The knowledge of adolescents with type 1 Diabetes Mellitus about their self-care

O conhecimento de adolescentes com Diabetes Mellitus tipo 1 sobre o seu autocuidado

El conocimiento de adolescentes con Diabetes Mellitus Tipo 1 sobre su autocuidado

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Objective: to identify the self-care actions of adolescents with Type 1 Diabetes Mellitus. Methods: qualitative study, carried out between 2019 and 2020, using the dynamics of creativity and body-knowledge sensitivity, in the pediatric endocrinology outpatient clinic of a university hospital in the Brazilian Federal District, DF, Brazil. Data were transcribed and subjected to thematic analysis. Results: 12 adolescents participated, of which 10 were male, seven were 15 years old, six were in elementary school and five were in high school. On previous hospitalizations, five of them hospitalized only once and five between two to five times. Six thematic categories were identified: (Lack of) Care with Food; (Lack of) Control of glycemic levels; (Lack of) Knowledge of the signs and symptoms of altered glycemia and strategies for control; Drug care; Physical activity; and Self-care in the school context. Conclusion: adolescents with Diabetes Mellitus 1 had adequate knowledge about self-care, but showed difficulties in performing the treatment. The role of the nurse is fundamental, not only in health education actions, but also in qualified listening, taking into account the individuality and the moment of each adolescent.

Descriptors: Adolescent; Diabetes mellitus, Type 1; Self care; Knowledge.
INTRODUCTION

Diabetes mellitus (DM) is an acquired and/or hereditary chronic disease in which the hormone insulin is poorly produced, is not efficient or is not synthesized by the body due to cellular resistance, which in turn leads to hyperglycemia, which consists of high concentration of glucose in the blood and, consequently, harms other systems of the body.

There are several types of DM, including type 1 diabetes mellitus (DM1), an autoimmune disease that usually manifests in childhood or adolescence, but can also develop in young adults. It is characterized by the immune system attacking the beta cells of the pancreas, which are responsible for the production of insulin. Faced with the change in insulin production, sometimes little or no amount is secreted in the body, people with DM can develop several complications, especially when there is no adequate control.

One of the actions to prevent complications is blood glucose control, which is directly related to adherence to treatment and, therefore, to self-care. According to the Self-Care Deficit Theory, self-care can be defined as the knowledge that an individual possesses and their ability to manage their own human development and functioning. It is the conduct that an individual intentionally assumes to preserve and guarantee their growth, development, human integrity and continuity of life.

A study pointed out that adolescents with DM1 made mistakes that could impair their self-care process and increase the risk of long-term complications. Another study showed that the self-management of the disease is associated with significant clinical differences, so making an intervention on self-management can improve diabetes control and, consequently, improve quality of life.

Adolescence is a period of transition from childhood to adulthood; it is a developmental moment in which the subject undergoes several transformations, both physical and psychological, and chronic illness can cause many changes in the adolescent’s daily life, imposing a readaptation through treatment, and thus, a new routine.

Adolescence is a phase that involves complex developmental challenges, which can be enhanced in the experience of chronic situations, such as type 1 Diabetes Mellitus. There is diversity and uniqueness in the transitional challenges, which involve the assumption of increasing responsibility for the treatment and autonomy in the process of self care. Thus, adolescents need support from health professionals, the family and extra-family support networks, in order to achieve and meet their health demands.

Thus, it becomes relevant to identify, from the perspective of adolescents, the knowledge and self-care actions developed to manage the disease and treatment, as well as the difficulties,
deficits and needs that emerge in the experience of being an adolescent with type 1 diabetes mellitus\textsuperscript{19-11}. Thus, this study aimed to identify the self-care actions of adolescents with type I diabetes mellitus.

**METHODS**

This is a descriptive and qualitative research using Dynamics of Creativity and Sensitivity (DCS)\textsuperscript{12} between December 2019 and March 2020, in a pediatric endocrinology outpatient clinic of a university hospital in the Brazilian Federal District. The guiding question was: *What is the commitment that adolescents with DM1 have on their self-care?*

Adolescents who met the inclusion criteria participated: ages 12 to 17 years with a diagnosis of DM1 who were being followed up at the endocrinology outpatient clinic, who agreed to participate and whose parents and/or guardians consented to their authorization. Adolescents with other underlying diseases in addition to DM1 and/or those with poor health conditions that made it impossible for them to participate in the dynamics were excluded.

Data collection was carried out in the waiting room, individually, with the presence of the parents, during the waiting period for routine consultation that the adolescents do at the hospital. The data collection was preceded by an explanation about the study proposal and, after acceptance, the Free and Informed Consent Term (FICT) was signed by those responsible for the teenager and the Free and Informed Assent Term (FIAT) for the teenagers. In addition to these terms, in order for the dynamics to be started, the Term of Authorization for the Use of Voice Sound for Research Purposes was also signed by those responsible. All terms were signed in two copies, one copy being delivered to the participant.

A self-administered form was used for the biosocial characterization of adolescents, in addition to the DCS technique, which is a data production strategy that favors reflective critical expression and the dialogic nature of the human phenomenon investigated. DCS combines art (artistic-type production) with dialogue\textsuperscript{12}.

Within the DCS, there are several types of dynamics used in this investigation the DCS Body-Knowledge. In it, a drawing of the human body is distributed to the participants, aiming to evoke memories regarding the care performed by them, which involves their body in order to evaluate the care related to the physical body\textsuperscript{12}.

Then, the design and the questions that generated debate were informed to carry out the dynamics: “*What do you understand by self-care?*”, “*How do you carry out your self-care?*” Next, the teenager described what was drawn, and this description was recorded and later transcribed for analysis.
Data collection ended when theoretical data saturation was reached\(^{13}\). The observation of the information collected was submitted to thematic content analysis\(^{14}\), which consists of three stages, namely: pre-analysis; material exploration; treatment of the results obtained and interpretation.

The study complied with Resolution 466 of 2012 of the National Health Council and was approved by the Ethics and Research Committee of the institution on 10/30/2019, under opinion No. 3,670,189 and CAAE: 19006919.4.0000.0030. Adolescents were referred to by the letter A and a sequential number for their protection.

RESULTS

Twelve adolescents with DM1 participated, of which 83.3\% (No.=10) were male and 16.7\% (No.=2) were female. Of these, 58.3\% (No.=7) were 15 years old, 16.6\% (No.=2) were 16 years old and 24.6\% (No.=3) were between 13 and 14 years old. Regarding age when they received the diagnosis, 25\% (No.=3) were up to 3 years old, 41.6\% (No.=5) were up to 10 years old and 33.3\% (No.=4) were up to 16 years old. As for education, 49.9\% (No.=6) were attending Elementary School (ES), 41.6\% (No.=5) were attending High School (HS) and 8.3\% (No.=1) had dropped out of Elementary School.

With regard to health monitoring, 58.3\% (No.=7) were attended only by the endocrinology area and 41.7\% (No.=5) were also monitored by other specialties such as nutrition, gastrology, nephrology and psychiatry. Regarding the number of hospitalizations due to DM1, 41.6\% (No.=5) were hospitalized only once, at the time they were diagnosed with DM1, 41.6\% (No.=5) were hospitalized between two and five times and 16.6\% (No.=2) were hospitalized ten times or more.

The thematic analysis of the dynamics allowed the identification of six representative thematic units: \textit{(Lack of) Care for Food; (Lack of) Control of glycemic levels; (Lack of) Knowledge of the signs and symptoms of altered glycemia and strategies for control; Drug care; Physical activity; and Self-care in the school context.}

\textit{(Lack of) Care for Food}

Adolescents reported being aware of the most suitable foods for glycemic control:

\textit{My diet is controlled, not much pasta and more vegetables […] fruits…, there's the fact that I can't eat sweets, but that doesn't interfere with my diet at all, because I've never had a sweet tooth. (A5)}
However, some adolescents, despite not enjoying this healthy diet, accepted it, as observed in the speeches of A2 and A9.

*It’s just that I eat this* (indicating the apple she drew), *but thinking about it* (indicating the cupcake she drew), *this is what happens... This is it, right, eating what’s healthy and not what you want.* (A2)

Yes, I eat well [...] ah it’s bad to have to eat healthier foods, but I eat fruits and vegetables almost every day. [...] I don’t like to eat sweets [...]. (A9)

**Figure 1.** Artistic production of creativity and sensitivity developed by adolescent A2. Brasilia, DF, 2020.

Some adolescents related self-care with their diet to quality of life and good prospects for the future:

*You are always taking care of yourself at the right times, not overeating, always exercising. I see that if I don’t treat it I can have several problems and I take care of myself as much as possible to make my dreams come true, to be employed in agricultural machinery, to have my own house, my car and a special woman in my life, where she will be in good and bad times, and, mainly, to make my mother proud.* (A3)

*I recently discovered diabetes and a good fact that I took away from it was that I would live in a healthier way.* (A5)

On the other hand, some adolescents reported not properly following the diet guided by the multidisciplinary team:

*Food for me is the most difficult thing, I don’t eat a lot of vegetables either [...] I eat a lot of pasta, fast foods and all that [...] mainly fast foods. And I don’t eat a lot of fruits, I don’t like vegetables, so I practically don’t eat.* (A1)
I don’t like vegetables very much [...] And from time to time, I like pasta and hamburgers [...] I like to eat a lot of sweets.

(A8)

(Lack of) Control of glycemic levels

Regarding self-control of capillary blood glucose, the adolescents reported doing the control without problems, although sometimes they did not perform the glucose measurement because they were busy with other activities:

I do it (blood glucose control), because I apply insulin at other meals, except for breakfast, which my mother makes. Sometimes I even manage to control what I eat and correlate the food with the blood glucose level being high. (A1)

Always before meals I measure glucose, but there are times I forget, I don’t remember, but most of the time I do... sometimes I tell my mother that I have already measured the glucose and applied insulin, when I forget for peace so my mother doesn’t keep talking... (A2)

Sometimes I don’t measure glucose. Now, I’m very busy these days, then I end up forgetting to measure the blood glucose... That’s because I forget, it’s not because I don’t want to do it. (A4)

(Lack of) Knowledge of the signs and symptoms of altered glycemia and strategies for control

Adolescents identify the signs and symptoms of hypoglycemia or hyperglycemia, as well as how to adjust blood glucose levels:

In situations of hypoglycemia, adolescents are usually able to identify symptoms, however, one of them said he did not have symptoms and, therefore, cannot identify when a hypoglycemic episode occurs, as shown below:

Headache and I break out in a cold sweat. (A3)

Hypo I know, I get blurry vision [...]. (A11)

I don’t feel anything in either of them. (Refers to hypo and hyperglycemia). Sometimes the blood glucose is 23 and I don’t feel anything. (A10)

Adolescents reported identifying symptoms when they have hyperglycemia:

Then I get a headache, I get cold sweats [...]. (A1)

When it’s too high, I feel something in my throat, there are also times when my body just shuts down. (A12)

On the other hand, some adolescents reported difficulty in identifying the signs and symptoms of hyperglycemia:

Just measuring blood glucose, because I don’t have any symptoms... so I only know if I measure it. (A3)
Faced with situations of hypoglycemia, the adolescents reported using strategies to manage and minimize symptoms:

*Then I’ll see how my blood sugar is and I’ll drink some sugar water.* (A3)
*I’ll measure it on my finger and if it’s too low I eat something with sugar [...] I drink a juice or eat a fruit.* (A9)

In situations of hyperglycemia, adolescents reported measuring blood glucose and correcting it:

*If it’s too high I take insulin.* (A9)
*Then I measure it, then I apply the insulin [...] I see it in the prescription (the right amount of insulin to apply).* (A12)

**Care while applying Insulin**

Here it is portrayed how adolescents manage the self-application of insulin. Some are unable to administer insulin in some parts of the body, in which case it is applied by a parent:

*It depends on the place, it is my mother who applies it, because I can only apply it on the stomach and occasionally on the arm, but in other places my mother applies it. I take insulin every time I eat.* (A2)
*To apply it here (indicating the gluteal region) it is my father or mother who apply it, but here on the arms and belly I apply it (insulin).* (A12)

Not all adolescents with DM1 showed self-care behavior in relation to medication, and they sometimes neglect insulin administration. One of the respondents described that she did not check her blood glucose due to lack of time. At the same time, this participant reported having undergone 16 to 20 hospitalizations:

*Sometimes I stop taking insulin. Now, I’m so busy these days, then I end up forgetting to apply the insulin dosages [...] Only when I’m too busy I forget to apply. Then I look at the clock, then I think it won’t do anything, then I don’t take it. Because I see that it’s already very late, then, for example, I woke up at 9 am, then I have to take basal insulin at 6 am, then I see that there’s no more time, so I’m only controlling the ultra-fast insulin.* (A4)

**Physical activity**

The practice of physical activities was reported by adolescents with DM1 as an activity to promote their self-care. Some practiced sport routinely:

*I play sports every day, soccer, from 2 am to 4 am a day... I have a very good tactic, leaving the glucose a little above normal so I don’t run the risk of having hypoglycemia during sports.* (Does not take the glucometer). (A1)
*I do everything, I’m a weightlifter and I play basketball.* (A5)

On the other hand, others only practiced physical activity sporadically, when in moments of recreation with friends:
Ah, I only play football once in a while. (A11)
I just play ball with friends. (A12)

**Figure 2.** Artistic production of creativity and sensitivity prepared by teenager A11. Brasilia, DF, 2020.

Some teenagers showed special skin self-care:

*I take great care when practicing any type of sport, as injuries can interfere with my future, always wearing white socks to identify any injuries on my feet.* (A4)

*You can’t cut yourself, right, because it takes time to heal.* (A11)

**Self care in the school context**

Most adolescents showed discomfort with the management of the disease (measuring glucose, administering insulin) at school, even though their peers knew:

*So, I told my friends, but I don’t like it, and I don’t apply it at school, I have lunch at home and I study in the afternoon, then I have lunch at home. I only take insulin every now and then.* (A10)

*Many of them don’t even know I have diabetes. I don’t like taking insulin in front of them.* (Refers to the school and its peers). *I don’t even take my insulin or glucometer to school.* (A1)

One teenager mentioned that she does not hide her illness from her school friends and does not fail to perform self-care related to blood glucose monitoring and insulin administration:

*My friends know about this, I never hid anything. I take the glucometer, and I only apply insulin when I need it.* (A2)
DISCUSSION

The adolescents surveyed take into account the issue of healthy eating as a way of self-care, which is essential for a good coexistence with the disease, as it was reported in a study, that children and adults had the habit of having a low-carbohydrate diet, with better glycemic control, fewer episodes of hypoglycemia and greater satisfaction with their health and DM1 control.

Despite this, some know what a healthy diet is and its importance, however, not all of them have this habit, because they do not find foods considered healthy to be pleasant or because they are in an environment outside their home, such as school. The perception of adolescents with DM1 of being different from their peers can be uncomfortable, but on the other hand, it can make them aware of the need to follow an appropriate diet. Sometimes they feel the desire to be 'normal', that is, to eat in the same way as their colleagues, interfering with the commitment to self-care.

Adherence to healthy eating is very important for people with DM1, however, this care in some situations can be neglected by parents and adolescents with DM1.

Carbohydrate counting is the control and correction of the blood glucose value with the application of insulin according to the food that is ingested and thus, they can have a greater view of the choice of food. However, there is a direct relationship between healthy eating and better glycemic control.

Demanding adolescents in self-care needs skill, so that there is no demotivation, as in the testimony of one of the participants, as he omits to the mother the fact that he had not checked blood glucose control and insulin administration as a way to not bother her.

Some teenagers do not seem to give enough importance to measuring blood glucose. It is possible that this occurs due to the lack of information about the physiology of the disease and the processes related to glucose regulation.

In situations of hypoglycemia and hyperglycemia, some adolescents report not having symptoms and only identifying the issue after measuring their glucose level, in order to proceed with the appropriate management. Thus, guidance on blood glucose monitoring for people with DM1, especially those who have a compromised symptomatology, is important.

In hyperglycemia, adolescents have more difficulty recognizing symptoms that are often nonspecific. This finding is consistent with an investigation in which 62% of children reported episodes of hyperglycemia that were only detected after measuring blood glucose. Thus, it is necessary to get into the habit of monitoring your blood glucose to avoid future chronic complications, such as diabetic retinopathy.
It appears that in the face of hypoglycemia, adolescents knew how to proceed to raise blood glucose levels and minimize symptoms, but only temporarily. The immediate consumption of sugar to raise blood glucose levels is a strategy that, despite solving the problem at the moment, does not solve it in the long term. Furthermore, no participant pointed to the later consumption of slowly absorbed carbohydrates so that the glycemic level remained balanced, which may indicate erroneous or insufficient knowledge in the management of glycemic levels.

When identifying hyperglycemia after measuring blood glucose, the adolescents used insulin administration as a strategy, so that some followed the guidelines of the multidisciplinary team regarding the amount to be administered. Insulin is a permanent medication for the person diagnosed with DM1, so it is essential that patients have a good understanding of their diet and glucose intake in order to make the correct adjustment of the hormone dosage.

As much as patients have the prescription to guide them, it would be more beneficial for them to get in the habit of performing carbohydrate counting. In a study, it was found that adolescents who received training on carbohydrate counting and calculated the insulin dosage for correction managed to avoid the risk of exceeding the dosage of the medication.

It appears that adolescents administer insulin, and in order to prevent lipodystrophy, they rotate the injection sites and, in some situations, need parents to administer insulin in places that are difficult to access. There is a need to periodically offer adequate guidance to parents and adolescents on the application of medication, especially to adolescents, considering that parents will not always be available to help, which can lead them not to administer insulin.

Self-care is integrated with treatment adherence, being a process that covers performing all the necessary care until reaching the established goals, that is, the commitment to self-care interferes with their adherence to treatment. In a survey carried out with parents and/or guardians of children with DM1, it was reported that there is a beneficial association between the time of living with the disease and the management of diabetes during childhood.

However, in another study, it was found that there is no direct relationship between the time of diagnosis and adherence to treatment of the disease during adolescence, since at this stage of life there is an intrinsic interaction between biopsychosocial issues, which are the factors that are directly associated with adherence to DM1 treatment and not the time of diagnosis. Such evidence is consistent with this study, as there were adolescents with a longer period with the disease, but their adherence to treatment was not ideal.
The regular practice of physical activity is something necessary and should be part of the treatment of children and adolescents with DM1, however, it is necessary to monitor blood glucose during activity and know how to balance the level of exercise with an adequate diet and insulin application\textsuperscript{24}. It can be observed in the speech of one of the adolescents that, in addition to not taking the glucometer during his practice of physical activities to monitor his blood glucose, he also does not use an appropriate strategy for managing blood glucose during physical activity, since it increases his blood glucose level. Intense exercise can also cause hyperglycemia, especially if the glucose level is already high before the activity\textsuperscript{24}.

The practice of physical exercises should be something that is part of the lives of people living with diabetes, however, with due care such as blood glucose control during it, which is not performed when such exercises happen sporadically, that is, unscheduled physical activity. In this way, health education actions on physical activity for adolescents and parents and/or guardians seem indispensable, aiming to increase knowledge, not only of the importance of physical exercise, but also of the necessary care\textsuperscript{24}.

As much as the behavior reported by the adolescents is not bad, but a self-care attitude that is beneficial to their health, they have a wrong understanding of wounds, since poor healing only occurs when the person does not have proper control of diabetes, that is, when their self-care and, consequently, their treatment of the disease are neglected. In a survey carried out with people diagnosed with DM, it was reported that there is a direct relationship in the increase of complications, in surgical incisions, in those people who had greater lack of control of glycemic levels\textsuperscript{25}.

From a continuous coexistence with the disease, the adolescent acquires maturity of having DM1 and learns to deal with the disease in a more palliative way, instead of treating it as something that brings limitations to their life\textsuperscript{26}. However, there may be a decline in disease management and glycemic control when adolescents gradually acquire more responsibility and autonomy over their care\textsuperscript{27}.

Another issue pointed out was the shame that many feel in relation to DM1, which in turn interferes with the proper management of the disease, as they fail to take the glucometer and insulin to school. This is consistent with a study that reported that young people with stigma were more likely to have poor glycemic control, higher levels of glycated hemoglobin, severe hypoglycemia, and a diminished sense of well-being\textsuperscript{28}.

Self-esteem, optimism and self-efficacy are essential components for diabetes management, as they are part of resilience and positively influence blood glucose control and disease management\textsuperscript{27}.
CONCLUSION

Adolescents with DM1 have adequate knowledge about self-care in relation to their diet, insulin administration, blood glucose monitoring and control of blood glucose levels, that is, they know how relevant self-care actions are for living with diabetes, as this is a chronic disease that needs constant care for the rest of their lives. However, in relation to self-care during physical activities and skin care, there is a misunderstanding of how to perform such care.

The difficulties in having a self-care behavior come from factors external to their learning and understanding, such as the shame of having to perform these self-care attitudes in the school environment. Therefore, it is essential to take into account that adolescence is a transitional phase, where adolescents are going through several biopsychosocial transformations and, little by little, acquiring greater autonomy in all areas of their lives.

Therefore, the role of the nursing professional is fundamental, especially when carrying out the nursing consultation, as it is necessary not only to provide continuous education with adolescents about their self-care habits, but also to listen, understand their stories, their difficulties and anxieties, so that the nurse can offer specific guidance to each teenager, taking into account their individuality and the environment in which they are inserted.

This work points to attention in the nursing performance in some topics such as: diet, glycemic levels, signs and symptoms of altered glycemia, medication care, physical activity and school context and, thus, recognize strengths and weaknesses in the self-care of each individual/young person, encouraging them to strengthen the areas in which they have the most facilities and to progress in the most arduous/challenging areas.

The study presented methodological limitations, since the dynamics planned for the adolescents was to have been performed in a group, but it was not possible due to the lack of physical space available in the hospital and thus, it occurred individually. Another difficulty generated by the physical structure of the place was the elaboration of the dynamics in the waiting room, where the parents and/or guardians were mostly present and close, and sometimes participated in the dynamics, so this may have interfered with the content verbalized by adolescents.
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