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Self-care and perception of the diabetes treatment by people using insulin

Autocuidado e percepção do tratamento para o diabetes por pessoas em uso de insulina Autocuidado y percepción del tratamiento de la diabetes por personas que usan insulina

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Abstract: Objective: to understand the perception of people with Diabetes Mellitus using insulin about their self-care and the repercussion of treatment in their daily lives. **Method:** exploratory and descriptive research, with a qualitative nature, performed in a medium-sized municipality in the Southern Region of Brazil, with 16 people using insulin who were being monitored in Primary Care. Data were collected from May to July 2017, through semi-structured interviews and submitted to thematic analysis. **Results:** it gave rise to three categories that address the difficulties in changing life habits, the repercussions of insulin use in daily life and the obstacles experienced in the purchase of pharmaceutical inputs for treatment. **Conclusion:** the practice of self-care by people with Diabetes Mellitus using insulin is permeated by several difficulties, where the main one is the need for changes in lifestyle. **Descriptors:** Diabetes Mellitus; Insulin; Self-care; Primary Health Care; Nursing

Resumo : Objetivo: apreender a percepção de pessoas com Diabetes Mellitus em uso de insulina sobre seu autocuidado e repercussão do tratamento em seu cotidiano. **Método:** pesquisa descritiva exploratória de natureza qualitativa, realizada em município de médio porte da Região Sul do Brasil, com 16 pessoas em uso de insulina que faziam acompanhamento na Atenção Primária. Os dados foram coletados no período de maio a julho de 2017, por meio de entrevista semiestruturada e submetidos à análise temática. **Resultados:** emergiram três categorias que abordam as dificuldades em mudar hábitos de vida, as repercussões do uso de insulina na vida cotidiana e os entraves vivenciados na aquisição dos insumos farmacêuticos para o tratamento. **Conclusão:** a prática do

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autocuidado, por pessoas com Diabetes Mellitus em uso de insulina, é permeada por diversas dificuldades, e a principal delas é a necessidade de mudanças no estilo de vida. **Descritores**: Diabetes Mellitus; Insulina; Autocuidado; Atenção Primária à Saúde; Enfermagem

Resumen: Objetivo: comprender la percepción de las personas con Diabetes Mellitus que usan insulina sobre su autocuidado y la repercusión del tratamiento en su cotidiano. Método: investigación descriptiva y exploratoria, de carácter cualitativo, realizada en un ayuntamiento de tamaño medio en la Región Sur de Brasil, con 16 personas que usaban insulina y que estaban siendo monitoreadas en la Atención Primaria. Los datos se recopilaron de mayo a julio de 2017, mediante entrevistas semiestructuradas y se sometieron al análisis temático. Resultados: surgieron tres categorías que abordan las dificultades para cambiar los hábitos de vida, las repercusiones del uso de insulina en la vida cotidiana y los obstáculos experimentados en la adquisición de insumos farmacéuticos para el tratamiento. Conclusión: la práctica del autocuidado por personas con diabetes mellitus que usan insulina está impregnada de varias dificultades, donde la principal es la necesidad de cambios en el estilo de vida. Descriptores: Diabetes Mellitus; Insulina; Autocuidado; Atención Primaria de Salud; Enfermería

Introduction

Diabetes Mellitus (DM), even though it is an ancient disease, with established pathophysiology and many preventable triggering factors, remains a global epidemic. The worldwide prevalence of DM almost doubled from 1980 to 2014, having increased from 4.7% to 8.5% in the adult population. It is estimated that there will be 642 million adults worldwide with DM in 2040, with 48.8 million living in Central and Latin Americas.¹

If not controlled, DM can trigger various health complications and increase the risk of early death.¹ The lack of access to medicines is still considered one of the challenges to be faced, but the success of the treatment of this disease also depends on non-pharmacological measures related to changes in lifestyle. The adoption of healthy habits – adequate nutrition, regular physical exercise and continuous and regular use of medicines – can result in clinical control, with improvement of symptoms and delay of complications.²

This individual behavior in relation to health has been defined as self-care, which was properly defined and explained by the Nursing theorist Dorothea Orem, in her theory entitled Self-Care Deficit Theory.³ According to Orem, self-care is the practice of care, deliberately, by the person, especially the one with some need, in order to maintain his/her own health and well-being.³

Accordingly, what differentiates human beings from other living beings is their ability to reflect on themselves and their environment, and, from there, take beneficial actions for themselves and others.³

Self-care practices are affected by biological factors, the health system and also by sociocultural factors, so that many people do not have habits considered healthy.⁴ Even people who already have some health problem, find it difficult to adhere to treatment, mainly in relation to changes in lifestyle, that is, they have a deficit of self-care, which raises the need for support from health professionals, especially nursing workers.³

In Primary Health Care (PHC), the nursing team acts directly with the community, being very close to users and families, which contributes to achieving more effective health education actions for self-care.⁵ When implementing these actions, we should take into account the person's health beliefs, his/her cultural and intellectual reality, physical limitations, emotional concerns, family support, financial situation, health history and other factors that can influence the ability of individuals to put self-care into practice.⁶

Knowing the way in which people with DM using insulin put into practice the proposed therapeutic plan, and how much they relate their behavior to disease control, can support health actions to be implemented with them. Based on these assumptions, we elaborated the following research question: "What is the perception that people with DM using insulin have about their self-care and how does the treatment impact their daily lives?". In order to answer it, we defined the objective of this study: to understand the perception of people with DM using insulin about their self-care and the repercussion of treatment in their daily lives.

Method

This is a qualitative, exploratory and descriptive research, which was performed in a medium-sized municipality in Rio Grande do Sul, with people with DM, using insulin, who were being monitored in PHC.

Participants were selected for convenience among those who participated in a quantitative research performed with 168 individuals who were using insulin.⁷ People who had time to be interviewed and willingness to talk about the topic were invited to participate. In the primary study, individuals under 18 years old and people with cognitive limitations and/or impaired verbal communication were excluded. For the latter, those who depended on caregivers for insulin administration were also excluded. The number of participants was defined based on the data saturation criterion. Therefore, the search for new informants was completed when the speeches started to become repetitive.⁸

The initial approach to the participants and the invitation to participate in the research were held during a home visit with the Community Health Worker (CHW). Data were collected from May to July 2017, through semi-structured audio-recorded interviews, with the participants' consent. All approaches and interviews were conducted by the first author, who is a nurse and was studying for a master's degree in nursing. The interviews lasted an average of 45 minutes and were conducted in the participants' homes, right after the data collection of the first stage of the quantitative research. In most cases, the participant was alone at home or in the company of the spouse, and the spouse was present in the same environment, but did not participate in the interview. As personal issues were not addressed, there was no concern with family secrecy.

All interviews were transcribed in full and the material submitted to thematic analysis.⁹ This methodology involved three stages: pre-analysis, where comprehensive reading of the content was carried out in an exhaustive manner; exploration of the material, with identification and problematization of the implicit and explicit ideas in the text, based on the criteria of

representativeness, completeness, homogeneity and pertinence to identify the units of records, and subsequent grouping by themes found; and, finally, elaboration of the interpretative synthesis.

This analytical process gave rise to three categories: "The (im) possible change in lifestyle"; "Repercussions of insulin use in daily life"; and "Access to pharmaceutical supplies: reality and adaptation". The development of the study complied with the national requirements for research involving human beings, having been approved by the Research Ethics Committee with Human Beings (Opinion number 1.889.132), on January 11th, 2017. The participants signed the Free and Informed Consent Form in two copies, after reading it and clarifying doubts together with the researcher. In order to preserve the participants' identity, their statements were identified by letters of the alphabet in the sequence of the interviews, followed by the age indicator number (for example: E, 71; F, 50).

Results

The study had the participation of 16 people with type 2 Diabetes Mellitus (DM2) using insulin, aged between 46 and 77 years old, family income of one to two minimum wages (corresponding to 937.00 in 2017) and time of insulin use between 01 and 18 years. The three categories arisen from the analysis process are presented below.

The (im) possible change in lifestyle

The reports allowed us to identify that, in the participants' perception, the biggest obstacle to self-care refers to non-drug treatment, especially in the adoption of healthy habits related to food and physical exercise.

It's easier to do the medicine, because taking care of the food, I'm not 100%. Because I think nobody is 100%. (F, 50)

Taking a remedy is easy. The other care that is more hard. (K, 46)

Yes, I take care of myself, I take everything rightly. However, the food doesn't work. Will we always eat the same thing?!(E, 72)

It is often a challenge to maintain a different diet from the rest of the family and participate in social events – parties or reception of visits – without sharing the same menu.

If there's candy in front of me, I eat it. Because they buy [family]. Just living alone to be able to keep my scheme. (N, 54)

As for the diet, I'm a little neglected. When there's a visit, I go off the diet. I can't run out of candies, while watching others eat them [...] I eat too! (F, 50)

The problem can be aggravated when the person with DM is responsible for preparing the family's food, even when he/she is aware of the importance of treatment to control the disease.

> I prepare the food very well. There are days when I put it on the table, but the Family says: "Gosh! What a bad food"! But it's good for health, you have to do your best, because if you wanna live a few more days [...] because diabetes kills! (H, 52)

The financial issue was also reported as an obstacle to adherence to some guidelines, especially those related to food.

I eat greens; when there is, I eat a lot of greens. (A, 53)

It's not difficult to follow everything that she [nutritionist] asks for, if the person has money. If the person has the opportunity to have everything she explains to eat, we even hold it. (L,59)

I think it's even impossible to eat rightly, mainly for people who can't afford it. Because they [health professionals] say: "then you have to buy this, that" but we can't manage this situation, because it's expensive. (P, 59)

Moreover, we found that the momentary control of glycemic levels and symptoms of the

disease, provided by the insulin use, can trigger the abandonment of non-drug treatment.

I'm eating normally. At the beginning, it attacked me and then I made a scheme over the script. I ate almost only greens. Therefore, I even went to a doctor, she congratulated me because everything was nice. After I got better with insulin, I started to eat everything again. I'm not taking care of the food. (N, 54)

Conversely, some people reported that they are aware of the fact that their health status depends on them.

I see people, even younger than me, that, for God's sake! They're there with their bellies [...] then they say, "Ah, but I have diabetes, I can't do it [...]". That doesn't justify! But we're going to do something to make it better. (C, 61)

It's no use to run away, [taking care of yourself] *is something you always have to hold, whether you want to or not, you have to do it! I know about it.* (F, 50)

In these cases, self-help mechanisms are created to facilitate treatment. The physical exercise practice, for example, can be related to something that generates pleasure, a motivation.

But you have to find something to do that you can work out, a good thing, that you like. If you're going to work out without purpose, you end up settling down. You think [...] "I walked more than an hour, I went further yesterday, oh [...] today you don't need it". Now, if you have a joyful commitment [...] (C, 61) Conversely, the lack of knowledge about the disease can hinder treatment, as observed in the case of a participant who had limitations/difficulties in recognizing the disease complications.

> The corner of the nail in my finger is hurt, then I put on my boots to go to work and got infected. Nevertheless, it was not due to diabetes, because the wound healed after the foot was amputated, and the diabetes doesn't heal, then my foot wound is not due to diabetes. (L, 59)

In other cases, the lack of guidance can result in the inappropriate and even dangerous use of medicines. One of the participants reported that, for five years, he used NPH (Neutral Protamine Hagedorn – intermediate action speed) and regular (fast action) insulins, which caused fluctuations between episodes of hyper and hypoglycemia.

> It's good to know, because, before, I had done it wrong for over five years. Why? Because of the lack of guidance. For me, regular [insulin] was supposed to make it regular, stable. I was taking the usual NPH dose [and vice versa], on the same day, I got sick and it was going down a lot, but soon It was up there again! It was a sort of hell. It took five years for someone to notice that I was holding it contrary to the standards. (G, 61)

In this specific case, the lack of guidance about the right use of drug treatment resulted in unmanageable glycemic control for a long time.

Repercussions of insulin use in daily life

The participants recognize that the insulin use provided an improvement in glycemic control, but they emphasize that, at the beginning of treatment, the need for subcutaneous administration of the medicine represented a challenge.

At the beginning, I screwed up. Then I got a little used to the idea, but at first it was a panic of the worst in the world. I've always had a needle-related panic. (N, 54)

I wasn't excited to do it, I was very afraid of the injection [insulin]. (J,58)

At first it was hard, it took time for me to accept the bite every day. Now, for me, it's simple. (E,72)

In any case, people perceive that the benefits of treatment outweigh the difficulties and

fears.

With insulin, I returned to my usual life. (J, 58)

For me, using insulin was easy, because my health improved. There was a time when I was unable to extend a clothesline, because I got tired. However, it has been controlled. I have never been bothered again. (K, 46)

Previously, I was under observation in the emergency room all day, it was about four times, because it went up too much [blood glucose]. After this insulin use, I don't need to come back to the hospital again. (E, 72)

The difficulty regarding the self-administration of insulin was experienced by some people, who recognize that overcoming this obstacle facilitates the continuity and regularity of treatment.

The bad thing about managing insulin was that I didn't use it at the beggining, then I always had to wait for my sister, who sometimes couldn't, so I didn't do it. That's why it was a little out of control. But, one day, I had no one to do it, then I said: "I have to do it." Therefore, the girls from the health center taught me and now I do it calmly. (J, 58)

Currently, I do that myself, I'm not afraid of bites anymore. (E, 72)

The need to use insulin is sometimes perceived as a negative consequence, a kind of punishment for irregular adherence to the proposed treatment, mainly in relation to changes in lifestyle.

I was warned when it appeared: "For now, you don't need it, but if you don't take care of yourself, you'll use insulin". Sometimes, we mess it up, exaggerate a little and then we need [...] I had to use insulin. (P, 59)

The kidney got complicated because of DM and high blood pressure. Now I undergo hemodialysis. This is a prison for me. I can't travel, I can't eat what I want. I see that, if I was careful before, it wouldn't have costs! (M, 55)

Conversely, in some cases, it is precisely the fear of disease complications that encourages the right use and acceptance of insulin treatment.

I didn't want to take insulin, but, if I don't, I'm afraid to see my kidneys stopped, then I'll have to undergo dialysis. (B, 77)

I undergo insulin properly, because it's for my health; I have to do it rightly, otherwise the things will get complicated. It's bad to be sick, that's true. (H, 52)

I have a vision problem; in the kidneys too. I had amputation on the left foot, a single toe, and on the right foot. Sometimes, I have a fever, which comes from the diabetic foot infection, I tremble a lot. There's no way, I've to use insulin. (A, 53)

The reports showed that the knowledge about specific cases of damage resulting from DM constitutes a positive motivation for the adoption of self-care behaviors.

Access to pharmaceutical supplies: reality and adaptation

In the municipality under study, we found that access to supplies – syringes, needles, reagent strips and glucometers – does not happen properly.

Material is precarious. Nevertheless, we always earn insulin. Sometimes, we don't earn there at the [municipal] pharmacy, but then at the pharmacies in the center, there is [from the program "Aqui tem farmácia popular"]. However, they do not give syringes and needles. (F, 50)

It's difficult to get the strips [hemoglycotest tapes – HGT], *it's supposed to be 100 strips per month, but they only give 50 strips, which is not enough. The syringe is also being a problem.* (G, 61)

I'm having difficulty with the device, which is the syringe. I went there [municipal pharmacy], but she said she didn't even know the day on which it was coming. (D, 56)

The material is very difficult. You go there [...] I went to the health department three times last month, but there is nothing there. They just say they don't have it. However, we earn just a little Money; then, buying is difficult. (K, 46)

In this context, some people reported that the need to purchase specific materials for their treatment compromises the family budget.

Every now and then, I have to buy a syringe, and that's why I've already spent about R\$ 300 on remedies. (Q, 55)

We've to buy, because we need it. What will I do? Going without doing isn't enough. However, we can manage [...] a little money here, a little money there [...]. (B, 77)

Because we can still buy, [...] we'll miss this bucks elsewhere, but we can buy. Nonetheless, who doesn't have any income, then will buy how? (K, 46)

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In cases where the patient's financial conditions are more precarious, treatment is no longer followed, or reuse of syringes and needles happens inappropriately.

> In our city, even the syringe we need isn't available, we've to buy it. Sometimes, we don't have financial conditions. (A, 53)

> I earn material when it's available. When the material is unavailable, we must be patient, what should I do? Sometimes, I end up not taking the insulin!(D, 56)

As for the syringes and needles that I'm not getting at the post, I'm buying them. Therefore, I use the same one more [...] sometimes more than a week. (I, 58)

Finally, we can observe that the materials freely provided by the municipal government do not always meet the users' needs in the best way. Accordingly, when they need to buy, those who have greater economic conditions, choose materials that cause less damage to the skin.

Therefore, I buy the thinner needle. It's better, it's doesn't leave my skin as purple as the municipal one. (O, 67)

We should highlight that the users' comfort in the administration of insulin can reflect even in adherence to treatment, because, at the beginning, the feeling of fear is common, which may be intensified by discomfort.

Discussion

The difficulty of self-care, mainly related to non-drug treatment, an aspect addressed in the first category, is not a strictly Brazilian reality. A study performed in the Netherlands found that both people with DM and the professionals who assisted them perceived that adherence to medicines and to a healthy lifestyle was not adequate.¹⁰ Accordingly, the difficulty in including self-care practices in the routine brings damage to health, because changes in eating habits and physical activity directly interfere with quality of life.¹¹

Despite the difficulties reported in the implementing of some care, it was possible to notice that most of the participants had knowledge, even if superficial, about the healthy lifestyle habits that they should adopt. In this sense, in a study performed with 13 elderly people with DM, in Sobral, Ceará, the reports revealed that many understood the need for differentiated care in the face of their disease, with changes in their lifestyle, such as the adoption of healthy eating habits and physical activity; however, they did not understand the disease satisfactorily, which may have made adherence to care difficult.⁵

We should underline that health education and regular monitoring with a health professional have the potential to change this reality. A clinical trial study involving 183 users of the Brazilian Unified Health System, with DM2, observed that the group that received the intervention consisting of group educational practice showed an increase in participation in the management of the condition, the empowerment and the adherence to self-care practices, mainly in relation to healthy eating and physical exercise practice. These changes resulted in a statistically significant reduction in glycated hemoglobin levels.¹²

The difficulty in making dietary changes due to financial issues has already been pointed out in a study performed in the state of Bahia, with 56 people assisted in the HIPERDIA program (Registration and Monitoring System for Hypertensive and Diabetics patients), which found a significant relationship between low income and difficulties to implement dietary changes.¹¹ In this sense, an intervention study through nursing consultation based on supported self-care, stated: when health professionals do not consider the individual's financial condition for health guidelines, they create an obstacle to the accomplishment of self-care.¹³

Family support also plays a significant role in food control and DM self-care. This is because the encouragement of close people facilitates adaptation and cooperates for successful treatment.¹⁴ Moreover, social support from family, friends and the community can strengthen the determination, belief and confidence in self-management of the health condition and, consequently, improve glycemic control and quality of life.¹⁵

Physical exercise was recognized by few participants as part of the DM treatment and only one did it regularly, which corroborates the results of a study that found that physical inactivity is a habitual behavior in this population.¹⁶ The regular practice of physical activity is associated with the control of blood glucose levels. In this sense, the inclusion of physical educators in the multiprofessional health care team can contribute to a better adherence to treatment.¹⁷

Support for people with DM is one of the PHC goals, which seeks, with its actions, to prevent complications of this disease. The lack of knowledge about the disease and treatment is an obstacle to a better quality of life, where PHC professionals are primarily responsible for minimizing this problem. Nurses have a fundamental role in guiding, educating and monitoring people in the self-care process.¹⁴ In this sense, the lack of motivation and involvement on the part of patients in the treatment is also the responsibility of health professionals, who should help them in decision making and in the establishment of achievable goals.¹⁰ The engagement of the multiprofessional team in educational, dynamic, attractive and interactive activities may entail a positive impact on the success of the treatment and its maintenance, an important factor in the case of chronic conditions such as DM.¹⁸

The changes resulting from insulin treatment may generate emotional stress.¹⁹ In the present study, feelings of fear of treatment and guilt for the possible lack of previous care were the cause of the need to use insulin. In China, a relationship was identified between the beginning of insulin use and negative emotions, highlighting the fear of the needle and the pain during administration, factors that led to less motivation to accept the treatment.¹⁹

In Blumenau, Santa Catarina, 196 people with DM were evaluated and it was found that those using insulin were 1.8 times more likely to develop severe mental distress, despite the fact that the majority believed in the clinical efficacy of insulin.²⁰ Accordingly, patient-centered care strategies and interventions that help recognize fears and demystify insulin use are essential before treatment begins.¹⁹ Moreover, dependence on others for insulin administration can cause treatment failures and anxiety.¹⁵ Therefore, self-care empowerment results in independence and increases the chances of success in insulin therapy.²¹

In the DM context, the people's relationship with their own bodies and the world around them undergoes changes, as the conflict between having desires that are inappropriate for health and the need to control them is always present.²² Unfortunately, in most cases, the guidelines about healthy lifestyle for people with DM are more strictly followed when the losses of the disease are already experienced.

In addition to these issues, we should highlight that, for adequate adherence to drug treatment, it is important to have the material necessary for the DM treatment. This availability becomes more relevant in cases of low-income population, as this factor is related to a greater deficit in health knowledge and less adherence to self-care habits.²³

One of the consequences of the lack of adequate supplies for insulin administration is the practice of reusing syringes and needles, which should be for single use. According to studies performed in Brazilian municipalities, reuse is a common practice, reaching 72% in Picos, Piauí, ²⁴ and over 90% in Parobé, Rio Grande do Sul.⁷ Despite the favorable position of the Brazilian Ministry of Health to the reuse of syringes and needles (up to eight times, if maintained in adequate conditions), this practice may be harmful to the skin, with an increase in the occurrence of lipodystrophy, besides the risk of administering wrong doses due to the disappearance of the marks printed on the syringe body with the handling.²⁴

In Brazil, the *Farmácia Popular* Program freely distributes medicines for some chronic diseases, including DM, which mainly benefits segments of the population with lower socioeconomic levels.²⁵ In addition to medicines, Ordinance nº 1.555/2013 also ensures access to pharmaceutical inputs necessary for monitoring blood glucose and insulin application, ²⁵ but the results of this study show that this right is not fully respected; at least, it is not respected in the municipality under study.

Moreover, the quality of the material may favor or hinder the right insulin use. The use of smaller diameter needles, besides reducing the occurrence of bruises, mitigates pain when it is introduced, which makes the treatment less uncomfortable.²⁶ We should highlight that the length of the needles may also affect insulin absorption, since long needles predispose to the risk of intramuscular administration.²⁷

A review study about the right insulin administration technique, whose results were validated by 183 diabetes specialists from 54 countries, recommended the use of shorter needles (4 and 6 mm) as the first choice for all individuals, regardless of the thickness of subcutaneous fat, in order to avoid intramuscular administration.²⁷ This recommendation, however, is not always followed, since public purchases depend on bids, with lower priced products being approved, which, occasionally, may compromise the quality of the purchased materials,²⁸ in addition to not always meeting the users' needs in the best way.

Possible limitations of the study are related to the type of adopted methodology, as the results represent the self-care practice of a group of people with diabetes using insulin, with specific socioeconomic characteristics (most elderly and with low income), inserted in given assistance and cultural context in Southern Brazil. Moreover, the fact that the interview was conducted by a nurse may have embarrassed the participants in terms of openly speaking about self-care practices recognized by them, but neglected in their routines. Anyway, the results allow us to know important aspects that permeate this practice at home.

Conclusion

The results showed that the practice of self-care by people with DM, using insulin, is permeated by several difficulties. Participants highlighted that, in most cases, the beginning of insulin use is accompanied by negative feelings, as it is an uncomfortable procedure and can cause pain. In addition to fears in the use of medicines, another obstacle to proper use is the lack of material for treatment, since it was identified that the reuse of syringes/needles is a practice commonly used by the people with DM under study. However, it was identified that the greatest obstacle to adequate self-care is the need for changes in lifestyle.

As the study was performed in a single municipality, and considering the fact that Brazil has an extensive territory and with cultural diversity, it is recommended to develop similar investigations in other locations, in order to obtain diversified and sufficient data to subsidize the elaboration of more comprehensive health policies and appropriate to different settings.

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