

# CUIDADO É FUNDAMENTAL

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RESEARCH

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## Self-Care Among Type 1 Diabetes Mellitus Bearing People: Adolescents' Experience

Autocuidado em Pessoas com Diabetes Mellitus Tipo 1: Vivências de Adolescentes

Autocuidado de Personas con Diabetes Mellitus Tipo 1: Vivencias de Adolescentes

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### ABSTRACT

**Objective:** This study aimed to identify the adolescents' experiences in the management of diabetes mellitus, regarding self-care. **Methods:** It is a descriptive research with a predominantly qualitative approach, which was carried out in a referral hospital in the assistance to patients with diabetes mellitus, located in *Fortaleza* city, *Ceará* State, Brazil. Fourteen adolescents bearing diabetes mellitus, within an age group from 12 to 18 years old, have participated in the study through semi-structured interviews. **Results:** The interviews were submitted to content analysis in order to identify the categories. After analysis, the following three thematic categories emerged: the first is related to patients who have demonstrated adherence to self-care; the second regarding the dilemmas of being an adolescent with diabetes; and the third concerning the actions of health professionals and the patients' relatives for the self-care management of adolescents. **Conclusion:** This research performed with adolescents bearing diabetes has revealed the importance of supported self-care as an instrument that can be worked out by both professionals and family, thus encouraging the treatment adherence.

**Descriptors:** Self-Care, Diabetes Mellitus, Adolescent.

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## RESUMO

**Objetivo:** Conhecer as vivências de adolescentes acerca do autocuidado. **Métodos:** Estudo qualitativo, entrevistas semiestruturadas foram conduzidas com 14 adolescentes, entre 12 a 18 anos, cadastrados em laboratório de endocrinologia pediátrica na cidade de Fortaleza, CE. **Resultados:** Com base nos dados desvelados observamos os seguintes enfrentamentos: adesão ao autocuidado; dilemas de ser adolescente com diabetes e ações do profissional de saúde e da família para o autocuidado do adolescente. **Conclusão:** Esta pesquisa com adolescentes portadores de diabetes demonstrou a importância do autocuidado apoiado como uma ferramenta que poderá ser operacionalizada por profissionais e família, favorecendo a adesão ao tratamento.

**Descritores:** Autocuidado, Diabetes Mellitus, Adolescente.

## RESUMEN

**Objetivo:** El objetivo fue identificar las vivencias de adolescentes en el manejo de diabetes mellitus, en relación al autocuidado. **Métodos:** Fue llevada a cabo investigación descriptiva, predominantemente cualitativa, en hospital de referencia en DM, en Fortaleza-Ce, Brasil. **Resultados:** Participaron del estudio a través de entrevistas semiestruturadas 14 adolescentes con DM, con edades entre 12-18 años. Las entrevistas fueron sometidas a análisis de contenido para desconexión de las categorías. Del análisis, emergieron tres temas: el primero relacionado con los pacientes que demostraron adherencia al autocuidado; el segundo acerca de los dilemas de ser adolescente con diabetes; y el tercero para actuación de los profesionales de la salud y familia para el adolescente manejar el autocuidado. **Conclusiones:** Esta investigación con adolescentes con diabetes señaló la importancia del autocuidado con apoyo como herramienta que puede llevarse a la práctica por profesionales y familia, fomentando la adherencia al tratamiento.

**Descritores:** Autocuidado, Diabetes Mellitus, Adolescente.

## INTRODUCTION

Currently, one of the most challenging situations in the field of health is the search for strategies that enable and maintain adherence to treatment, which is intensified when it comes to chronic health conditions. One of these conditions is Diabetes Mellitus (DM), which requires the patient's lifestyle changes in order to take on self-care. In this perspective, supported self-care emerges as a strategy to empower users to self-manage their own health.<sup>1</sup> Through joint action by the health team, self-care might become an effective instrument for this clientele.

It is imperative that the patient must be aware of the risks related to the health problem as well as the control of the disease.<sup>2</sup> Empowerment allows the subject, oriented and conscious of the disease, to make the decision for changes in lifestyle, which contribute to the adequate control through adherence to the treatment. It goes beyond the fulfillment of the prescriptions made by professionals, which limit the autonomy of the subject. There is influence of the environment that permeates your life, such as family, school, friends, etc.<sup>3</sup>

For this, it is necessary to develop the responsibility not only of the patient but also of the family, friends, with the continuous support of the multi-professional health

team, so that the patient assumes self-care. The roles of self-care are as follows: health maintenance, prevention of both acute and chronic complications, self-diagnosis, self-treatment and self-medication, and active participation in health services.<sup>4</sup>

The professional accompaniment allows the conduction of activities that collaborate for the development of self-care, with a consequent maintenance of the life quality. Therefore, the life quality concept depends on the individual's perception of a series of elements and particularities of his life.<sup>5</sup>

In this illness, daily activities have individual implications that arise from this chronic condition, which depends on continuous care, including strict glycemic control, diet, physical activity, and insulin usage, which must be balanced to maintain health and prevent complications.<sup>6</sup>

The teenager experiences a critical phase, sometimes alternating moments of conflict and harmony with the family, with friends and with him. In this way, the responsibility for the care with the disease that is charged to him can occur in moments in which the acceptance of the disease has not happened yet, which can be negative for the self-care.<sup>7</sup>

In this perspective, the guiding principle of self-care is that people with chronic diseases should recognize their needs in face of everyday experiences, and health professionals should collaborate in this relationship with their knowledge and skills, so that they can know the problem, choose the treatment, adopt or maintain healthy behaviors, aiming to enjoy the resources necessary to change and overcome the difficulties that are presented.<sup>1</sup>

The proposal is consistent with that recommended by the World Health Organization, when it states that the treatment of chronic diseases requires a new model of healthcare, aimed at intensifying the performance of patients and their families, promoting quality of life for them, and recognizing that both can be self-managed through the support of health teams, the community, and comprehensive policies for prevention and effective management of chronic conditions.<sup>8</sup>

In this sense, it is necessary to provide a voice to the adolescent diabetic, so that he/she exposes the difficulties, needs, and abilities developed throughout the illness, with a view to identifying possible strategies that encourage the improvement of supported self-care.

Given the aforementioned, the study's goal was to identify the experiences of adolescents in the management of diabetes mellitus with regards to self-care. Thus, it will be possible for the professional to recognize the facilities experienced by the patient for self-care, to reflect on the care practices developed and to plan a more targeted care to this clientele, then promoting the subject's empowerment.

## METHODS

It is a descriptive study with a predominantly qualitative approach, which was carried out in a pediatric endocrinology ambulatory in Fortaleza city, Ceará State, Brazil. Fourteen adolescents bearing DM, of both sexes, coming from either countryside or capital, within an age group from 12 to 18 years old, have participated of this research.<sup>9</sup> The inclusion criteria were the minimum period of one year of treatment.

A semi-structured interview was performed in a single moment, through the guiding question: How do you deal with the DM treatment?

The data were transcribed, immediately after recording and subjected to floating readings.<sup>10</sup> After transcribing the fourteen interviews, the data were validated by adolescents, and important aspects were either added or clarified. In order to avoid identification of the adolescents, flower names were used to characterize the participants' speeches.

The method of content analysis was used around three chronological poles, as follows: the pre-analysis, which was constituted by the floating reading of the interviews; to move in the analysis, were coded the speeches, referring to the theme as being the unit of meaning that is naturally freed from an analyzed text, according to criteria relating to the theory that serves as a guide to reading; the exploitation of the material consists of coding operations, i.e., it is the process by which the raw data is aggregated into registration and context units, allowing exact description of the relevant characteristics of the content. At this point, clipping and aggregation of the convergent responses were performed, using the theme as a unit of registry.<sup>10</sup>

The following three thematic categories emerged from the adolescents' speeches: the first is related to patients who have demonstrated adherence to self-care, bringing the subcategories: adaptation to insulin therapy, management of glycemic crises and adoption of a healthy lifestyle; the second addresses the dilemmas of being an adolescent living with diabetes; and the third deals with the actions that the health professional and the family can implement towards the adolescent, in order to encourage them to do self-care management, with the subcategory: guidance and support during the self-care management.

The analysis of the results was supported in light of the pertinent literature on diabetes mellitus and the Attention Model for Chronic Conditions.<sup>1</sup>

The study proposal was approved by the Research Ethics Committee that deals with Human Beings studies, according to protocol No. 038.0608, complying with the recommendations of the Resolution No. 466/12 regarding to researches developed with human beings.<sup>11</sup>

## RESULTS AND DISCUSSION

Participated 10 female and 4 male adolescents; four subjects were within the age group from 12 to 13 years old,

nine were from 14 to 15 years old, and seven were from 16 to 18 years old. Regarding the schooling level, six adolescents were attending elementary school; seven had incomplete high school level and one had already completed high school. About the family income, eight adolescents had up to a minimum wage income, five between 2 and 3 wages and one mentioned receiving 7 minimum wages [the value of the minimum wage in the period corresponded to R\$415.00]. The adolescents lived with their relatives, eight with the parents, four with only the mother, one with brothers and one with aunt and cousins. With regards to the diagnosis time, three reported a year, eight with a five-year period and two knew the diagnosis nine years ago.

### Adherence to self-care

This category has been divided into four subcategories: adaptation to insulin therapy, management of glycemic crises, and adoption of a healthy lifestyle

### Adaptation to insulin therapy

In this subcategory the realities evidenced through the speeches in the dimension of the treatment with the insulin therapy show that the adaptation allied to know how to do and to understand all the nuances of the treatment with the insulin of the type 1 DM requires of the adolescents abilities for self-administration through the confrontation of the barriers like the fear, the understanding of the ideal times of insulin usage, but always allied to the support of the family in the person of the mother.

*The insulin, I'm already used to it; because I already know the schedules, I already know how it should be administered. And also had great support from my mother, she is a nursing assistant, she taught me from an early age. (Jasmine).*

*I take it normally, I got used to sticking, at first it was bad, I did not even use it, it was my mother, then one day it took time to arrive and I administered myself and I lost my fear. (Calla lily).*

### Management of glycemic crises

This aspect was evidenced through the speeches as an important point for the more accurate identification of adolescents in the face of glycemic changes. It is essential for them to differentiate the symptoms of hypo and hyperglycemia so that they can take accurate and correct actions or to use the cooperation of those who are close when decompensating glycemic crises occur. Another also relevant point is the identification of who is carrying diabetes in order to get help from people who are unaware of their chronic condition.

*Yes, I've had hypoglycemia, it shakes, and the vision became blurred. Usually, I get to feel it, then I eat something, so*

*it goes back to normal, but then when it comes back it goes high. (Calla lily).*

*Talking about hypoglycemia, I always walk with a little card that has the identification that I am diabetic and what should be done, what are the symptoms. But, I always like to comment this with the people who are around me, what should be done, whom they should communicate and they help in the time that is needed. (Jasmine).*

*I feel hungry, I take the Dx and then if it is low, I eat something. I've had hypoglycemia. I feel headache. (Gillyflower).*

### **Adoption of a healthy lifestyle**

Adopting a healthy lifestyle through regular physical activity, balanced diet, with restriction of carbohydrate intake requires adolescents a balanced financial situation to provide means that cooperate with the various aspects of their treatment. Following are the testimonies of adolescents.

*It's in physical exercises, I have a little difficulty, it's because I do not have a fixed activity, I do not play football, and I do not swim. I try to do more are exercises at home on my own and I really like to dance, then it becomes a bit easy in a way. (Jasmine).*

*In my daily life, I do six to eight meals; in the morning I eat my breakfast at 7:00 a.m., at 9 a.m. I eat a vitamin in high school, then I eat lunch 12 o'clock, I eat there again 3 o'clock, When it's eight or nine o'clock, I take oatmeal, then I take the insulin and go to sleep. (Sunflower).*

*The difficulty I have is with the money to buy my food. Well I try, I try, then I make it, this is life. (Narcissus).*

*A dificuldade que eu tenho mesmo é com o dinheiro para comprar os meus alimentos. Bom eu tento, tento, mas eu consigo essa é a vida. (Narciso).*

### **Dilemmas of being an adolescent living with diabetes**

Providing a voice to the teenager is providing the chance to expose the day-to-day, often neglected by the professional. With these speeches, we have perceived their appeal to look after them not only to make demands, but also rather to understand them in the face of living with a chronic health condition that requires discipline.

*Now, also that they (the professionals) try to put themselves in our place, because it is difficult to live with it, not very easy to control because it has always that is practicing exercise and some days you are not willing to do so; you have to eat in the right time, sometimes you feel like eating something like that between one meal and another, you cannot, you have to wait, if everyone is eating something, you have to eat only on your schedule, but the person eats,*

*but they do not look good and I know that too is not good for me, but it's difficult. (Jasmine).*

*I do carry out the diet, but some times, every human being is weak, we fall into temptation, and in middle of the night I go to the refrigerator and eat everything, the next morning I wake up with the best poker face in the world and everybody wondering where the chocolate was? Where's the cake that was here? (Orchid).*

*It is me who administer the insulin in myself, I try to make the rotation, but as it is four times a day, it becomes very heavy for me. I think, in my opinion, that there are few places for so much insulin, that's a bit bad for me, but whenever I can, I do the rotation. (Delfim).*

### **Actions that the health professional and the family can implement towards the adolescent**

#### **Guidance and support during the self-care management**

This category demonstrates that adolescents with diabetes perceive that the actions of health professionals and the family benefit from self-care through the support they provide when guiding care in decompensating glycemic crises, learning to self-administer insulin, and when they provide educational material, then facilitating the learning process about diabetes.

The family is also relevant at the moment of the consultation, because sometimes the teenager is afraid to clarify doubts, and the presence of the relative helps clarify what was not understood.

*The first time I came here to the clinic, the nurse soon taught me how I should administer the insulin, she also taught me what I did when I had hypoglycemia, so she was very good to me. I really like this part of nursing and I thought they were going to take care of me otherwise, because the day I came I was a bit full, I thought she was going to hurry a lot, but she had the patience to teach me everything and I liked it and I'm still here at the hospital. (Delfim).*

*[...] they gave me magazines in order simulate me to learn more about diabetes, then I am learning. There is a book in my home, we read it, so we learn a little more. (Gillyflower).*

*I like the service here, they are nice, they help us, they clarify a lot of questions [...] there are things that I do not understand, but they explain a lot to us to understand everything that we do not know; When I arrive with my mother what I do not know that I'm ashamed to ask, then she asks, sometimes what I do not understand, by the time we get home I ask her and she explains what I did not understand. (Tulip).*

CoBased on the findings, the insulin usage is bad, it hurts, it has its inconveniences, but one gets used to it by having no other option. Parents also suffer, forced to “hurt” their children. The rigor of the daily application of insulin is seen as enslaving the adolescent and his relatives. In the perspective of some, it is what gives life to the person with diabetes.<sup>12</sup> In view of this information, one can see the need to promote supported self-care.

Given this context, there is a need to guide the adolescent and his family regarding the prevention of complications and the capacity for self-care, in order to obtain the best treatment and quality of life success. Influence in this process, the state of the person, the age, the time of living with the disease, the costs of treatment and the psychological and cognitive state of the patient.<sup>13</sup>

The therapeutic use of insulin directs us to the risks of glycemic problems in daily life. In view of this, the Brazilian Diabetes Society has created an ID card for people with diabetes. It becomes useful in unexpected situations, such as in cases of accidents and hypoglycemia, where the loss of consciousness can occur in public places, away from home or family.<sup>14</sup>

It is essential for the young person with DM to recognize the signs and symptoms and to differentiate the crises from hypoglycemia and hyperglycemia. In both children and adolescents, glycemic variations may interfere with cognitive growth and development, in addition to anticipating complications.<sup>15</sup> Therefore, adolescents are required to self-monitor glycemic.

Hence, it is relevant to adhere to treatment and self-care, during adolescence, those responsible need to delegate to the adolescent the control of their disease, through the daily practices of glucose monitoring, insulin usage, and carbohydrate counting. Therefore, it is necessary to have quality communication between parents and children, an adequate division of roles, follow up of consultations, supervision of those responsible for metabolic control and treatment.<sup>16</sup>

Many adolescents have been adapted to the routine of the bites for the continuous monitoring of the blood glucose and this strategy is important, since it allows the regular evaluation of the therapy and the adjustments in the dosages of insulin, in the diet and in the physical exercises, which must be done with parsimony.<sup>17</sup> Nevertheless, some activities related to self-care may cause embarrassment or embarrassment in the child with type 1 DM, such as explaining to friends about illness or applying insulin.<sup>18</sup>

We have observed in the reports that the adolescents demonstrated ambiguous knowledge regarding the procedure in the moments in which the blood glucose undergoes acute oscillations and it is important that the health professionals are attentive to these aspects to promote effective interventions that will enable the adolescent against this condition.

Several strategies can be used to promote self-care by assessing health status, setting goals, developing care plans, problem-solving and monitoring technologies, with indivi-

dual and group interventions. Strategies such as motivation for change, motivational interviewing, problem solving, relapse prevention, operative group facilitate supported self-care.<sup>1</sup>

The aspect of regular practice of physical activity, for some was already part of the routine, often associated with school and leisure activities, but for this it is perceived the need for time, dedication, guidance, patience, support of family and professionals to be successful in the changes to be made in the adolescent's diabetic lifestyle.

The literature already shows the benefits of regular practice of physical activity. A study carried out with children with DM in *São José do Rio Preto* city found that families and friends had no difficulties regarding this habit in respecting the children's wishes regarding the type of physical activity of preference. Nonetheless, it is known that the results are maintained, as this practice occurs continuously and in the long term.<sup>19</sup>

The adolescents also expressed a sense of difficulty in facing internal desires and appeals to external stimuli around feeding, which interferes in their process of self-control. These factors can often contribute to dietary transgressions. Another factor mentioned by the adolescent in following a healthy diet was the limitation in family income to meet the caloric requirements satisfactorily.<sup>20</sup>

The disease causes significant changes in the person's relationship with diabetes with their own body and with the world around them. The conflict between the desire to feed and the imperative need to contain it is present in the daily life of the adolescent.<sup>19</sup> Faced with the desire to eat sweets,<sup>21</sup> he observed in children bearing type 1 DM feelings of revolt and sadness. It is also emphasized that the impact of diabetes on eating behavior cannot be underestimated and may cause psychological disorders.<sup>22</sup>

The dilemma between following the diet and falling into the temptation to eat foods considered inadequate by the doctor, nurse, nutritionist and/or parents is part of their daily routine. This worries the teenager's awareness of diabetes.

The testimonies also show us that adolescents experience conflicts to confront insulin therapy, because of the stuck constants, both for glycemia and for insulin application, are uncomfortable for pain, even among young people already accustomed to treatment.

There is general difficulty with regard to a rotation at the sites of insulin usage. A study carried out with 58 adolescents evaluated the auto-application of insulin, noting the presence of lipodystrophy in 29.8%. The possible causes can be attributed to the non-realization of rotation, gaps in health education of this theme, physical or psychological deficiencies that make it difficult to perform.<sup>23</sup>

A survey accomplished in *São Paulo* with children and adolescents within the age group from 4 to 18 years old, with 24 participants having type 1 DM diagnosis, has found that only 30% of those who mix insulin performed correctly, this means that the vast majority, 70% of them do not. On the

other hand, it was found that 85.7% of those who did not mix insulin types were rotated.<sup>24</sup>

Guiding the patient to perform the rotation on the insulin application requires knowledge of its importance, the consequences of not doing it, the competence to do it and the examination of the body itself to detect changes that indicate the presence of lipodystrophy early. The recommendation to perform this procedure systematically aims to prevent the formation of lipodystrophy, since the presence of lipodystrophy promotes irregular and possibly slower absorption of insulin, and may have consequences for good glycemic control.<sup>25</sup>

In this sense, the relation between the adolescent and the health professional can influence the motivation and the abilities for the learning, control, and management of the DM.<sup>26</sup> There are, therefore, differentiated roles to facilitate adherence to the treatment and changes in the lifestyle required to a better quality of life that correspond to self-care.

Changing lifestyle is difficult for any individual, associated with decision-making for a better quality of life and disease control. This impacts more than the decisions made by health professionals, which is related to the lower adherence, especially when associated with the prohibition or restriction, as is the case of the changes related to DM.<sup>27</sup> It is important to emphasize the important role of the caregiver is to incite the desire for care, and even to provoke in the adolescent the desire to take care of himself.<sup>28</sup>

For this interaction between professional and patient, the empathy solicited by the adolescent is understood as an ability for the success of the treatment. It may occur verbal or non-verbal, and mutual respect between the two is fundamental.<sup>29</sup>

In order to support DM bearing adolescents, interventions that address their self-care needs are needed. Among the approaches to behavior change, empathic listening leaves the prescriptive and informational attitude on the part of health professionals.

The pillars of supported self-care are three, as follows: information and education towards self-care, so that the patient consciously takes care of the care that will develop in daily life; the preparation and monitoring of the self-care plan, in order to maintain the patient's follow up continuously; and the material support for self-care, so that both have access to current information and consistent with patient care.<sup>1</sup>

Health professionals are facilitators for the adolescent to manage self-care, because they are also participants in the process of living of this adolescent, seeking to be on the side of the same so that they can be empowered through the adoption of balanced diet, practice of physical activity, insulin administration, management of glycemic decompensating issues, as well as helping them to coexist in everyday life with quality of life, even in the face of diagnosis.

Health professionals are able to influence the success of diabetes management, and the nurse is in a privileged situation, so he should seek to know the factors that interfere with the management of diabetes, in order to plan, in consonance

with the individuals, a care service able to meet the needs of those people.<sup>30</sup>

Demonstrating support, exemplifying what can happen with hypoglycemic crises, guiding the behaviors to be taken and demonstrating patience during the information exchange; all those approaches are perceived by the adolescents as attitudes that favor self-care.

Studies on the importance of health professionals' assistance practices and the capacity of people with diabetes to improve self-care due to satisfactory care were focused on the relational dimension through attention, understanding, and dialogue, as well as individualized, comprehensive and humanized care.<sup>31</sup> Through the statements, it was also noticed the importance of these attitudes among the professionals of the institution that cared for adolescents living with diabetes.

The presence of the parents at the time of the consultation was also evidenced by the adolescent as support for the clarification of the doubts, is the same a facilitator for the process of capturing the information that was not processed at the moment of the attendance.

At the same time, the health professional and parents should always encourage the teenager to feel free to remove their doubts whenever necessary, until learning occurs. For this, it is important a warm environment and demonstration of empathic attitudes.

Supported self-care allows reinforcement to the necessary attitudes to recognize the importance of people being empowered to participate proactively in the social production of their health.<sup>1</sup>

The valuation of adolescents' perceptions of the care of the health professional and the family are important aspects of the management of diabetes. It is necessary to identify actions that favor the self-care process of adolescents through the support of the educational teams of the health teams, to improve conventional treatment and to continuously plan behaviors that promote the health of adolescents with diabetes and their families.

In the context of adolescents living with DM, the supported self-care<sup>1</sup> emerges as a significant health strategy, considering that dealing with a chronic condition such as DM is not an easy task, since daily care with food, glycemic monitoring, use of insulin, management of hypoglycemia or hyperglycemia and practice of physical activity.

For the development of supported self-care, professionals should improve attitudes that are already part of daily life, guiding people to take care of themselves, encouraging them to adopt healthy behaviors, that is, to adopt the necessary changes to their lifestyle.

Therefore, supported self-care pursues to empower users to become agents of their health, in other words, health professionals significantly support people, so that these self-manage their health.

## CONCLUSIONS

In the adolescents' reports, it was observed the disclosure of aspects such as adaptation, dilemmas of being diabetic and the influence of the family, as well as the health services impact upon this process.

It is clear the need for comprehensible health care based on empathic actions, on a horizontal relationship, and linked to the adolescents' experiences. Furthermore, the data have allowed us to perceive that family and health professionals together are pillars in the construction of supported self-care. Therefore, changes in praxis are necessary, which implies adequate therapeutic listening to accommodate the specific demands of adolescents, naturally complex, experiencing a chronic health situation.

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