

Diabetes mellitus in adolescence: experiences of adolescents and their mothers*

DIABETES MELLITUS NA ADOLESCÊNCIA: EXPERIÊNCIAS E SENTIMENTOS DOS ADOLESCENTES E DAS MÃES COM A DOENÇA

LA DIABETES MELLITUS EN LA ADOLESCENCIA: EXPERIENCIAS Y SENTIMIENTOS DE LOS ADOLESCENTES Y DE LAS MADRES CON LA ENFERMEDAD

Maria Auxiliadora Ferreira Brito Almino¹, Maria Veraci Oliveira Queiroz², Maria Salette Bessa Jorge³

ABSTRACT

The growing rate of chronic diseases among children and adolescents, especially diabetes mellitus, calls for integrated health care of the individual in his or her social environment. The objective of this study was to understand the health care experiences and feelings of adolescents and their mothers about having diabetes and the treatment. Semi-structured interviews were performed with eight adolescents and seven mothers at a public healthcare service in the city of Barbalha, in the state of Ceará, Brazil. Analysis revealed the following categories: feelings expressed when the disease was diagnosed; living with the disease and its psychosocial implications; and changes in one's lifestyle. The adolescents' difficulties raise concerns about behaviors and adaptations to the new way of being and self-care. There is a need for care that integrates physical and psychosocial dimensions to improve the care that is delivered to adolescents and their families.

KEY WORDS

Diabetes mellitus.
Adolescent.
Family.

RESUMO

O aumento de doenças crônicas entre crianças e adolescentes, especialmente a Diabetes mellitus, requer conhecimentos que integrem os cuidados à saúde e a integração do indivíduo ao seu meio social. O objetivo foi compreender as experiências e os sentimentos de adolescentes e de suas mães sobre a condição de ser diabético, o tratamento e os cuidados à saúde. Realizamos entrevista semiestruturada com oito adolescentes e sete mães em um serviço público de Barbalha - Ceará - Brasil. A análise dos discursos resultou nas categorias: Sentimentos expressos diante da descoberta da doença; A convivência com a doença e as implicações psicossociais; Mudanças no estilo de vida. As dificuldades dos adolescentes induzem à reflexões sobre comportamentos e adaptações ao novo modo de ser e ao autocuidado. Há necessidade de um cuidado integrando as dimensões físicas e psicossociais de modo a melhorar a assistência ao adolescente e à sua família.

DESCRITORES

Diabetes mellitus.
Adolescente.
Família.

RESUMEN

El aumento de enfermedades crónicas entre niños y adolescentes, especialmente la Diabetes mellitus, requiere conocimientos que integren los cuidados a la salud y la integración del individuo a su medio social. El objetivo fue comprender las experiencias y los sentimientos de adolescentes y de sus madres sobre la condición de ser diabético, el tratamiento y los cuidados de la salud. Realizamos una entrevista semiestructurada con ocho adolescentes y siete madres en un servicio público de Barbalha - Ceará - Brasil. El análisis de los discursos resultó en las categorías: Sentimientos expresados delante de la descubierta de la enfermedad; La convivencia con la enfermedad y las implicaciones psicossociales; y, Cambios en el estilo de vida. Las dificultades de los adolescentes inducen a la reflexión sobre comportamientos y adaptación al nuevo modo de ser y al auto cuidado. Hay necesidad de ofrecer un cuidado integrando las dimensiones físicas y psicossociales de modo a mejorar la asistencia al adolescente y a su familia.

DESCRIPTORES

Diabetes mellitus.
Adolescente.
Familia.

* Extracted from the thesis "Cuidar/cuidado no adolescer com Diabetes mellitus tipo 1: o olhar dos adolescentes e das mães", Ceará State University, 2005.
¹ Physician. M.Sc. in Children and Adolescent Health. Professor at Federal University of Ceará. Coordinator of the module in Pediatrics and Pediatric Surgery. Fortaleza, CE, Brazil. mafrito_2@hotmail.com ² Nurse. Ph.D. in Nursing. professor at Ceará State University. Coordinator of Professional Master's Course in Child and Adolescent Health. Member of the Research Group on Mental Health, Family, Health Care Practices, and Nursing at Ceará State University, Fortaleza, CE, Brazil. veracioq@hotmail.com ³ Nurse. Ph.D. in Nursing. Full Professor at Ceará State University. Leader of the Research Group on Mental Health, Family and Health Care Practices at Ceará State University. Fortaleza, CE, Brazil. masabejo@uece.br

INTRODUCTION

Diabetes mellitus (DM) is a metabolic disorder associated to relative or absolute insulin deficiency, whose full clinical expression is characterized by metabolic changes and neuropathic and vascular complications. The metabolic components involved in DM are characterized not only by hyperglycemia, but also by changes in the metabolism of proteins and lipids. Vasculopathy, when present, may be macroangiopathic, which could endanger coronary, lower limb and brain arteries; or microangiopathic, which may particularly affect the retina and the kidneys⁽¹⁻³⁾.

DM is one of the most critical healthcare problems nowadays, both regarding the number of people afflicted, the disabilities it causes and the costs to control and treat its complications. Mostly, DM cases are included in two main etiopathogenic categories: type 1 *Diabetes mellitus* (DM1), in which there is a deficiency of insulin, and type 2 *Diabetes mellitus* (DM2), resulting from a combination of insulin resistance and/or compensatory insulin secretion⁽⁴⁾.

A study performed in 50 countries by the DiaMond Project (Multinational Project for Childhood *Diabetes*) from 1990 to 1994 diagnosed 19,164 cases of children with DM 1, aged 14 years or older. The incidence found varied from 0.1/100,000 per year in China and Venezuela to 36.8/100,000 per year in Sardinia (Italy) and 36.5/100,000 per year in Finland. In most of the studied population, incidence increased with age, with the worst hit age range between 10 and 14 years old⁽⁵⁾.

A study held in 1998 estimated 171 million diabetic patients in the world in 2000. These figures are predicted to increase to 366 million in 2030, due to higher longevity observed in people. Such an elevation in the number of diabetics would be associated to an increasing consumption of fat, sedentary behaviors and consequent obesity⁽⁶⁾.

In many countries, the prevalence of DM has strikingly increased, and an even higher increase is expected. In developing countries, there is an increased frequency trend in all ages, especially the younger ranges, whose negative impact on quality of life and the burden of the disease in healthcare systems is relevant⁽⁷⁾. *Diabetes* is associated to higher hospitalization rates, increased need for medical care, higher incidence of cardiovascular and cerebrovascular diseases, blindness, kidney failure and non-traumatic lower limb amputations⁽⁷⁻⁸⁾.

Besides, it should be considered that DM is a disease that demands special self-care behavior from the patient, so that glucose can be maintained within a certain range of tolerance.

A recent study about hospitalizations due to *diabetes mellitus* showed that the most common occurrences in a

year happen with females; however, lethality in males is higher, and death is more likely in less-developed regions. The study also noted that 2.2% of the funds made available by the Brazilian Ministry of Health was used to provide hospital care for patients with DM between 1999 and 2001⁽⁸⁾.

In Brazil, the number of diabetics is estimated at five million, most of whom are unaware of the diagnosis. Incidence levels of type 1 in childhood and adolescence are as high as one or two for every 1000 youths. It is considered the fourth most frequent cause of death in the country, in addition to being the second most common chronic disease in childhood and adolescence⁽⁹⁾.

The Health Secretariat in the city of Barbalha, Ceará (Brazil) has no records of a study to reveal the incidence and prevalence of DM 1 in children and adolescents⁽¹⁰⁾. Empirical observation of healthcare provided at the Integrated Center for *Diabetes* and Hypertension in that town, where one of the authors of this article is active as a diabetologist pediatrician, points to an increase of DM cases among children and adolescents. This raises concerns about how to address and deal with these patients, considering that it involves psychosocial aspects in addition to the biological condition.

Adolescence is considered a phase of human development marked by biological, psychological and social maturation. Since this is a complex process of psychosocial development, the frontiers of this period are seldom clearly defined, and this period becomes especially vulnerable, which may cause the manifestation of psychological and behavioral problems⁽¹¹⁾.

It is indispensable for professionals in this field to know the experiences and feelings involved in the process of falling ill at this stage. When we consider the aspects that will influence adolescents' responses to the disease and treatment, we can invest in actions focused on damage prevention and health promotion, a situation that will imply the participation of everybody involved in healthcare, including the individuals themselves, who will have to take on healthy behaviors.

The adolescent with *Diabetes mellitus* experiences several setbacks that interfere in the development process of. As this is a phase with constant changes⁽¹¹⁾ and conditions imposed by the disease – since treatment covers dietary restrictions, multiple insulin injections, need for regular physical activity – and also fear of the possible complications and sickness caused by the symptoms of hyper and hypoglycemia, these repercussions can affect the quality of life of patients and their families. The healthcare provided to children and adolescents should contemplate not only the technical aspects, but also their emotional, physical and social needs⁽¹²⁾. Therefore, the emotional, affective,

In developing countries, there is an increased frequency trend in all ages, especially the younger ranges, whose negative impact on quality of life and the burden of the disease in healthcare systems is relevant.

psychosocial aspects, the family dynamics and even the physician-patient relationship are increasingly admitted to influence *Diabetes* control. As such, the importance of psychological factors is acknowledged for both the onset and control of the disease, especially among adolescents, since the disease can jeopardize their development⁽⁹⁾.

The systematization of the information produced in this investigation will bring a different perspective and new insights about the care provided to diabetic adolescents and their families. As such, the study results could support professionals, offering new spaces for discussions and practices that are consonant with the multidimensional clinical approach focused on the prevention of complications and health promotion of adolescents with *Diabetes*.

GOALS

In this perspective, the research was executed according to the following goal: understanding the experiences and feelings of adolescents and their mothers amidst the acknowledgement of the *Diabetes* diagnostic, its treatment and healthcare.

METHOD

This is a reflexive, qualitative study that seeks the meanings of the phenomenon. The qualitative approach allows for the description of human experiences according to how they are undergone and defined by their actors. Thus, it is possible to understand meanings, senses inscribed in subjective issues that are inherent to acts, attitudes, relationships and social structures⁽¹³⁾.

The study was performed at the Barbalha Integrated Center for Hypertension and *Diabetes* – *Centro Integrado de Diabetes e Hipertensão de Barbalha* (CIDHB), a town located in the south of the state of Ceará, about 530 Km away from the state capital Fortaleza (Brazil). The town of Barbalha has a total population of 47,715 inhabitants, with an estimated 6,159 in the 10-14 age range and 5,642 inhabitants for the 15-19 age range, which corresponded to 12.90% and 11.82%, respectively. Its public service has 16 basic healthcare units, 3 hospitals associated with the Unique Health System – *Sistema Único de Saúde* (SUS) offering high complexity care, and a center focused on patients with hypertension and *diabetes*, with 12 Family Healthcare Program teams (10). In April 2000, the Cariri Medical School was created and established as an extension of Universidade Federal do Ceará, whose positive repercussions were observed through the insertion of professionals committed with education, healthcare provision and research in the healthcare services.

The study subjects were adolescents with DM1 and their mothers, followed at CIDHB. The inclusion criteria for the subjects were: registered users who received care at the service from April to June, 2005, aged 10 to 19 years, and

who agreed, along with their parents, to take part in the research. Eight adolescents and seven mothers participated in the interview, being identified with the initials (A)dolescent or (M)other according to the order of the interview (A1, A2... A8 and M1, M2... M7). Adolescents with other types of endocrinal diseases and those who had had their disease diagnosed less than one year before the study were excluded.

Data collection occurred in two phases. Initially, a meeting was held with the adolescents and their mothers, providing them with information about the research, such as: goals, aims and form of participation, among other ethical issues. The subjects were invited to take part in the research, and the adolescents and their parents or legal guardians signed the term of consent. Next, a semi-structured interview was used to collect information, including the characterization of the subjects and information related to their experiences with the disease and healthcare. The interviews were recorded with the permission of the research subjects, lasting for 40 minutes on average. The adolescents were asked the following questions: What is the meaning of being diabetic for you? What has it been like to undergo treatment? For the mothers, the interview was guided by the questions: what is the meaning of having a diabetic child for you? Talk about the discovery of Diabetics in your child. What has it been like to have your child undergo treatment?

The research project was approved by the Review Board of Universidade Estadual do Ceará (File #05050795-8), and all procedures were performed in accordance to Resolution #196/96 about research involving human beings⁽¹⁴⁾.

Interviews were analyzed according to thematic content analysis, focused on comprehending communications, with latent or manifest content of explicit or implied meanings, according to the researcher's inferences⁽¹⁵⁾. The following operational stages were followed to develop this technique: constitution of the *corpus*, floating reading, exploration of the material, composition of the units of registry corresponding to the units of meaning (excerpts from the statements), which were classified in order to compose the categories. These were formed according to semantic criteria, i.e. the contents with similar senses were grouped and resulted in the following categories: *Feelings expressed when the disease was discovered; Living with the disease and its psychosocial implications; Changes in lifestyle*. These categories were built according to the descriptions of the interviews, which permitted comprehending the experiences and feelings of the adolescents and their mothers, using the reviewed literature as the theoretical framework, since it addresses psychosocial aspects and themes that permeate this approach.

RESULTS AND DISCUSSION

The sociocultural characterization of the subjects facilitated the comprehension of the context in which the expe-

periences of being a diabetic adolescent and their families implied coping with the disease and seeking health.

The age of the interviewees varied from 10 to 19 years. Six were females and only two males. Education varied from 5th grade to full high school. The time since diagnosis varied from one to three and a half years. Six of the eight interviewees had glucose meters and were capable of using them, but all of them reported financial difficulties to acquire test strips and to use the device. In addition, five of them come from families gaining twice the minimum wage or less.

With all this information, it is important to note certain critical points, such as the situation of a 14-year old adolescent taking the 8th grade, with a family income of twice the minimum wage. *Diabetes* was diagnosed five years ago. She has a glucose meter, but does not self-apply insulin.

Another adolescent, a 10-year-old 5th-grader, has a family gaining one minimum wage and had his *diabetes* diagnosed three years ago. He has a glucometer and self-applies insulin. These indicators could signal the need for strategies to support and comprehend the adolescents and their families regarding their sociocultural context, favoring the development of the family and the possibility of granting autonomy to the adolescent, considering that responsibilities can be transferred at this age, even though this is a reason for conflict between parents and adolescents⁽¹⁶⁾.

As for the mothers, the data show that their age range varied from 36 to 54 years, all of them in stable unions; five of them had high school education and two had college education. One of the mothers was remarkable, having difficulties to come from her home to the *Diabetes* Center (300 Km away). She had to face this distance in addition to other structural situations, consequences of the family's socioeconomic conditions.

Feelings expressed due to discovering the disease

This category shows the feelings of the adolescents and their mothers in the experience with the disease since it was discovered, going through the daily concerns that are manifested as *disquietudes* and uncertainty – living in risk – which features ambiguities in the form of conjuring the daily routine. At the same time as they consider that, being diabetic is not difficult, they expose feelings of sadness, concern and other manifestations, since they are different from the others. Such feelings can be perceived between the lines that portray the meaning of being diabetic.

It's being different from the others, I'm setting limits [...] (A3).

It's not so difficult to live with it; the disease is not too simple or too complex [...] (A5).

It was very hard to know that my daughter was going to depend on insulin [mother's eyes become teary], living constantly at risk is very worrisome. I'm always anxious [pauses; voice falters], always disquieted and worried whether the *Diabetes* is under control (M1).

For some teenagers, it is not difficult to live with the disease and, even then, they manifest a duality in their expressions. At the same time as they consider it possible to have a normal life, they refer to themselves as people with *something bad* and their faces express suffering.

[Being diabetic] is being normal. I found no difficulties in being diabetic [...] it's something that you have, that is bad, but you have to see the benefits, you can't let the disease consume you, can't get lost in life (A4).

When I became diabetic I didn't care much about it. Later [tone changes], my father and my mother got really worried about me, they cried a lot! (A6).

It can be seen that, when *Diabetes mellitus* type 1 was first diagnosed, there was a temporal rupture between before and after the diagnosis, and the subject had to face the irreversibility of the disease, self-surveillance to perceive acute complications, glucose monitoring, multiple insulin injections and dietary demands. For the adolescent, particularly, awareness of the problem slowly leads to conformity, and the responsibilities that used to be attributed to the mother or the healthcare team are progressively taken over by the adolescent.

This health condition, with dietary requirements, daily application of insulin and strict control of glucose levels demands adaptation to the changes, not only for the patient but also for the family. The changes go beyond the physical aspects, covering also psychosocial aspects, involving the field of interactions and personal development. The situation of becoming chronically ill and the constant treatment cause frustrations due to the reduction of personal autonomy. In addition, the diabetic patient has concerns and fears related to other serious health problems that are consequences of the evolution of the disease. Feelings like insecurity, fear, helplessness, anxiety and others may be present and, in turn, may cause serious problems for treatment compliance⁽¹⁷⁾.

Such feelings cause dissatisfaction with the new way of living. We can see the demands for care because of the disease in the following testimony:

Being diabetic is having to do glucose tests [...] is having to take walks, [...] is having to take daily injections (A8).

In this sense, the social support offered by the family is expressed in the mother figure, as she is closer and more present during the treatment, as seen in the reports of care delivery experiences to these adolescents.

Chronic diseases, considered incurable and permanent, demand that individuals rethink their existence, adapting to the limitations, frustrations and losses. These changes will be defined by the type of the disease, how it is manifested and how it develops, in addition to the meaning the patient and the family attribute to the event⁽¹²⁾.

The discovery of the complications and the chronicity caused by the disease is disturbing for both the adolescent

and the family; it is living under stress. The adolescent expressed this concern:

I'm aware of the complications for the rest of my life (A1).

The difficulty in having her adolescent daughter accept the disease could be noted in the testimony of a mother:

She doesn't want to do physical activities [...] doesn't want to accept the diet that was prescribed by the doctor, doesn't take the insulin at the right time (M8).

Denial may be a mediating process for the time someone needs to adapt to a disease. The way in which a family deals with the situation will influence the child to accept or deny the disease. It is better to understand the limitations than to rebel against her state; it is also wise not to make use of overprotective mechanisms⁽¹²⁾.

The comprehension of being diabetic involves different aspects for the mother and the child, since both portray the thoughts and feelings according to their experiences. In the case of adolescents, each responds differently, although with certain similarities. Chronic disease, especially in children and adolescents, changes daily routine, often imposing limitations. New demands arise because of the signs and symptoms of *diabetes* as the disease progresses, changing the routine in varying degrees.

As the adolescent is in a transitory state of evolution and psychosocial transformations, he perceives and feels the events in a different way when compared to an adult. As such, adolescents, children and adults are dissimilar according to how they manage their problems. Older adolescents (15-19 years) are more mature, which seems to reduce their levels of stress. The motivations that guide the adolescent are focused on immediate satisfaction, although some of them are already at a stage of self-determination, acquiring their own *autonomy*. For the mothers, their feelings go beyond immediacy, being concerned with the changes in their new way of life, with demands for care that will certainly affect the family routine.

Due to the complications that *Diabetes* causes in the life of the child and her family, it is up to healthcare professionals to identify people at risk for this disease and intensify actions to promote and control the disease among those who have already been diagnosed⁽¹⁴⁾. As such, it is important for caregivers to acknowledge the moment and context of each sick person, as well as to understand feelings and experiences in the patient's reality, in order to contribute for the youths to have a quieter life, where the disease will not hamper their development.

Living with the disease and the psychosocial implications

Living with *diabetes mellitus* forces the adolescent to experience feelings of loss, grief, fear, rebellion and powerlessness, i.e., discomfort, while at the same time seeking self-achievement, acceptance and resignation. These are feelings that overcome those commonly experienced in

adolescence and entail the desire to returning to the past. Such experiences, made evident in the voice of the adolescents, were shown to be different according to their maturity, the phase of the disease and the context of life. They expressed themselves as follows:

I didn't want to accept [...] I'm used to it nowadays. I don't like to get injections in my stomach, it hurts a lot, but then [pauses] I apply them on my thigh (A7).

It was different before, my father bought me chocolates, all the good things [...] I don't like taking injections, or doing glucose tests [...] My mother is the one who applies the insulin. I don't like being diabetic, taking insulin hurts, doing the tests hurts, I wish I could get back to being who I was (A6).

The adolescents portray the daily routine of being diabetic by confirming the dependence on exams and insulin therapy. Therefore, they translate the ways of living with the disease, the feelings in the face of the restrictions and suffering under the strict control of conducts and medical prescriptions. The negative perception one has of *Diabetes* may be related to how healthcare professionals direct the treatment and healthcare, focusing on prohibitions as the center of orientations. These people need to receive professional and family support and help so that they do not feel so limited and overburdened, in order to reduce their suffering⁽¹²⁾.

The adolescents reveal acceptance and need for self-achievement and adaptation to the new reality as ways of coping. These feelings may also vary according to the family life and support, and, when the parents treat the diabetic child differently from the other children, it may bring negative feelings to the relationship, as the transcribed excerpt describes:

My father treats me differently at home, sometimes I think he rejects me (A3).

In the adolescent's imaginary, being treated differently awakens a feeling of rejection, which may not correspond to the father's attitude. As seen in the daily routine of families whose children have chronic diseases, the parents may be frustrated with the onset of the disease, as they always expect an intelligent, strong and healthy child. They visualize a future without interferences in the development and conditions of life. These are occurrences that can alter the relationship with the children. The feeling of loss towards a normal child, as well as of social isolation, can be perceived in the mothers' statements, representing the social imaginary of families with diabetic children:

[...] My daughter was healthy, very playful. [...] We have been to few parties, when we go I bring food that she can eat (M5).

[...] I really wished that my daughter could be like she used to be, a healthy child (M6).

Supported by the diagnosis of the chronic disease, the project of the child's future is totally modified by all family

members, and determines that the diabetic child change her projection of a perfect body in a distant future. There are several conditions that influence the way of living with the disease and, consequently, the control and maintenance of a healthy life. By living with *Diabetes*, the adolescent being experiences attitudes that reveal specific characteristics – a being in development, in a transitional phase where personality is being structured, experiencing new challenges due to the responsibilities that have to be assumed. As one of the adolescents said,

you have to want it in order to overcome it (A7).

In this situation, it is necessary to have a dialogic relationship that will open spaces for understanding what the other (the being who receives care) feels and says, in order to contribute, not only in the apprehension of orientations but also in conscious decision making in healthcare. Such evidence shows that educational practice, as a continuous exercise for the development of the subjects' autonomy, is essential in providing care for patients with chronic diseases, as many interactive encounters in the monitoring process to control the disease favor the educational process focused on coping with and solving the practical problems of daily life⁽¹⁸⁾. Experience exchange and active participation of the subjects grant security and autonomy for decision-making.

Technical and scientific advances bring hopes of reducing the grief of adolescents with type 1 *Diabetes mellitus*. However, several procedures depend on the client's compliance, i.e. on meeting the demands that the disease and the treatment put forth. As one of the adolescents says:

I didn't want to accept it, I felt I was going to be different from the other girls, but my mother, my grandmother and my aunt comforted me [...] they told me that I'd be like the other girls if I complied with the treatment (A6).

Support from the family and other social networks may influence acceptance of the disease and compliance with treatment. The family plays a fundamental role in maintaining the child's and the adolescent's emotional balance. The way chosen by the family to deal with the situation will influence acceptance or denial of the disease; it is important for the parents to understand their children without overprotecting them⁽¹²⁾.

The family often acts with its own resources, trying to solve or relieve the health problem. As such, the family is seen as essential for the balance of its members, strengthening bonds and socialization networks.

Lifestyle changes

This category reveals the daily routine of the adolescent with *Diabetes* when faced with the organic changes that demand specific care and influence the psychosocial dimensions. Disease is considered a process entity, caused by several factors (multicausality), but the form of seeing the disease is related with the experiences of the people in their cultural environment carried with meanings⁽¹⁸⁾. The

meanings are constituted based on past experiences, as different meanings arise according to each person's history. The adolescents, in their testimonies, manifest the changes in their way of living with the disease and express the many difficulties that were made present in their lives, especially regarding their diet.

My life has changed according to my daily habits; I started taking insulin, to control myself with the glucose device (A4).

We see the reality as time goes by: being careful when we go out, responsibility to eat at the right times, having to exercise [...] (A1).

When I became a diabetic, I started to set some limits to my excesses (A3).

The motivation for more autonomy and improved control of the disease is also related with the help of the healthcare team, providing technical support and encouragement regarding the changes in behavior. Therefore, when the therapeutic staff tolerates choices, informs about risks and understands the patient's emotional responses, it provides higher possibilities of compliance and acquisition of the new desired habits.

As such, for some of the adolescents, the changes also come as a way of reflecting about behaviors and attitudes and using the necessary resources to stay healthy:

[...] now the dietician helped me with the dieting plan, my diet is more balanced, with a few more rules [...] I learned that if you don't control the disease, it's going to control you. If you don't follow the doctors' advice, you won't have a long life (A4).

These changes are also reported by the mothers, who refer to the normal events of adolescence, associated to the changes in behavior due to the disease, which cause discomfort for the adolescent.

It was easier to follow the treatment at first, then she grew up and it became more difficult around age ten. She wouldn't accept the diet that had been prescribed by the doctor. Wouldn't take the insulin at the right time (M8).

She's been very rude in the past year. I don't understand why she's so angry. She doesn't want to do any physical activity. I tell her what can be caused by lack of physical activity [...], but she doesn't listen to me (M6).

There are certain weeks in which she becomes very rebellious [...] she humiliates me [...] it's like she blamed me for having diabetes. At those times she doesn't comply with the treatment (M1).

Diabetic children create a fragile, inadequate self-image as they do not correspond to their parents' image; insufficient for not being able to keep up with their friends or classmates intellectually⁽¹⁹⁾. The adolescents, when evidencing their condition of being diabetic, mention these conceptions about themselves, their self-image and their socio-affective repercussions.

I used to like being heavier [...] (A3).

My friends mock me, they don't wait for me to take the insulin [...] and then I arrive late for the games [adolescent cries] (A2).

During adolescence, individuals undergo an intense process of constitution and reconstitution of their body image. The body, at this moment, has an important role in being accepted or rejected by the group. The perception of non-correspondence to the body idealized for oneself and for the group may cause anxiety and social isolation⁽¹¹⁾. Diabetic adolescents with a negative body image have an inadequate perception of their health, with a higher risk for glucose control⁽²⁰⁾.

In this study, the mothers showed that, in an attempt to comply with the demands of their diabetic children's treatment, they move to other towns, looking for security and new knowledge in order to contribute to better health for their children.

We decided to move to Barbalha so that we could live near the Diabetes Center (M7).

Their concerns for their son were capable of making the parents sacrifice for the child in an attempt to promote and preserve this child's health, giving rise to new manners of dealing with him and with life.

FINAL CONSIDERATIONS

By allowing adolescents and mothers to voice their experiences and feelings, we noticed the dimension of the disease in their lives, as well as their singular way of living with change. Due to the many demands of the treatment, represented by the need for continuous professional monitoring, hospitalizations and requirements for exams at a time of deep biological and psychosocial changes, the adolescents had their routines changed, while the care provided by the multiprofessional team became essential in the treatment and actions to control aggravations.

It is clear that the socioeconomic and cultural aspects, as well as the healthcare received intensely influence the way of living with the disease and complying with the treatment, reducing the risks to health. The results show the influence of such aspects, entailing consequences for social life, such as studying, leisure, interaction with the adolescents' social groups, among others.

The feelings expressed by the mothers and the adolescents in coping with the disease reflected, at that moment, the manifestations of being unhealthy, according to the perspective of each of those, since mother and child elaborate such an experience differently. In the adolescents'

speech, falling ill is not so bad, although it surely sets certain limits to their lives. Adaptation/re-adaptation to a new way of life due to the biological necessities leads to a different way of life, loaded with psychosocial meanings in the narrated experiences. The mothers' reports show that the negative feelings go back and forth, strengthened by the family's inability to meet the demands brought about by the disease and the fears of its complications.

Regarding lifestyle changes, indispensable due to the condition of *being diabetic*, some of the adolescents acknowledge them as necessary to obtain health. This fact shows, therefore, how it is possible for the adolescent to comply with the treatment in order to maintain health, even when faced with so many demands imposed by the disease. For other adolescents, however, the loss of a healthy body was mentioned as an obstacle for their development, triggering negative attitudes in their life with the disease.

Even if there were some positive aspects, mothers and adolescents show the vulnerability of the family towards the disease, giving rise to several necessities. A common point in the interviewee's testimonies was the relative difficulty to adapt to changes in diet and doing physical activities. Acknowledging and being encouraged to do physical activities is not enough for the person to develop such a habit. As such, it is important to create strategic programs to encourage the changes in dietary behaviors and the practice of physical exercise in those people, not only as part of the treatment for *Diabetes*, but as an essential part of the adolescent's daily activities. This would bring possibilities for an interdisciplinary project that would involve healthcare and education professionals.

Finally, we consider that, in this study, the subjects showed the limitation of the services in meeting the psychosocial needs surrounding both the adolescent and the mother, accompanying the routine of the diabetic child. However, based on the aforementioned descriptions, we suggest that professionals should consider the feelings and experiences of the subjects, based on sensitive listening and, therefore, find healthcare intervention means that can meet their needs in a wider scope. Thus, the production of healthcare actions could be developed and shared between professionals and users, which would meet the demands and needs to recover and maintain health.

We understand that the ideas exposed herein are not final, but considerations to be reflected upon in the restructuring of healthcare for adolescents with type 1 *Diabetes mellitus*, in order to bring new dimensions to care, going beyond the biological aspect of having the disease, as it involves the integration of biological and psychological dimensions, including the family contexts of these subjects.

REFERÊNCIAS

1. Wajchenberg EL. Disfunção endotelial no diabetes mellitus tipo 2. *Arq Bras Endocrinol Metab.* 2002;46(5):514-19.
2. Gross JL, Silveiro SP, Camargo JL, Reichelt AJ, Azevedo MJ. Diabetes melito: diagnóstico classificação e avaliação do controle glicêmico. *Arq Bras Endocrinol Metab.* 2002;46(1):16-26.
3. Gross JL, Scheffel RS, Bortolozza D, Weber CS, Costa LA, Canani LH, Santos KG, et al. Prevalência de complicações microvasculares e macrovasculares e seus fatores de risco em pacientes com diabetes mellito tipo 2 em atendimento ambulatorial. *Rev Assoc Med Bras.* 2004;50(3):263-7
4. American Diabetes Association. Diagnosis and Classification of Diabetes Mellitus. *Diabetes Care.* 2008;31 Suppl 1:S55-60.
5. Wild S, Roglic G, Green A, Sicree R, King H. Global prevalence of diabetes. *Diabetes Care.* 2004;27(5):1047-3.
6. Karvonen M, Viik-Kajander M, Moltchanova E, Libman I, La Porte R, Tuomilehto J. Incidence of childhood type 1 diabetes worldwide. *Diabetes Care.* 2000;23(10):1516-26.
7. Sartorelli DS, Franco LJ. Tendências do diabetes mellitus no Brasil: papel da transição nutricional. *Cad Saúde Pública.* 2003;9(1 Supl):529-36.
8. Rosa RS, Schmidt MI, Duncan BB, Souza MFM, Lima AK, Moura L. Internações por diabetes mellitus como diagnóstico principal na Rede Pública do Brasil, 1999-2001. *Rev Bras Epidemiol.* 2007;10(4):465-78.
9. Chipkevitch E. Puberdade e adolescência: aspectos biológicos clínicos e psicossociais. São Paulo: Roca; 1994.
10. Barbalha. Secretaria da Saúde do Município. Plano Municipal de Saúde 2002-2005. Barbalha (CE); 2005.
11. Outral J. *Adolescer: estudos revisados sobre a adolescência.* Porto Alegre: Artes Médicas; 2003.
12. Pliger C, Abreu IS. Diabetes mellitus na infância: repercussões no cotidiano da criança e de sua família. *Cogitare Enferm.* 2007;12(4):494-501.
13. Minayo MCS. *O desafio do conhecimento: pesquisa qualitativa em saúde.* 10ª ed. São Paulo: Hucitec; 2006.
14. Conselho Nacional de Saúde. Resolução n. 196, de 10 de outubro de 1996. Dispõe sobre diretrizes e normas regulamentadora de pesquisas envolvendo seres humanos. *Bioética.* 1996;4(2 Supl):15-25.
15. Bardin L. *Análise de conteúdo.* Lisboa: Edições 70; 1991.
16. Miller VA, Drotar DMA. Discrepancies between mother and adolescent perceptions of Diabetes-related decision-making autonomy and their relationship to diabetes-related conflict and adherence to treatment. *J Pediatr Psychol.* 2003;28(4):265-74.
17. Messias E, Skotzko CE. Psychiatric assessment in transplantation. *Rev Saúde Pública.* 2000; 34(4):415-20.
18. Silva DMGV. *Narrativa do viver com diabetes mellitus: experiências pessoais e culturais.* Florianópolis: Ed. UFSC; 2001.
19. Grossi SAA, Ciaccirullo TI, Manna TD. Avaliação de dois esquemas de monitorização domiciliar em pacientes com diabetes mellitus do tipo 1. *Rev Esc Enferm USP.* 2002;36(4):317-23.
20. Farrell SP, Hains AA, Davies WH, Smith P, Parton E. Impact of cognitive distortions, stress and adherence on metabolic control in youths with type 1 Diabetes. *J Adolesc Health.* 2004;34(6):461-67.