understand the experiences of people who use insulin with diabetes mellitus, to identify possible factors that may influence adherence to self-care and thus define their learning demands for diabetes self-management.

Method

Design

This is qualitative research, which allows us to explore and understand certain phenomena based on the reality of the people who experience them(16). The qualitative design was chosen because it is the most appropriate to understand the experiences related to DM self-management from the perspective of those who live with this health problem on a daily basis.

Study scenario

Given that this study took place during the COVID-19 pandemic, the interviews were conducted online using the Google Meet® platform, in order to respect social distancing. Participants were previously instructed to preferably stay in a private place, with little external noise, and to feel comfortable answering the interview questions.

Period

The interviews were conducted between March and April 2021.

Selection criteria

The inclusion criteria adopted were: age 18 or over; both sexes; a diagnosis of type 1 (DM1) or type 2 diabetes mellitus (DM2); being on insulin; self-applying insulin; and being able to conduct the interview online. The exclusion criterion adopted was interviews whose audio quality made it impossible to transcribe the statements.

Sample definition

Participants were selected using convenience sampling, characterized by the selection of participants based on their accessibility(16). This sampling was necessary because the most efficient strategy for identifying people who met the research's inclusion criteria in the context of social distancing from the COVID-19 pandemic was through the creation of an interactive video that explained the purpose of the survey in a simple and attractive way.

The video was shared on the internet via the social media channels WhatsApp®, Instagram® and Facebook® of the researchers and collaborators in their research group. Following the video, those interested in the research contacted the researchers by telephone to show their interest in taking part. Interviews were only scheduled for people who met the research inclusion criteria.

Of the 13 people who got in touch, two were not included because they were parents of children with DM1, which did not meet the inclusion criteria established in the research. As people contacted the researchers, the interviews were scheduled, carried out, transcribed and analyzed. Data collection ended after the reports had been saturated, as proposed by Fontanella, Ricas and Turato(17), and reached when 11 interviews had already been carried out. After saturation, four more people showed interest, but they were informed that the data collection had already ended. No participants met the study's exclusion criteria.

Data collection

A semi-structured interview was adopted as the method for collecting data, using a script containing previously prepared guiding questions(18). The script of questions was initially structured based on the literature review on the subject in question and the research objectives(18). Subsequently, a pilot study was carried out with one participant to check that the questions met the research objectives and were clear, and also to test how the interview could be conducted online. The same inclusion criteria and selection strategy were adopted for the other participants.

The interview was recorded, transcribed and analyzed by two researchers in order to identify possible flaws in the script and change the wording of some questions. After analysis, it was noted that more questions needed to be added to meet the research objectives, which are represented by the numbers 8 and 9 (Figure 1). The data obtained in the pilot study was not included in the final data analysis.

1. Can you tell me what you understand about your diabetes?
2. Could you explain how you use your medication? What do you find most difficult about using insulin?
3. Tell me a little about your experience of living with diabetes. What is the most difficult part(s) of having/living with diabetes?
4. How does using insulin affect your day-to-day activities?
5. What motivates you to use your medication every day?
6. Do you use a glucose meter? If so, tell me a little about the difficulties you have or have had in using it.
7. From your point of view, how important is it for you to measure your blood sugar at home?
8. How does having to measure blood sugar interfere with your daily activities?
9. Tell me a little about how it feels to use insulin and the device that measures blood sugar on days that are out of the ordinary (traveling, eating out, parties, etc.). Does anything bother you about having to use insulin and/or measure your blood sugar in these situations? Does it embarrass you?
10. How would you describe the thoughts and feelings that recur to you when your blood sugar rises too high? And when your blood sugar is lower than normal?
11. Could you tell me a bit about how you deal emotionally with your diabetes?

Figure 1 - Final version of the script for the semi-structured interviews

The interviews were carried out individually, always by the same researcher, at a time and date agreed with the participant, and lasted an average of one hour each. The interviewees were asked to authorize video and audio recording of the interviews. Another researcher remained in the virtual room with the camera and microphone turned off, in order to provide any technical support during the interviews and to discuss points for improvement in conducting the interviews with the interviewer.

Data analysis

All the interviews were transcribed reliably and analyzed in duplicate. The researchers met periodically to discuss and agree on the analysis. Thematic Content Analysis was used to evaluate the data, divided into the following stages, as proposed by Minayo and Gomes(19): categorization, inference, description and interpretation.

The transcribed data was transferred to Atlas.ti software (https://atlasti.com/pt)(20), in which the categorization stage was carried out. Initially, the material was read and broken down into parts, using the theme as the recording and context units (elements obtained from breaking down the text)(19). These parts were allocated to the categories initially created on the basis of the interview script (Figure 2).

After a pre-analysis of the material, it was observed that some themes were not covered by the predefined categories. Thus, the emerging category "how to deal with diabetes" was created, to which some of the predefined categories were also relocated, later renamed into subcategories that covered situations related to diabetes self-management (Figure 3).

Predefined categories	Script questions
Understanding diabetes	Can you tell me what you understand about your diabetes?
Difficulties with insulin use	What do you find most difficult about using insulin?
Difficulties with self-monitoring	Do you use a glucose meter? If so, tell me a little about the difficulties you have or have had in using it.
Influence of diabetes and treatment on daily routine	Tell me a little about your experience of living with diabetes. What is the most difficult part(s) of having/living with diabetes? How does taking insulin affect your day-to-day activities?
Adapting treatment to days outside the routine	Tell me a bit about what it's like to adjust to using insulin and the device that measures your blood sugar on days that are out of the ordinary (traveling, eating out, parties, etc.). Does anything bother you about having to use insulin and/or measure your blood sugar in these situations (eating out; parties; trips)? Does it embarrass you?
Emotional adaptation	What motivates you to use your medications every day? How would you describe the thoughts and feelings that come to you when your blood sugar rises too high? What happens when your blood sugar is lower than normal? Could you tell me a little about how you deal emotionally with your diabetes?

Figure 2 - Pre-defined categories for analyzing the interviews

Categories and subcategories
Understanding diabetes
How to deal with diabetes: • Nutrition • Physical activity • Self-monitoring • Fluctuations in blood glucose • Special situations • Insulin use
Difficulties related to insulin use
Emotional adaptation

Figure 3 - Definitive categories for analyzing the interviews

The excerpts (themes) from the transcribed interviews were grouped into the same category when similarities were inferred in more than one statement. Subsequently, the categories, together with the extracts for each one, were exported to Microsoft Word®, where the data obtained was described. Finally, the results were interpreted using the Health Belief Model as a theoretical framework(21-22), composed of four dimensions (Figure 4).

According to the model, people are inclined to act if they perceive the susceptibility and severity to which they are exposed, and if they perceive that the benefits of a given action outweigh the barriers to be faced(21-22).

Dimension	Definition
Perceived susceptibility	Refers to the belief that the individual is vulnerable or susceptible to the disease or its consequences.
Perceived severity	Refers to how seriously an individual believes in the consequences that can result from the disease.
Perceived benefits	Beliefs that adhering to health-related recommendations will be beneficial in reducing the threat or severity of the disease.
Perceived barriers	They refer to the negative aspects (costs of time and money, adverse reactions, annoyances, among others) that can result from a health action.

Figure 4 - Dimensions of the Health Belief Model

Ethical aspects

The study was approved by the Research Ethics Committee of the Ribeirão Preto School of Pharmaceutical Sciences, University of São Paulo (opinion no. 4.418.475).

Results

The names of the 11 study participants are presented as pseudonyms to ensure data confidentiality (Figure 5).

Name	Age (years)	Gender	Type of diabetes	Educational level	Current profession/ occupation	Place of residence
Flávia	51	Female	DM1*	Postgraduate studies	Businesswoman	Barueri - SP†
Lídia	40	Female	DM1*	Postgraduate studies	Journalist	São Paulo- SP†
Carina	32	Female	DM1*	Postgraduate studies	Biologist/PhD student	Inconfidentes - SP†
Joana	47	Female	DM1*	Postgraduate studies	Teacher	Primavera do Leste - MT‡
Helena	54	Female	DM1*	University degree	Self-employed	São Sebastião do Paraíso - MG§
Sérgio	71	Masculino	DM2‖	University degree	Retired	Indaiatuba - SP†
Nicole	59	Female	DM2‖	University degree	Civil engineer	Orlândia - SP†
Sara	41	Female	DM1*	University degree	Pharmacist	Rio Grande - RS¶
Geralda	53	Female	DM1*	Postgraduate studies	Teacher	Petrolina – PE**
Marlene	47	Female	DM1*	University degree	Administrator	Teresina - PI††
Célia	44	Female	DM1*	University degree	Federal civil servant	Teresina - PI††

*DM1 = Diabetes mellitus type 1; †SP = São Paulo; ‡MT = Mato Grosso; §MG = Minas Gerais; ‖DM2 = Diabetes mellitus type 2; ¶RS = Rio Grande do Sul; **PE = Pernambuco; ††PI = Piauí

Figure 5 - Sociodemographic and clinical characteristics of people with diabetes interviewed. Brazil, 2021

The categories identified are described below.

Understanding diabetes

DM has been described as a threatening disease due to the risk of life- and health-threatening complications, being a gateway to other health problems (e.g. vaginal candidiasis; hypertension, among others) and being silent.

... I know very well that I could still have a problem, that I could need hemodialysis, I'm aware of that, right?!... (Helena).

... when it's too high, I know it's undermining my whole body inside, you know?...I don't feel bad, so that's why I see that they say it's a silent disease, because you don't feel bad, right?!... (Nicole).

Although there is a view that DM can have negative consequences for health, the participants recognize that it is possible to be healthy even with the disease, as there is treatment that allows them to live well as long as they take care of themselves.

... as time went by, I began to have more information... that I wouldn't be cured, that I would have a good survival as long as I took care of myself... (Helena).

DM was also seen as an expensive disease due to the higher costs the disease requires, not only in terms of supplies and medication, but also in terms of food. Finally, there was also an understanding that DM has a negative influence on emotional health, as well as on blood glucose control.

... Worry and stress are two things that alter my blood sugar a lot... (Célia).

... I've even had a bit of depression... I see that diabetes affects the psyche a lot, right?!... (Nicole).

How to deal with diabetes

This category includes reports describing how people manage DM on a daily basis. In the subcategory related to diet, reports showed the perception that the diet of people with DM is the same as that of people who do not live with the disease. Carbohydrate counting, self-monitoring and correcting blood glucose with insulin were cited as strategies that allow for greater flexibility in dieting.

... if you know how to use the right medication, carbohydrate counting, you don't need to restrict yourself from anything...

you can eat anything by counting carbohydrates and using the right insulin...I don't deprive myself of anything, I just can't go and eat a sweet without thinking, you know?!... (Flávia).

One participant associated eating sweets with being "forbidden" and contributing to the emotional burden of living with the disease.

... sometimes I feel the urge to eat a sweet... there are times when I'm crazy, I want to eat, you know?... it's a mental thing, right, but I think it affects the emotional level a lot, a lot, a lot... (Nicole).

Within the "physical activity" subcategory, there was recognition of the importance of physical activity in the routine of people with DM to prevent complications from the disease, and of some important precautions during practice, such as carrying a glucometer and food to correct hypoglycemia, if necessary.

In the "self-monitoring" subcategory, this practice was cited as essential in the routine and an important ally in day-to-day life because, in addition to providing greater safety and freedom in food intake, since the test results guide the correction of blood glucose with insulin, it also makes it possible to assess the impact of the daily routine on blood glucose and correct hypoglycemia/hyperglycemia that may arise from day-to-day activities.

... at work... I move around a lot, because of that my glucose drops, so I always have to be monitoring it... measuring it so I know what I have to do... (Marlene).

However, the daily number of tests to be carried out makes the routine tiring, as well as causing minor injuries to the fingertips. Despite these disadvantages, all the participants reported testing their blood glucose frequently.

... tell you that I'm not afraid of negative consequences? Yes! So that's why it motivates me to measure...so eight bites hurts?! Yes! But it's better than the negative consequences I might have... (Joana).

Difficulties with using the glucometer at the start of treatment were mentioned by one participant. New technologies such as the Flash Glucose Monitoring System, on the other hand, were cited as facilitating the practice of self-monitoring, as they reduce the number of daily pricks, allow a greater number of glucose results to be obtained, as well as facilitating adherence to the practice.

In the subcategory "fluctuations in blood glucose", it was observed that most participants recognize that glycemic control is not perfect all the time and that various factors can interfere with blood glucose, making it important to know how to deal emotionally with these fluctuations, identify possible causes and how to treat them. On the other hand, one participant said she felt so frustrated with the results that she stopped taking blood glucose tests.

... Like, I see that when it's low, it's fine, then I'm totally happy to measure, then when it starts to get too high...I don't want to measure anymore, you know! So sometimes I run away too, I don't measure for days... (Nicole).

Some participants reported a loss of sleep quality and mood the next day as a result of nocturnal hypoglycemia. In addition, hypoglycemia also interferes with physical activity and achieving results. Participant Carina, for example, reported that in order to do aerobic exercise, she had to eat some sweets to avoid hypoglycemia, but this hindered her weight loss.

Just as hyperglycemia is seen as a threat to health, participants also reported recognizing the dangers of hypoglycemia, with some associating it with the sensation of death. However, hypoglycemia poses a short-term threat, while hyperglycemia brings long-term dangers.

... but what does hypoglycemia bring us? A feeling of death... (Sérgio).

... the hypo, if it's not rescued in time, can kill you, the hyper will take a little longer, but the hypo will kill you in one night... (Helena).

In the subcategory "special situations" (managing diabetes in situations that are out of the ordinary, such as traveling, eating out, etc.), there are reports of the difficulty in controlling blood glucose when food is not eaten at home due to the quality of the food eaten. It is also recognized that there are no dietary restrictions, as long as blood glucose corrections with insulin are adjusted to the situation.

... I'll be able to make anything I want, like jam, brigadeiro, cake, no problem. I'll have problems later, for sure, but they're adjustable problems that I already know enough about to adjust... (Lídia).

They also stressed the importance of always carrying supplies such as insulin and a glucometer, as well as light snacks for possible hypoglycemia, as this gives them greater freedom of choice when it comes to eating and provides security against possible hypoglycemia or hyperglycemia.

... I'm going for a birthday, then I want to eat brigadeiro (laughs), then if I'm going to a party, I take my device and my insulin... there's a sweet that I might need and the food hasn't been served yet... (Marlene).

With regard to the subcategory "use of insulin", the participants reported a routine well adapted to the use of insulin, knowledge about the different types of insulin used (prandial and basal), as well as recognition of the importance of the use of insulin in promoting health.

... I've never stopped using it...because whoever does, the consequences are very bad, right?! ...I have to take it, the doctor says it's for my own good...it's to improve my life, so I'll take it. (Joana).

Difficulties related to insulin use

In addition to the difficulties already mentioned, there were also difficulties related to the use of insulin, such as the challenge of mimicking the role of endogenous insulin with applications, finding an insulin with which the body adapts better and defining the right dose to control blood glucose with minimal fluctuations.

... sometimes I take the dosage that the doctor tells me to, then it seems like I'm drinking water, right? and then it kicks in and gives me hypoglycemia? I've already changed insulin that the doctor told me to change, but then it was worse, I had to go back to the old one again, my body didn't adapt to it... (Sara).

One participant reported that she did not know how to transport insulin correctly, because no health professional had given her any advice. Other difficulties included counting carbohydrates, the occurrence of hypoglycemia as a result of insulin use, remembering to use insulin at the correct time and taking care when transporting it.

The use of syringes was cited as a difficulty due to the greater social stigma associated with the use of this device compared to insulin pens.

... when you had a bottle of insulin and a syringe, it was very complicated and there's also that stigma of people seeing you with that, of the bouncers at the club looking at you...thinking it's a drug... (Carina).

It has been reported that it is difficult to achieve good glycemic control with NPH (neutral protamine Hagedorn) insulin due to the higher occurrence of hypoglycemia compared to long-acting analogs.

...when I used human insulin, NPH, I had a lot of hypoglycemia in the early hours of the morning...it was terrible... After I started using insulin analogues, which are longer-acting, then this hypoglycemia thing stopped... (Sérgio).

Fear of the needle was a difficulty faced only at the beginning of treatment, which does not rule out the current emotional overload due to the number of pricks the treatment requires.

... ah, so it's the insulin that's pricking me all the time, you know?...I prick myself six times a day...it's a bit complicated, so there are days when I'm like "oh my God, I have to take all of this!?!" (Nicole).

Emotional adaptation

This category grouped together reports involving feelings related to diabetes and the way participants deal emotionally with the disease. It was noted that although all the participants currently live well with and accept the disease, several of them reported anger and difficulty accepting the disease at the beginning of their diagnosis. Lack of acceptance, in turn, implies behaviors that go against self-care, as seen in the following speech.

It's mainly in adolescence and early adulthood, there was a moment of rebellion, and recently there was also a moment of rebellion, because with the increasingly busy routine, you end up forgetting... and one day this forgetfulness becomes chronic... and this will be reflected down the road... (Carina).

Also in this regard, several participants reported being afraid of chronic complications and hypoglycemia, which motivates them to be disciplined with their health.

... I've always been afraid of getting sick in front of other people... So I think that's why I've become more strict... (Joana).

Participants reported not feeling embarrassed when they had to administer insulin or measure blood glucose in public places. Situations in which they felt stigmatized were triggered by society's behaviour and not by the beliefs of the person with diabetes.

...we went to a restaurant and I went to the restroom so I wouldn't have to take insulin in the middle of the restaurant. In the bathroom, a woman made a fuss that I was using drugs. I was very upset that day... (Marlene).

Feelings of guilt over hypoglycemic episodes, the expense of treatment and overeating, as well as embarrassment and anxiety resulting from hypoglycemia were also reported.

... I think I'm irresponsible in this sense, of hypoglycemia, right, which are things I could be more attentive to, in this sense, and sometimes I let happen... (Célia).

... ah, sometimes I feel guilty (...) well I really ate too much, I ate what I shouldn't have, I know it's going to hurt me here... (Sara).

Discussion

Preventing the development and/or delaying the onset of DM complications depends on adherence to treatment and a healthier lifestyle(1). Based on the participants' reports, it was observed that one of the factors influencing them to adhere to self-care behaviors is based on their perception of the severity of the disease and its complications(21-22), as well as recognizing the benefits of adherence to treatment and self-care in controlling the disease and promoting health(22).

The silent characteristic of DM seen as something threatening was mentioned by a participant who had been diagnosed with DM2, in which it is known that the symptoms of hyperglycemia can be milder and may even go unnoticed(1).

DM has also been described as an expensive disease. The expense of treatment is often cited as one of the difficulties faced in managing diabetes(23-24) and can be seen as one of the perceived barriers to adherence to self-care behaviors(21-22). However, it should be noted that in Brazil, access to some medicines and supplies needed to treat DM is guaranteed free of charge by the Unified Health System (SUS), as provided for in Federal Law No. 11,347 of September 27, 2006.

However, the high cost of the disease was not only mentioned in terms of supplies and medicines, but also food. It is important to emphasize that the diet of a person with DM follows similar recommendations to those defined for the general population and it is up to the health professional who accompanies them to define a dietary plan that takes into account not only nutritional needs, but also access to food(1).

Perceptions about the physiological effects of stress on glycemic control, and about the emotional stress that DM brings, identified in this study, are also cited in other studies(23-25). Living with DM can be considered difficult and stressful due to the large number of self-management activities, which can leave people feeling frustrated, overwhelmed and discouraged(26-27). Psychological factors can have both a direct impact on glycemic control, through physiological changes in blood glucose (release of stress hormones) and an indirect impact, by demotivating the individual and reducing adherence to self-care(26,28).

With regard to the diet of people living with DM, most of the participants recognize that there are no dietary restrictions. However, some foods still seem to be seen as "forbidden", even though nowadays there is no longer the concept of a restrictive diet, but rather a healthy and balanced one(1). Health professionals play an important role in deconstructing beliefs that involve the existence of permitted and forbidden foods, which contributes to adherence to nutritional treatment, as well as minimizing judgment about what is eaten.

Furthermore, as some participants pointed out, and in line with current diabetes guidelines(1), strategies such as carbohydrate counting, self-monitoring and insulin dose adjustment can provide greater flexibility in eating, avoiding negative impacts on glycemic control. These strategies, in turn, help to minimize the perception of barriers(21-22) and the limitations associated with diet, since they bring more flexibility and freedom of choice.

Recognizing the importance of physical activity and self-monitoring in the routine of people with DM can be seen in the "perceived benefits" dimension(22), as it is a habit that helps to minimize the threat of DM complications to health. Self-monitoring, however, brings some discomforts and inconveniences such as excessive pricking, pain and injury. Despite these disadvantages, all the participants reported that they tested their blood glucose frequently, inferring that the perceived benefits of this practice outweighed the barriers encountered(22).

It should be emphasized that for self-monitoring to be effective, it is up to the health professional to identify difficulties related to the use of the glucometer, in order to develop educational strategies that provide the patient with the necessary autonomy to use the device correctly(1), especially at the beginning of treatment, when these difficulties may be more common, as identified in this study.

The use of technologies such as the Flash Glucose Monitoring System, in turn, has been associated with improved self-care behaviors(29), as well as improving patient satisfaction with treatment(30), because it reduces the daily number of bites. However, these technologies are not currently available in the Unified Health System (SUS).

The study participants generally recognized that there is no such thing as perfect glycemic control and that you have to know how to deal with fluctuations in blood glucose (hyperglycemia and hypoglycemia). However, one participant reported feeling frustrated by hyperglycemia, which discourages her from carrying out glycemic tests. This report draws attention to the importance of health professionals working not only on the technical and practical knowledge of self-monitoring, but also on the feelings that can be involved with the test results, since frustration can discourage the practice of self-monitoring(31).

Although there is recognition that glycemic fluctuations are part of DM control, they do have an impact on the daily routine, such as compromising sleep quality and productivity in the case of nocturnal hypoglycemia, an association also mentioned in other studies(32-33). Despite these disadvantages, it was observed that experiences with hypoglycemia did not prevent adherence to self-care behaviors that may be associated with the occurrence of hypoglycemia, such as physical activity and the use of insulin(1).

The fear of hypoglycemia, in turn, can cause people with diabetes to adopt behaviors such as decreasing or skipping insulin doses and increasing food intake, as well as being a barrier to not exercising(32,34). However, it was observed that among the participants in this study, the perception of the severity of the chronic complications associated with poor glycemic control outweighed the perception of the dangers of hypoglycemia. Thus, the benefits of using insulin correctly and practicing physical activity seem to outweigh the risks that these practices can have on the occurrence of hypoglycemia.

In relation to special situations, such as eating out or traveling, the participants complained of greater difficulty in glycemic control when meals are not eaten at home, as in these cases the food tends to be fattier. These fluctuations in glycemia are to be expected in these situations, as it is known that protein and fat content can also influence the postprandial glycemic profile(1).

To minimize the impact of these meals on blood glucose, participants recognize the importance of carrying insulin and a glucometer to monitor and control blood glucose. Although this need to carry supplies is not a problem for the participants in this study, for some people, the need for constant planning creates inconvenience and overload(27).

The study participants showed good acceptance of the disease and adherence to treatment. The perception of the benefits of using insulin seems to be associated with the belief that this medication contributes to minimizing the threat of diabetes to health, reinforcing the influence of the perception of the severity and susceptibility of the risks of the disease on the acceptance of the condition and the performance of self-care(22).

Although there is good emotional adaptation to the disease, negative feelings such as guilt, anxiety and embarrassment are part of living with DM on a daily basis. In this context, the importance of psychosocial assessment in the routine care of people living with DM is reinforced, as well as the importance of guiding and implementing interventions that help people not only to solve problems (for example, preventing and correcting hypoglycemia and hyperglycemia), but also to cope emotionally with the variations of the disease(1).

The limitations of this study refer to the sociodemographic characteristics of the participants, all of whom had completed higher education and most of whom (n=10) were women. Higher levels of education and being female are factors often associated with adherence to self-care behaviors(35-37), which may have been reflected in the good adherence to DM self-management activities observed in most of the participants. Although this behavioral profile is not the reality of many people living with diabetes, it was nevertheless observed that the study participants are not exempt from difficulties related to managing the disease on a daily basis. Furthermore, as the interviews were conducted online, it was possible to include participants from different geographical regions of Brazil (South, Southeast, Midwest and Northeast), which allowed us to obtain accounts of experiences with managing DM from different places.

This study contributes to enriching the literature on diabetes education, since by considering the opinions and experiences of people who live with this condition on a daily basis, it gives greater visibility to their beliefs and difficulties, which influence adherence to self-care behaviors and should therefore be considered by health professionals in their educational interventions. However, the uniqueness of each individual is recognized, and it is important to consider their particularities in health promotion and education.

Conclusion

It was possible to understand, from the point of view of those who live with DM on a daily basis, their health care routines, their main difficulties, feelings and emotions involved in managing the disease. Furthermore, from the perspective of the Health Beliefs Model, it can be inferred that the perception of the severity of the disease and its complications, as well as the benefits of adhering to treatment, positively influences adherence to self-care behaviors.

Although the participants in this study have lived with DM for many years, especially since most of them have DM1, the diagnosis of which occurs mainly in childhood and adolescence, it was observed that they are not exempt from difficulties related to insulin use and diabetes management, which reinforces the importance of continuing health education. In this sense, the findings of this study guide important educational themes to be worked on by health professionals to promote autonomy in diabetes self-management, such as knowledge about the disease and its complications, correct practices in insulin use and self-monitoring, how to solve problems and how to adapt emotionally to the daily routine of treatment.

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References

1. Sociedade Brasileira de Diabetes. Diretrizes Sociedade Brasileira de Diabetes 2019-2020. São Paulo: Editora Clannad; 2020.

2. Reis P, Marcon SS, Nass EMA, Arruda GO, Back IR, Lino IGT, et al. Performance of people with diabetes mellitus under insulin therapy. Cogitare Enferm. 2020;25:e66006. https://doi.org/10.5380/ce.v25i0.66006

3. Castro PC, Ribeiro TS, Faraoni AG, Matumoto S, Souza FB, Viana AL. Insulin self-application in adults with diabetes mellitus in the home contexto. Rev Mineira Enferm. 2022;26:1-10. https://doi.org/10.35699/2316-9389.2022.38799

4. Santos WP, Sousa MM, Gouveia BLA, Soares MJG, Almeida AM, Oliveira SHS. Factors related to tissue complications resulting from insulin therapy: a cross-sectional study. Rev Esc Enferm USP. 2022;56:1-8. https://doi.org/10.1590/1980-220X-REEUSP-2021-0249

5. Association of Diabetes Care and Education Specialists. An Effective Model of Diabetes Care and Education: The ADCES7 Self-Care Behaviors™. Sci Diabetes Self Manag Care. 2021;47(1):30-53. https://doi.org/10.1177/0145721720978154

6. American Diabetes Association. Standards of Care in Diabetes. Diabetes Care. 2023;46(Supplement_1). https://doi.org/10.2337/dc23-Sint

7. Zanatta EA, Scaratti M, Argenta C, Barichello A. Experiences of adolescents with type 1 diabetes. Rev Baiana Enferm. 2020;(4):1-7. https://doi.org/10.18471/rbe.v36.46696

8. Batista AFMB, Nóbrega VM, Fernandes LTB, Vaz EMC, Gomes GLL, Collet N. Self-management support of adolescents with type 1 Diabetes Mellitus in the light of healthcare management. Rev Bras Enferm. 2021;74(3). https://doi.org/10.1590/0034-7167-2020-1252

9. Aguiar GB, Machado MED, Silva LF, Aguiar RCB, Christoffel MM. Children with type 1 diabetes mellitus: the experience of disease. Rev Esc Enfermagem USP. 2021;55:1-8. https://doi.org/10.1590/S1980-220X2020011803725

10. Silva CV, Bird D, Clemensen J, Janda M, Catapan SC, Fatehi F, et al. A qualitative analysis of the needs and wishes of people with type 2 diabetes and healthcare professionals for optimal diabetes care. Diabetic Med. 2022;39(9):1-20. https://doi.org/10.1111/dme.14886

11. Macedo JCL, Soares DA, Carvalho VCHDS, Cortes TBA, Mistro S, Kochergin CN, et al. Self-Care in patients with non-Optimal diabetes management in Brazilian rural areas: a mixed-methods study. Patient Prefer Adherence. 2022;16:1831-42. https://doi.org/10.2147/PPA.S373302

12. Barichello A, Scaratti M, Argenta C, Zanatta EA. Experiences of family members of adolescents diagnosed with type 1 diabetes mellitus: coexistence, care and changes. Rev Baiana Enferm. 2022;36:e46696. https://doi.org/10.18471/rbe.v36.46696

13. Gouveia BLA, Sousa MM, Almeida TCF, Sousa VAG, Oliveira SHDS. Beliefs related to insulin use in people with Type 2 Diabetes Mellitus. Rev Bras Enferm. 2020;73(3):1-8. https://doi.org/10.1590/0034-7167-2019-0029

14. Lopes GSG, Rolim ILTP. Diabetic foot: social representations about the experiences of people with diabetes mellitus. Texto Contexto Enferm. 2022;31. https://doi.org/10.1590/1980-265X-TCE-2021-0115

15. Pecoli PFG, Rosa AS, Gabbay MAL, Dib SA. Psycho-behavioral characteristics perceived as facilitators by brazilian adults with type 1 diabetes mellitus in a public health service. Healthcare. 2023;11(16). https://doi.org/10.3390/healthcare11162300

16. Renjith V, Yesodharan R, Noronha J, Ladd E, George A. Qualitative methods in health care research. Int J Prev Med [Internet]. 2021 [cited 2023 Aug 11];12(20). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8106287/pdf/IJPVM-12-20.pdf

17. Fontanella BJB, Ricas J, Turato ER. Amostragem por saturação em pesquisas qualitativas em saúde: contribuições teóricas. Cad Saude Publica. 2008;24(1):17-27. https://doi.org/10.1590/S0102-311X2008000100003

18. Busetto L, Wick W, Gumbinger C. How to use and assess qualitative research methods. Neurol Res Pract. 2020;2(1). https://doi.org/10.1186/s42466-020-00059-z

19. Minayo MCS, Gomes SFDR. Pesquisa social: teoria, método e criatividade. 26. ed. Petrópolis: Editora Vozes; 2007.

20. ATLAS.ti Scientific Software Development GmbH. ATLAS.ti Software. Version 1.9.7.0 [Homepage]. c2024 [cited 2022 Dec 13]. Available from: https://atlasti.com/pt

21. Rosenstock IM. Historical Origins of the Health Belief Model. Health Educ Monogr [Internet]. 1974 [cited 2023 Aug 11];2(4):328-35. Available from: https://www.jstor.org/stable/45240621

22. Rosenstock IM. Understanding and enhancing patient compliance with diabetic regimens. Diabetes Care. 1985;8(6):610-6. https://doi.org/10.2337/diacare.8.6.610

23. Adler AJ, Trujillo C, Schwartz L, Drown L, Pierre J, Noble C, et al. Experience of living with type 1 diabetes in a low-income country: a qualitative study from Liberia. BMJ Open. 2021;11(10):e049738. https://doi.org/10.1136/bmjopen-2021-049738

24. Davoodi M, Dindamal B, Dargahi H, Faraji-Khiavi F. A phenomenological study on barriers of adherence to medical advice among type 2 diabetic patients. BMC Endocr Disord. 2022;22(1):18. https://doi.org/10.1186/s12902-021-00928-x

25. Taumoepeau J, Knight-Agarwal CR, Tu'i ' Esiteli AP, Jani R, Osuagwu UL, Simmons D. Living with type 2 diabetes mellitus in the Kingdom of Tonga: a qualitative investigation of the barriers and enablers to lifestyle management. BMC Public Health. 2021;21(1):1307. https://doi.org/10.1186/s12889-021-11391-7

26. Fayed A, AlRadini F, Alzuhairi RM, Aljuhani AE, Alrashid HR, Alwazae MM, et al. Relation between diabetes related distress and glycemic control: The mediating effect of adherence to treatment. Prim Care Diabetes. 2022;16(2):293-300. https://doi.org/10.1016/j.pcd.2021.12.004

27. Orben K, Ritholz MD, McCalla M, Beverly EA. Differences and similarities in the experience of living with diabetes distress: A qualitative study of adults with type 1 and type 2 diabetes. Diabetic Med. 2022;39(10). https://doi.org/10.1111/dme.14919

28. Skinner TC, Joensen L, Parkin T. Twenty-five years of diabetes distress research. Diabetic Med. 2019; 37(3):393-400. https://doi.org/10.1111/dme.14157

29. Hayek AA, Robert AA, Dawish MA. Impact of the FreeStyle Libre flash glucose monitoring system on diabetes-self-management practices and glycemic control among patients with type 2 diabetes in Saudi Arabia: A prospective study. Diabetes Metab Syndr. 2021;15(2):557-63. https://doi.org/10.1016/j.dsx.2021.02.027

30. Hayek, AA, Dawish MA. The potential impact of the FreeStyle Libre Flash Glucose Monitoring System on mental well-being and treatment satisfaction in patients with type 1 diabetes: a prospective study. Diabetes Ther. 2019;10:1239-48. https://doi.org/10.1007/s13300-019-0616-4

31. Liang W, Lo SHS, Chow KM, Zhong J, Ni X. Perception of self-management and glycaemic control in people with type 2 diabetes receiving insulin injection therapy: a qualitative study. Prim Care Diabetes. 2023;17(6):587-94. https://doi.org/10.1016/j.pcd.2023.08.006

32. Chatwin H, Broadley M, Jensen MV, Hendrieckx C, Carlton J, Heller S, et al. "Never again will I be carefree": A qualitative study of the impact of hypoglycemia on quality of life among adults with type 1 diabetes. BMJ Open Diabetes Res Care. 2021;9(1):e002322. https://doi.org/10.1136/bmjdrc-2021-002322

33. Zhu B, Irsheed GMA, Martyn-Nemeth P, Reutrakul S. Type 1 Diabetes, Sleep, and Hypoglycemia. Curr Diab Rep. 2021;21(12). https://doi.org/10.1007/s11892-021-01424-1

34. Pang J, Zhang L, Li X, Sun F, Qiu J, Zhao Y, et al. Identification of factors associated with fear of hypoglycemia using the capability, opportunity, motivation and behavior model in people with type 2 diabetes mellitus: a cross-sectional study. Acta Diabetol. 2023;60(10):1405-15. https://doi.org/10.1007/s00592-023-02132-w

35. Peres GB, Nucci LB, Andrade ALM, Enes CC. Lifestyle behaviors and associated factors among individuals with diabetes in Brazil: a latent class analysis approach. Cien Saude Colet. 2023;28(7):1983-92. https://doi.org/10.1590/1413-81232023287.05622022

36. Skriver LKL, Nielsen MW, Walther S, Nørlev JD, Hangaard S. Factors associated with adherence or nonadherence to insulin therapy among adults with type 2 diabetes mellitus: a scoping review. J Diabetes Complications. 2023;37(10):108596. https://doi.org/10.1016/j.jdiacomp.2023.108596

37. Portela RA, Silva JRS, Nunes FBBF, Lopes MLH, Batista RFL, Silva ACO. Diabetes mellitus type 2: factors related to adherence to self-care. Rev Bras Enferm. 2022;75(4). https://doi.org/10.1590/0034-7167-2021-0260

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