

THERAPEUTIC ITINERARY AND EXPERIENCE OF FAMILIES AND ADOLESCENTS WITH TYPE 1 DIABETES MELLITUS

Itinerário terapêutico e vivência dos familiares e adolescentes com diabetes mellitus tipo 1

Itinerario terapéutico y vivencia de los familiares y adolescentes con diabetes mellitus tipo 1

Original Article

ABSTRACT

Objective: To know the experience of families and adolescents with type 1 diabetes mellitus (DM1) regarding the disease and the therapeutic itinerary to the public health care system. **Methods:** Qualitative exploratory research conducted from August to September 2015. Participants were ten adolescents with type 1 diabetes mellitus and their family members who participated directly in their care in three Health Centers of Santa Catarina - Brazil. Open interviews were carried out with adolescents and their family members in addition to field observation. Data underwent thematic analysis. The analysis resulted in the construction of three categories: feelings experienced after the discovery of the disease; living with type 1 diabetes mellitus and; health care system in monitoring the person with DM1. **Results:** The discovery of the disease is accompanied by concern and requires changes in the routine of the whole family. The biggest challenge relates to adjusting eating habits. Acceptance of the disease is complicated by the adolescence condition and living with diabetes is riddled with doubts about the future. In the health care system, the therapeutic choices of families and adolescents are focused on specialized care. **Conclusion:** The constitution of the therapeutic itinerary of adolescents and family members is marked by the use of several resources that go beyond the boundaries of health services, which should be prepared to support families living with this condition.

Descriptors: Adolescent; Diabetes Mellitus; Chronic Disease; Public Health.

RESUMO

Objetivo: Conhecer a vivência dos familiares e de adolescentes com diabetes mellitus tipo 1 (DM1) em relação à doença e ao itinerário terapêutico para a rede pública de saúde. **Métodos:** Pesquisa exploratória de natureza qualitativa, realizada nos meses de agosto a setembro de 2015. Os participantes foram dez adolescentes com diabetes mellitus tipo 1 e seus familiares que participavam diretamente dos cuidados em três Unidades de Saúde de Santa Catarina - Brasil. Realizou-se entrevista aberta com adolescentes e familiares, bem como observação de campo. Os dados foram tratados por análise de conteúdo temática. A análise resultou na construção de três categorias: sentimentos manifestados após a descoberta da doença; conviver com diabetes mellitus tipo 1 e; a rede de atenção à saúde no acompanhamento da pessoa com DM1. **Resultados:** A descoberta da doença vem acompanhada de apreensão e requer mudanças na rotina de toda a família. O maior desafio refere-se à adequação dos hábitos alimentares. A aceitação da doença é dificultada pela condição da adolescência e a convivência com o diabetes é permeada de dúvidas quanto ao futuro. Na rede de atenção à saúde, as escolhas terapêuticas utilizadas pelas famílias e adolescentes estão centradas na atenção especializada. **Conclusão:** A constituição do itinerário terapêutico dos adolescentes e familiares é marcada pelo uso de variados recursos que extrapolam as fronteiras dos serviços de saúde, que devem preparar-se para apoiar as famílias que vivem com esta condição.

Descritores: Adolescente; Diabetes Mellitus; Doença Crônica; Saúde Pública.

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RESUMEN

Objetivo: Conocer la vivencia de los familiares y adolescentes con Diabetes Mellitus tipo 1 (DM1) respecto la enfermedad y el itinerario terapéutico de la red pública de salud. **Métodos:** Investigación exploratoria de naturaleza cualitativa realizada en los meses de agosto y septiembre de 2015. Los participantes fueron diez adolescentes con DM1 y sus familiares que participaban directamente de sus cuidados en tres Unidades de Salud de Santa Catarina - Brasil. Se realizó una entrevista abierta con adolescentes y familiares así como la observación de campo. Los datos fueron analizados a través del contenido temático. El análisis ha resultado en la construcción de tres categorías: sentimientos manifestados después del diagnóstico de la enfermedad; convivir con el DM1 y; la red de atención a la salud en el seguimiento de la persona con DM1. **Resultados:** El diagnóstico de la enfermedad se junta a la aprensión de la persona y requiere cambios de la rutina de toda la familia. El mayor desafío se refiere a la adecuación de los hábitos alimentarios. La aceptación de la enfermedad es más difícil debido la condición de la adolescencia y la convivencia con el diabetes es llena de dudas sobre el futuro. En la red de atención a la salud, las elecciones terapéuticas utilizadas por las familias y adolescentes están centradas en la atención especializada. **Conclusión:** El itinerario terapéutico de los adolescentes y familiares es marcado por el uso de varios recursos que ultrapasan las fronteras de los servicios de salud los cuales deben prepararse para apoyar a las familias que viven con esta condición.

Descriptor: Adolescente; Diabetes Mellitus; Enfermedad Crónica; Salud Pública.

INTRODUCTION

Chronic conditions begin and evolve slowly. They usually present multiple causes that vary over time, including heredity, lifestyles, exposure to environmental factors, and physiological factors⁽¹⁾. Diabetes mellitus is a chronic disease, for which there is no cure; however, one can control glycemic levels in order to avoid complications and lead a quality life, which requires changes in lifestyle, particularly the adherence to healthy eating and physical activity associated with pharmacological treatment⁽²⁾.

Type 1 Diabetes Mellitus (DM1) is the second most common chronic disease of childhood, accounting for 90% of cases of childhood diabetes; however, only 50% of cases are diagnosed before age 15⁽³⁾.

Adolescence is the transition period between childhood and adulthood encompassing ages 10 to 19⁽⁴⁾. It is characterized by physical, mental, emotional, sexual, and social development impulses and by the individual's efforts to achieve goals related to the cultural expectations of the society in which they live⁽⁵⁾. After finding out they

have a chronic disease, such as diabetes mellitus, the child and/or the adolescent change their behavior. In turn, family members will also have to adjust to this new situation and are very important for the support and success of the adolescent's treatment.

Given the chronic condition of the adolescent with DM1 and the need for more integrative professional practices, it becomes relevant to understand the experience of illness and the search for care, highlighting the road taken and hence providing answers⁽⁶⁾.

Knowing the Therapeutic Itinerary-TI of these users in the search for DM treatment in the primary health care system allows to analyze the support networks built by them and their family during the experience of illness and the search for care, showing that new networks are built while these people move from one place to another⁽⁶⁾.

On the other hand, health care networks (*Redes de Atenção à Saúde – RAS*) should be configured as institutional designs in the various points of health care and support systems in a balanced way, establishing criteria for access to services⁽⁷⁾.

Professional care for adolescents with DM1 in the public health system – where the authors work – is a reality. Because it is a phase of many transformations, the disclosure of the diagnosis triggers a new phase of adaptation and search for care in the services available in the public health system.

The Médio Vale do Itajaí-MVI region, in Santa Catarina – Brazil, has an extensive Primary Health Care (PHC) network consisting of Primary Health Care Centers (*Unidades Básicas de Saúde – UBS*) and Family Health Strategy (*Estratégia Saúde da Família – ESF*) centers, which are responsible for monitoring and organizing the care provided to the population living in territories under their coverage at any point in the RAS.

There is still little participation of the primary health care system in the care of these adolescents. Therefore, the secondary health care system assumes such responsibility and does not share the therapeutic project with the primary care team. The services overlap and are often characterized by a dispute over efforts for care and the non-delivery of networked care. The adolescent with DM1 is linked to the medical specialist and the family seems to find more safety against instability in the course of the disease. Thus, the contact of this family with the ESF, in relation to the follow-up of this patient, can be limited to the delivery of the necessary inputs.

In view of the difficulties faced by adolescents and their families in discovering DM1 and the various possibilities of family and professional care, the present study included the following presuppositions: What is the experience of family members and adolescents with type 1 diabetes mellitus

(DM1) regarding the disease and the therapeutic itinerary to the public health care system?

Given this context, the present study aimed to know the experience of families and adolescents with type 1 diabetes mellitus (DM1) regarding the disease and the therapeutic itinerary to the public health care system.

METHODS

This article is part of a qualitative exploratory Public Health Master's thesis.

The research was carried out at a Specialty Polyclinic (*Policlínica de Especialidade-PU*) and a Diabetes Support Center (*Núcleo de Apoio ao Diabético – NAD*) run by Municipal Health Secretariat (*Secretaria Municipal de Saúde – SEMUS*) of a region of the state of Santa Catarina, Brazil, and at a University Polyclinic (*Policlínica Universitária – PU*) of the Regional University of Blumenau (*Universidade Regional de Blumenau – FURB*). These facilities account for 100% of the services that exclusively serve users of the Unified Health System (*Sistema Único de Saúde – SUS*) and constitute secondary care reference facilities in the Médio Vale do Itajaí region, with 78 children and adolescents enrolled.

Participants were ten adolescents with DM1 and ten family members directly involved in the adolescent's care. The study included adolescents with DM1 aged 12 to 17 years receiving care at one of the region's reference who had been diagnosed with DM1 for at least one year and accepted to participate in the research.

The adolescents and their families were invited to participate by the researcher while they waited for the scheduled medical appointment in the waiting room and by telephone using the list of adolescents enrolled in the services due to the low attendance at the medical consultation. The interviews were carried out in the facilities (six) and at home (four) according to participants' choice.

The study excluded adolescents who: did not have DM1; were less than 12 or over 18 years old; were not served by one of the region's reference services; had not been diagnosed for less than 1 year; did not agree to participate in the study; did not have the time and availability to participate in the research.

Saturation of data occurred from the seventh until the tenth interview. Therefore, the sample was completed.

Open interviews were carried out with each family member and adolescent, as well as field observation, linked to the medical consultation or at home, from August to September 2015 by the researcher. The interview contained identification data addressing the variables (gender, age, place of birth, time since diagnosis, interviewee's degree of kinship and reference service used).

All the interviews were fully recorded and guiding questions were: Tell me what you felt when you discovered that you or your child had this disease? Tell how you have experienced diabetes after discovering that you/your child had the disease? How has the path from the discovery of the disease to the treatment facility been followed?

Field observations of posture, expressions of joy, sadness or anguish were recorded in the observation sheet after each interview. Interviews were transcribed by the researcher on the day of collection and on the following day in order to maintain the reliability and comprehensiveness of the statements.

Data were treated using content analysis⁽⁸⁾. Each interviewee was identified by the letter I and a sequential number until I10. Adolescents were identified by the letter A1 successively until A10. The following sequential order – I8, I8f and I8m was used to identify the father, grandfather and grandmother, respectively. After successive readings of the interviews, the material was organized according to the methodological procedures of content analysis on the basis of qualitative approach: categorization, inference, description and interpretation. These steps do not necessarily occur in a sequential way⁽⁹⁾.

The categories that emerged from the study were: feelings experienced after the discovery of the disease; living with type 1 diabetes mellitus and; health care system in monitoring the person with DM1.

The project was approved by the FURB Ethics Committee under Opinion No. 1.124.736. Data collection began after clarification of the research objectives, guarantee of anonymity, clarification of doubts and signing of a Free Informed Consent Form.

RESULTS AND DISCUSSION

The research results and analysis section will discuss the identification data of the adolescents and the degree of kinship of family members. The categories that emerged from the study are also presented.

Adolescents' identification data

The adolescents who participated in the study were mostly female: seven girls and three boys. They were between 12 and 15 years old. Eight of them lived in Blumenau, one in Pomerode and one in Benedito Novo. Time since diagnosis ranged from two to 13 years. Six participants received care at the PU-FURB, three at the NAD and one at the PU-SEMUS. The family members who participated in the study were four mothers, three fathers, one stepmother and one brother. Additionally, a collective interview was held with one father, one grandmother and one grandfather.

Feelings experienced after the discovery of the disease

This category describes the feelings experienced by adolescents and families after discovering the disease. For most of the interviewees, the discovery of the disease occurred unexpectedly as a surprise or fright, and for many of them the discovery meant a new demand for care that led family members to give up time for themselves, causing even changes in their work routine. This is reported as follows:

"In fact, the discovery of the diagnosis was a surprise [...], an unexpected one." (A3)

"Pretty bad! We live our lives for him, we no longer live for ourselves, only for him [...]. It's difficult for us." (I9)

"I had to change my work schedule and everything [...]. I had to change all the service routine, everything. [...] I worked the first shift in the morning, now I work at night." (I9)

This renunciation of self can suspend activities carried out by parents and involve work, school, leisure and family relations. It keeps them, most of the time, in expectation of the health needs imposed by adolescents' chronic disease, a situation that is also found in families that have children with sickle cell anemia⁽¹⁰⁾.

The way one's work is organized is fundamental to allow adjustments in order to take care of the children⁽¹⁰⁾. The changes do not occur only in the work schedule, but also in the financial adjustments that the family has to restructure.

The suspected diagnosis was identified by family members and adolescents in various ways, mainly due to signs and symptoms reported by health services and the media, such as the smell of acidosis, weight loss, polydipsia, polyuria, tiredness and sweating, as observed in the following statements:

"I was feeling very tired and my legs ached for about 15 days and my mother felt my breath smelled of apple" (A1)

"My wife noticed he was going to the toilet frequently, drinking a lot of water, then she suspected of something and took him to take a test and the test diagnosed diabetes." (I9)

After the identification of signs and symptoms suggestive of diabetes for the majority of people with diabetes, the family seeks health services in search for treatment. Regarding the diagnosis, the majority were confirmed in primary health care services and the rest were confirmed in private clinics, services covered by health insurance or at a hospital:

"At the health center [...]. As soon as I mentioned my thirst, he (the physician) took the glucometer, did the test

and the level was five hundred and something." (A3)

"I took him to the pediatrician who has treated him since she was a baby. He suspected and requested some examinations and she was already like that, she was practically going to get into a coma because her blood glucose level was very high." (I5)

Emotion, apprehension and fear could be noticed when they talked about the time between suspicion and confirmation of the diagnosis, and it seemed that they felt lost. The confirmation of the diagnosis of diabetes has a strong impact on the family and gives rise to many concerns⁽¹¹⁾.

The information acquired through the posters displayed at the health center assisted one of the mothers in suspecting the diagnosis:

"I always go to the center and I always read the posters there [...] I told everyone at home that I thought he had diabetes because I saw those posters at the center talking about the symptoms of diabetes." (I7)

The visual information provided by the team helped this mother to suspect the disease that was confirmed. It was verified that health education is a potential tool widely used by professionals in the waiting room, as users awaiting care can read the material displayed on the walls. Knowledge about oneself and the health-disease process contributes to the change and adoption of new habits⁽¹²⁾.

One of the mothers initially suspected that her daughter was trying to lose weight given that she was in her teens and did not accept her weight:

"She began to lose weight, lost more than 20 kilos, and began to get really thin [...]. She was very thirsty and very sleepy, so I even thought she was having fat loss issues, you know, those girls who are chubby and want to lose weight [...]." (I6)

The mother related her daughter's weight loss to aesthetic, moral, cultural values and the body control demanded by contemporary society, which may have delayed diagnosis. The cult of the good shape socially imposed is associated with health as opposed to obesity stigmatized as morbid⁽¹³⁾. In addition, adolescents are often considered a nutritional risk group due to inadequate eating habits⁽¹⁴⁾.

One participant who took her granddaughter to the health center due to suspected diabetes said his feelings, anxiety and knowledge were disregarded by the physician, delaying diagnosis and making the family look for another service which embraced and investigated the complaint and thus confirmed DM1.

Studies indicate that the experience of illness is delegitimized by medicine when not proven by medical diagnoses⁽¹³⁾. In this case, the complaint was neither valorized nor investigated in order to explain and signify the signs and symptoms perceived by the grandfather. The family that sought the primary health center, which is the main gateway to the Unified Health System (*Sistema Único de Saúde – SUS*), had to knock on the door of a reference service in order to be listened to. There is evidence of a rupture in the institutional road taken by the family that started with the physician who did not embrace them. After that, the continuity solution in the RAS is materialized as the secondary care service does not communicate with the primary care team that serves the family.

The practices carried out by health professionals since the discovery of the disease, in daily living and in the future phases, are fundamental for families and adolescents as they will always be present, whether in primary, secondary or tertiary care.

Families seek the health services that best embrace and meet their needs. However, the decision to remain at a diabetes treatment facility appears to be related to the family's relationship with the physician.

“She was a diabetes physician whose services were covered by the health insurance [...] He (the son) did not like her very much.” (I9)

“[...] There was just that little problem there [Furb], we even liked her when we came here. It (NAD) is more specific, we think we'd better stay here.” (I1)

Living with type 1 diabetes mellitus

After the feelings triggered by the impact of the discovery of the disease, the adolescents and their families needed to adjust to a new reality: living with type 1 diabetes mellitus, which is the theme of this category.

Accepting diabetes disease is a major challenge for parents and adolescents, but facing the new reality and adjusting to many changes are inevitable, as shown in the following statements:

“Yes, I was hospitalized because my blood sugar levels topped 600 mg/dl. Then the psychologist came to talk to me, a lot of people came to talk to me, to explain to me what diabetes was, [...] even then, I did not understand. I spent some time there to get to know what diabetes was, but until now I just cannot get it, you know.” (A2)

Accepting the disease requires time and support from health professionals, family members, friends, and the school. It is fundamental that the person and his/her family members receive clear information about their health status at the right time⁽¹¹⁾.

It is difficult for adolescents to understand and accept that diabetes will be present throughout their life, even when they are diagnosed in childhood. When they reach adolescence, they start going through moments of denial. In this period of many transformations, there is a need for multidisciplinary support and networked care, for adolescence is already a phase of many physical, mental, emotional, sexual and social transformations⁽⁵⁾. And along with the questioning of the disease comes the need to control blood glucose and to test and take insulin, causing suffering in parents and children:

“Think about it! Every day you have to handle insulin. Now he injects it on his own, but I used to inject it. It was also not easy for me, I'm not a nurse, I never handled a needle. Think about his situation night and day. Everybody says 'oh, it could be worse', each one is unique.” (I7)

The mother's despair at her child's daily routine is evident. Given that, professionals often focus on providing guidance to mothers rather than involving all the family members and the adolescent himself.

Physicians see the family, particularly the mother, as the protagonist of the child's pain and hence mythicize the mother, who is seen as heroine, in such a way that the child becomes “invisible”. Therefore, they underestimate the woman with regard to the greatness of the “mission” that fits the mother's role⁽¹⁵⁾.

Many participants related the onset of diabetes with stressful events experienced by their children.

“His disease came after his mother died. And because of this, the feeling triggered by such a loss [...]. She had breast cancer, completed the treatment and after five years it came back stronger and she passed away.” (I3)

It became clear to the family members that diabetes can be triggered by traumatic events. Authors state that the interaction of genetic, immunological and environmental factors in the etiology of type 1 diabetes is a subject of constant research⁽¹⁶⁾.

Adolescents find it difficult to change their daily routine for the disease and often demonstrate this in the form of rebellion:

“He is rebellious. [...] He is, how can I say, sick and tired of this. It is hard to deal with him. [...]. Because he was not like that. He does not want to go to the consultations anymore, does not want to take the test, he sometimes gets angry, he eats a candy in secret.” (I7)

The statements proved that the adolescence phase makes it even more difficult to accept the disease and the care needed to keep it stable. On the other hand, the

adolescent wanted to be like his/her peers, but the care imposed by the disease makes it difficult.

Restrictions and limitations were perceived by parents and children as punishment and orders to be followed. However, in their current life, they are duties that have no meaning in their experience of illness, but if not followed, there may be complications in the future⁽¹⁷⁾.

Living with diabetes is full of doubts and fears about the future and the availability and possibility of accessing new technologies for treatment and cure of the disease, as seen in the following statements:

“Sometimes I have doubts. Her pancreas does not function properly. How much does it function? Where should you go to get a pancreas transplant? Is it normal? Is it easy to get? [...] If one day she marries, will she get pregnant? [...] Will she need a C-section?” (I10)

It is observed that even after years of the discovery of the disease, families still have many doubts that lead to questioning how the care of these family members has been performed. Have professionals during consultations taken the time to clarify patients’ and families’ doubts? Once again, the importance of networked and multidisciplinary care should be highlighted.

The challenge regarding food was reported by all the interviewees as the one that mostly interferes in family life. Dietary adjustments are required and are often seen as a sacrifice:

“Everyone has changed their eating habits along with me.” (A1)

“Oh, controlling candies. [...] I like candies, but then you have to control them because she cannot eat them, we have to try to take it easy.” (I5)

The aforementioned statements corroborate a study⁽¹⁶⁾ that emphasizes the restructuring of the food menu used before the discovery of the children’s diabetes and the adoption of new habits through the education of the whole family group.

Dietary changes involving the whole family are fundamental for the glycemic control of adolescents, making this change less difficult to adolescents as they realize that the family is involved in this process.

Close relatives such as uncles and grandmothers shared some concerns regarding food when they receive the adolescent in their home, which can be seen as follows:

“Even when we go to someone’s home, they usually prepare something for him to eat.” (I3)

This statement reinforces the need for the involvement of all direct or indirect family members who collaborate in

the care of adolescents with DM1. Health professionals play an essential role in the exchange of information to assist in this demand.

The school’s participation in the control over adolescents’ dietary habits was seen as a positive factor by several interviewees:

“The school provides a special snack to her. We sent them a document and informed them about it. Then, they soon started to care about.” (I8)

“It is that his food would be good for the others as well. Better than that sugar crap [...].” (I7)

I7’s concern and understanding is highlighted here as the participant states that the healthy food given to the child should be the same for all students at the school. It is believed that this change in the preparation of school meals could provide a healthier life to all students regardless of whether or not there is a disease that requires such care.

It should be emphasized that diabetes education should be centered on the multidisciplinary team, the family system, the user, and on social facilities such as schools with a view to promoting adherence to aspects of treatment other than medication⁽¹⁷⁾.

However, for some of the study participants, the social interaction with friends or close people was seen as negative factor regarding food issues:

“[...] the most difficult thing is hanging out with friends. Friends are there drinking soda and it is difficult for him to control himself.” (I9)

“She even controls herself at home, but she hangs out a lot, then she eats a candy at someone else’s home, there is no candy at home [...] she goes to the gas station and they give her lollipop and she cannot have it. [...].” (I4)

Close people’s and friends’ lack of knowledge or concern ended up causing great distress to adolescents and their parents as food control is deregulated, which may have serious effects on blood glucose levels.

The greatest difficulty reported by parents is related to diet; on the other hand, children and adolescents with diabetes feel different from their peers due to dietary restrictions⁽¹⁷⁾. Eating is related to socialization in adults as well. Studies⁽¹²⁾ show that hypertensive people’s adherence to salt and fat restricted diets is low because they contradict the habits in which they were socialized.

The research participants reported that another factor hindering the adoption of a healthy diet was the cost of special foods for their children:

“Food for people with diabetes is more expensive. [...] a lot more. How are you going to treat a patient if things are

more expensive than normal? [...] if they (the government) could lower the price of food, they would help everyone.” (I9)

The high cost of purchasing adequate food for DM1 patients ends up compromising adolescents' glycemic control because it is known that food is one of the main items for such a control.

The cost of new and specific foods for the disease and the children's dietary restrictions justify the parents' difficulty in relation to food⁽¹⁷⁾.

With regard to the diet that would be adequate for the adolescent with diabetes, there are two different views. First, the healthy food targeted at any individual can also be consumed by the person with diabetes. Second, foods for the person with diabetes should be special and mostly composed of light and diet products, which is recommended by many professionals.

One study showed that the knowledge of Primary Care professionals about the relationship between diet and diabetes is still permeated by confusion, especially regarding the differences between diet and light products and the need to recommend their intake by people with diabetes⁽¹⁸⁾.

Notwithstanding these different perceptions, both diet and light products and those that should constitute a healthy diet have a high cost that makes them difficult to be bought.

There is a need for public policies to stimulate the marketing of healthy foods, not only to people with diabetes, but also to people in need of health care in order to prevent the onset of diseases.

The health care system in monitoring the person with DM1

This category explores the points of the health care system – primary, secondary and tertiary care – in the monitoring of the person with DM1 and in the constant search for a better resolution capacity.

All the interviewees revealed that when they are faced with the disease they use the secondary level of care for the treatment and follow-up of their children, maintaining a weak relationship with the primary level of care, which is mostly used to access the inputs offered by SUS:

“We get the insulin at the health center.” (I9) “We get the test strips.” (A9)

“Sometimes, we hardly ever go there [the health center]. But if we do everything he asks us to do, we get the exams, the medicines, the prescriptions, we get almost everything here.” (I1)

Other authors⁽⁹⁾ also verified that the family maintains an extremely weak relationship with the ESF center in the neighborhood where they live.

The lack of a networked care was identified in both the SUS and the private services and is a great challenge to be faced. This finding contradicts the recommendations of the Ministry of Health, which establish that the RAS must act in an articulated way in the different levels of care with a view to guaranteeing comprehensive health care⁽¹⁹⁾.

The care provided should be ordered by primary health care centers with the support from secondary and tertiary care services so that it is possible to intervene – in a balanced way – in the social determinants of health⁽¹⁾. Therefore, communication between the teams of the different points of the health care system is essential to the care of adolescents with diabetes.

It can be seen that the relationships built narrowly were established between the physician and the user and family, that is, the user was bound to the physician and not to the service, even in cases where he/she is enrolled in a family health center:

“By phone. He (the physician) is very dear to us, very attentive. He sent emails and other stuff. If I have any doubts and I cannot talk to him right away, he calls me back or sends an email.” (I5)

However, some individuals had their access to PHC denied or reported the little resolution capacity of specialized care services, highlighting conflicts in the relationship with the services:

“I hit the health center door several times, she was going into a coma and they did not take care of her.” (I4)

“I consulted with him (the physician), he could not normalize my glucose levels so he decided to refer me to FURB.” (A2)

The difficulties faced at the health services cause family members and users to move from one place to another within the health care system in search of a service that best addresses their needs and the treatment of their children. Authors⁽²⁰⁾ comment that several factors contribute to access to health services, such as adequate flow, resolution capacity and quality.

If on one hand it is desirable that every meeting between each health professional and the user be a space for the manifestation of their subjectivities and co-responsibility in the construction of the therapeutic project, on the other, this restricted relationship with the physician greatly limits the chances of a successful therapy, which, when it comes

to diabetes, is not possible without interprofessional work. It seems that even in the services in which the adolescent received care from other professionals, the biomedical care model still predominates.

A good relationship between health professionals and the person with the disease and their families is fundamental to providing guidance on the care.

Several adolescents reported having, at some point, received care from other health professionals such as nutritionists, psychologists and dentists, and the possibility of scheduling a consultation with various professionals in the same period was a facilitating factor.

Based on these findings, the comprehensive care provided to DM1 patients needs to be put into effect by health professionals in their care practices as the probability of facing this experience and accepting other ways of living life depends on it⁽²¹⁾.

“There is a physician there (PU/Furb) [...], there is a nutritionist, a psychologist, so we see them all at once.” (18)

This report corroborates that the understanding and empathy of the multidisciplinary team that serves the family will facilitate the adherence of the adolescent with diabetes to the treatment and its integration into the society⁽¹¹⁾. In addition, adolescents who have a good family structure are more able to cope with diabetes and manage to improve their pathology. Additionally, the disease interferes less with their life⁽²²⁾.

The offer of education groups was a mechanism cited as a tool to support, guide and clarify doubts:

“It helped a lot, we learned a lot of things we did not know about food. Now, of course, we search a lot on the internet.” (17)

“[...] sometimes there is (in the education group) a nutritionist, a psychologist, a nurse, and they talk, they always talk about diabetes.” (A9)

Many professionals are discovering the great potential of a good dialogue with local community users and groups for the reorganization of health promotion and health care practices⁽¹²⁾.

It is believed that the involvement of people in the group may be positively influencing the way they understand the information by enabling the exchange of experience among participants.

FINAL CONSIDERATIONS

The results of this research allowed to know the experience of family members and adolescents with type 1

diabetes mellitus regarding the disease and the therapeutic itinerary used in the public health system.

The statements have revealed feelings of fear, anxiety, suffering, and uncertainty about the future triggered by the discovery of the disease, but the biggest challenge for adolescents and families to cope with diabetes is to change their dietary habits.

The therapeutic itinerary of adolescents with diabetes and their families includes the use of several resources until finding the one that best suits and assists them in the treatment and care of their children. This search for care ran through private clinics, facilities covered by the health insurance and services provide by the Unified Health System, characterizing a network of diversified paths and guidelines.

The therapeutic choices made by families and adolescents were focused on secondary care, with strong relationships with the physician and occasional support from other professionals such as nurse, nutritionist, and psychologist. Listening to the user's feelings and knowledge as “other”, diverse and legitimate, must be incorporated into professionals' practices as an ethical and technical imperative.

There is an urgent need to implement a public policy for networked care targeted at adolescents with DM1. In this model, the primary level of care should lead the care line and health teams should play a key role. Additionally, there should be collaborative interprofessional work and development of practices that contribute to comprehensive care.

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