

## **THERAPEUTIC ITINERARY OF THE FAMILY AND ADOLESCENT WITH TYPE I MELLITUS DIABETES<sup>1</sup>**

Mariza Maria Serafim Mattosinho<sup>2</sup>  
Denise Maria Guerreiro Vieira da Silva<sup>3</sup>

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*This is a qualitative assistential convergent study. Its main objective is to understand the therapeutic itinerary of adolescents with type 1 mellitus diabetes, as well as that of their families. The sample was composed of adolescents, between 15 and 25 years old, involved with a health institution in Florianópolis through the Health Care model that includes professional, family, and popular subsystems. Data were obtained through in-depth interviews and field observation of 20 people (relatives and adolescents with diabetes). The data analysis included data codification and categorization. Two categories were constructed: Decisions and negotiations about health, care and treatment; and the journey through the three subsystems of health care. The study permitted to understand that the treatment and care within the professional subsystem are not the only ones available. There are different practices in health performed from the evaluation each family makes, of what they believe adequate for their adolescent with diabetes.*

*DESCRIPTORS: diabetes mellitus; adolescent; empathy; family*

## **EL ITINERARIO TERAPÉUTICO DEL ADOLESCENTE CON DIABETES MELLITUS TIPO I Y SUS FAMILIARES**

*Estudio de naturaleza cualitativa, de tipo convergente-asistencial, tuvo como objetivo comprender el camino terapéutico de los adolescentes con diabetes mellitus tipo I y sus familiares, vinculados a una institución de salud de Florianópolis, entre las edades de 15 y 25 años, a través del modelo del Cuidado para la Salud, que incluye los subsistemas profesional, familiar y popular. Los datos fueron obtenidos a través de la entrevista en profundidad y la observación de campo con 20 personas (familiares y adolescentes con diabetes). El análisis incluye la codificación y la categorización de los datos. Fueron construidos dos categorías: Las decisiones y negociaciones sobre la salud, los cuidados y los tratamientos y El percurso en los tres subsistemas de la salud. El estudio permitió comprender que los tratamientos y los cuidados del subsistema profesional no son los únicos, existiendo diferentes prácticas en la salud que son realizadas a partir de la evaluación que cada familia hace a partir de aquello que considera adecuado para el adolescente con diabetes mellitus.*

*DESCRIPTORES: diabetes mellitus; adolescente; empatía; familia*

## **ITINERÁRIO TERAPÊUTICO DO ADOLESCENTE COM DIABETES MELLITUS TIPO 1 E SEUS FAMILIARES**

*Estudo de natureza qualitativa, do tipo convergente assistencial, objetivou compreender o itinerário terapêutico de adolescentes com diabetes mellitus tipo 1 e seus familiares, vinculados a uma instituição de saúde de Florianópolis, SC. Foi utilizado o modelo de Cuidado à Saúde de Kleinman que inclui os subsistemas profissional, familiar e popular. Os dados foram obtidos através de entrevistas semi-estruturadas e observação de campo com vinte pessoas: familiares e adolescentes com diabetes. A análise incluiu a codificação e categorização dos dados. Foram construídas duas categorias: decisões e negociações sobre a saúde, os cuidados e os tratamentos e o percurso nos três subsistemas de saúde. O estudo permitiu compreender que os tratamentos e cuidados do subsistema profissional não são únicos, havendo diferentes práticas em saúde que são realizadas a partir da avaliação que cada família faz daquilo considera adequado para o adolescente com diabetes mellitus.*

*DESCRIPTORES: diabetes mellitus; adolescente; empatia; família*

<sup>1</sup> Article extracted from Master Thesis, funded by CNPq; <sup>2</sup> RN, State Secretary of Health, Santa Catarina, Brazil, Health Education School /EFOS, Brazil, e-mail: marizaserafim@yahoo.com.br; <sup>3</sup> PhD Professor, Santa Catarina Federal University, Brazil

## INTRODUCTION

We have noticed, in our health care practice developed at a teaching hospital with adolescents suffering from type 1 diabetes mellitus, that health professionals focus their practice on health education, but from a perspective that involves information regarding the disease, treatment, and the procedures to be performed, mostly concerning glycemic control. However, we observed that a majority of adolescents present exams with glycemia parameters above normal range. This fact aroused some questions regarding the developed practice, revealing a gap between what we instruct and what they actually do.

The impact of diabetes on society has been discussed for quite some time<sup>(1)</sup>, not only through social and economic repercussions, but also by the implications it entails for the person's life, which include: pain, suffering, hopelessness, anxiety, isolation, incapacity, mutilation and death. Chronic diseases cause changes not only to the organism's structure and functioning, but also to one's living conditions and quality. Living with a chronic disease becomes a reality people and their relatives have to learn how to deal with<sup>(2-3)</sup>.

This impact on people's lives appears to be even more important when it affects an adolescent and his/her family. The adolescence phase often becomes a critical moment for controlling the disease because the necessary restrictions oppose the quest for independence, the tendency of belonging to a group, the idea of indestructibility, risk behaviors, among other characteristics of this age group.

Considering health care to adolescents with diabetes mellitus, the family plays a fundamental role. Since 1962, it has been emphasized<sup>(4)</sup> that one of the main causes of emotional troubles involving adolescents is their parents' attitude. Their feeling of guilt, which sometimes takes over them, makes them assume excessively protective behavior towards the adolescent, making him/her dependent<sup>(5)</sup>.

Diabetes entails important repercussions for adolescents' everyday life because this health condition requires a series of special habits, which reinforces even more the family's importance in caring for its members and the influence it exerts on health care practices.

Therefore, families and adolescents with diabetes mellitus should be known and recognized considering their histories and experiences, regarding

the structure, various conformations and meanings they attribute to health and disease, but also regarding mutual commitments, interactions, role performance, cultural aspects and life modes<sup>(6)</sup>. The family participates in health care, helping them in different ways, but mainly by staying together and giving support in making decisions regarding healthcare procedures and treatments, in the search for a better-quality life<sup>(7)</sup>.

In chronic health situations, like in the case of diabetes mellitus, people perform different care procedures and treatments, with a view to finding a solution to their problem. The medical prognosis that diabetes is incurable, and that it can only be controlled, is often extremely aggressive to people. They have to believe that something else can be done and, therefore, they search for treatment alternatives. Professional knowledge is not the only knowledge involved in health care. There are others: the knowledge of the person living the situation of their loved ones (relatives, friends, neighbors) and of other cure agents.

Until today, little is known about the care and treatment used besides biomedicine. This makes it difficult to maintain an open dialogue with these adolescents with diabetes mellitus and their families. When we provide health care service to a person with a chronic health condition, with a view to a healthier lifestyle, it is important to go beyond the physical and psychological. It should be understood that the experiences obtained by these people throughout the process of living with the disease will guide the decision making process regarding health care procedures and treatments they will subject themselves to, which is referred to as the therapeutic itinerary.

Hence, we believe that studies about therapeutic itinerary can play an important role to understand how people build their own paths to deal with the demands and consequences of a chronic disease.

In this perspective, this study aimed to find answers to the following question: **What is the therapeutic itinerary followed by adolescents with type 1 diabetes mellitus and their relatives in the search for treatment and health care?**

The study objectives were: 1) to learn about the healthcare practices and treatments performed by adolescents with type 1 diabetes mellitus and their relatives; 2) to identify the elements that participated

in the evaluations carried out by adolescents with type 1 diabetes mellitus and their relatives regarding the performed health care and treatments; 3) to identify the influence of popular, family and professional subsystems on healthcare practices of adolescents with type 1 diabetes mellitus and their relatives, in the search for treatment and care.

## THEORETICAL BACKGROUND

The research was guided by Arthur Kleinman's method and by the concept of therapeutic itinerary. Healthcare activities are social responses organized to face diseases and can be understood as a cultural system: the Health Care System<sup>(8)</sup>.

The Health Care System provides people with paths to interpret their condition and possible actions in the search for treatment of their disease. Moreover, it is in the mutant and dynamic social reality that diseases are constructed, as well as their treatment and cure process<sup>(8)</sup>.

This System is internally constructed by the interaction of three subsystems: **Family Subsystem, Professional Subsystem and Popular Subsystem.**

The **Family Subsystem** is the arena of popular culture, non-professional and non-specialist common sense, where diseases are first identified and dealt with. This subsystem includes the individual, the family, the social network and the members in the close community. It is in this subsystem that the disease is identified, and the first decisions and actions are made, which initiate the therapeutic process<sup>(8)</sup>.

The **Professional Subsystem** consists of the organized cure propositions, legally recognized, involving formal learning, and extremely developed systematic registers. In most societies, biomedicine prevails, despite the existence of other professional medical systems, like Traditional Chinese medicine<sup>(8)</sup>.

The **Popular System** consists of non-formal cure specialists, who are not legally recognized, and with registers limited to their knowledge. They are widely recognized by society and are generally connected to the family subsystem<sup>(8)</sup>.

The therapeutic itinerary includes a sequence of decisions and negotiations among several people and groups with diverse interpretations regarding disease identification and choosing adequate treatment. It includes the path followed in the search

for treatment and cure, as well as the evaluations of the different results obtained<sup>(9-10)</sup>. In this study, the therapeutic itinerary was understood as the path the adolescent with diabetes and their relatives follow in their search for care and treatment of his/her health condition.

Several aspects are taken into consideration when choosing the path, including disease signs (regarding the body or not), beliefs, diagnoses and prognoses. In addition to these factors, there is a plurality of interpretations represented by the person's position, resource availability and a previous relationship with cure specialists<sup>(10)</sup>.

## METHODOLOGICAL ASPECTS

This is a qualitative, convergent care research, performed at a teaching hospital and at the homes of adolescents with diabetes and their families, who received health care at this hospital.

The main characteristic of a convergent care research is its intentional articulation with healthcare practice. It is conducted to discover realities and solve specific problems in specific contexts<sup>(11)</sup>.

Healthcare practice includes the development of a health education proposal with the intention to promote greater participation of adolescents and their families in care and treatment through home visits.

### Study subjects

Twenty subjects participated in this study: five adolescents with type 1 diabetes mellitus and fifteen family members. These adolescents were residents of the Florianópolis Region, who participated in a multiprofessional healthcare service for people with diabetes mellitus, linked to a teaching hospital. Adolescents were selected according to the following criteria: aged between 15 and 21 years and 11 months; diagnosed with type 1 diabetes mellitus established for at least two years; time and availability to participate in the research and difficulty to follow the treatment, represented especially by repeated results with high glycosylated hemoglobin levels.

During the home visits, relatives who lived in the same home and participated, directly or indirectly, in the healthcare provided to the adolescent, were invited to participate in the research.

## Data Collection

Data were obtained through interviews and field observation, performed at the homes, with an average of three to five meetings per family. The purpose of the interviews was to learn about and understand what people did to care/treat diabetes. The interviews were tape-recorded.

## Data Analysis

Data analysis was performed according to the following steps: data organization; repeated readings of the obtained data by the research group; identification of the codes related with care and treatment, as well as the evaluations about the decisions that were made and the obtained results; creating categories, understood as the set of expressions with similar characteristics that represent the therapeutic itinerary of the people who took part in the investigation; discussion regarding the categories found; and interpretation of the findings<sup>(11)</sup>.

## Ethical aspects

The research was approved by the UFSC Human Research Ethics Committee, according to Resolution 196/96 by the National Health Council for research involving human beings, regarding secrecy, anonymity, informed consent (which adolescents with diabetes agreed to and with their parents' signature) and the right to withdraw from the research at any time.

## RESULTS AND DISCUSSIONS

Two categories were created as a result of data analysis: a) decisions and negotiations concerning care procedures and treatments; and b) the pathway in the three subsystems.

### Decisions and negotiations concerning the disease, care procedures and treatments

This first category was created based on the understanding of the study subjects' reports regarding what they did to take care of or treat their chronic health condition; that is, their therapeutic pathway. We realized that there is no linear sequence. Rather,

there is a process, with distinct moments, which initiates with the verification that something is different with their body, because they feel exaggeratedly thirsty, hungry and lose weight. Adolescents and their families start to search a name for that health condition and to identify the possible causes in order to establish possibilities of what to do. They begin experimenting from a wealth of knowledge they have about health care. If they do not achieve an effective result through these family practices, they look for the help of healthcare professionals, who then establish the medical diagnosis of diabetes mellitus and indicate some care and treatment alternatives.

### - The performed treatments and care

After establishing the medical diagnosis of diabetes mellitus, despite performing the indicated care and treatment, they continue searching other forms of caring for and treating their disease, motivated by the hope of curing and/or controlling the disease.

They use various treatments and care procedures, with no specific sequence, but according to the opportunities that come up, new indications and the achieved results. Some of these procedures and treatments are more common than others, and represented a reference for the study subjects.

**Teas and insulin** stand out because every adolescent in this study used them simultaneously with other therapeutic resources.

Teas are indicated by relatives and neighbors, who generally provide the plants. The indication is based on successful experiences of family and friends from using specific teas. Even when using the same type of tea (jambul - *Syzygium cumini*, pata de vaca - *Bauhinia forficata*, carqueja - *Baccharis trimera*), they use it in different ways concerning doses, preparation or form of ingestion (quantity and hours).

Regarding insulin, despite their understanding that it is essential to control the disease, it is hard for them to accept. Accepting it would mean that they understand that they have an incurable disease, which will demand significant changes, and that they will use insulin forever, which evidences their dependence on a chemical substance.

**Spiritual practices** experienced as a form of health care and treatment of the disease, followed by adolescents and their relatives, including visits to spiritualist centers, healers and specific prayers.

Adolescents and their families initially search for healers and spiritualist centers when they notice something different is happening and soon after the diagnosis. This search is based on the interpretation of the symptoms and on the search for an explanation of why they were affected by the disease.

Patients and relatives usually seek spiritual practices as a support for tense moments when coping with the disease, and they traditionally converge to a God that is powerful and above any human being.

For many people, these practices are comforting, relieve the symptoms, and can cure the disease. Besides, people who perform these practices are available to listen, interpret others' feelings and give advice with a more popular discourse. They report that the procedures do not cause any pain, are not bad for their health and are always available.

One element permeates every spiritualist practice performed by the adolescents and relatives: religious faith. It is present in every procedure and treatment they follow, regardless of the health subsystem. If faith is not present, they believe that neither the procedures nor the treatment will achieve the desired effect. This is strongly emphasized by the women, especially mothers.

**Diets and physical exercises** are considered the most difficult treatments. Patients recurrently report these treatments, even in different moments of the disease.

The conflict between recognizing its importance and not complying is not much explored and, thus, becomes a complex issue, difficult to define. Health professionals instruct these treatments, but the family also recommends them, with reinterpretations about what is or is not permitted. They focus the diet on excluding "sweets".

Cultural and food habits, as well as economic and social factors, contribute to this difficulty. In our culture, food plays several roles. It serves to supply our nutritional needs; to reward certain actions; in moments of anxiety and stress; and is the center of our social events. Food is the *sine qua non* element in social gatherings among friends and families<sup>(12-13)</sup>.

Participants report that the difficulty to perform physical exercises is associated with the lack of time, especially for those who work. They emphasize that physical exercises are not part of their daily habits.

**Medical appointments and exams** are considered "procedures" performed every two to three

months, and are not clearly recognized as health care or treatment.

For many adolescents, the constant need of being evaluated is tiring, stressful and becomes a source of apprehension. They report that contact in healthcare services with other people affected by diabetes complications, like blindness and amputations, makes them have negative expectations.

**Bottled balms** are used based on indications from relatives and neighbors, and are not referred to as a common practice.

Similar to teas, bottled balms are treatments people have used for quite some time to treat illnesses. They are prepared with roots, leaves, fruits and barks that are infused in sugar-cane brandy or wine. Most balms are administered orally, though some are only for topic use. We notice that participants are rather resistant to talk about this practice.

These care procedures and treatments do not follow any logic and are chosen in social interactions. The choices are associated with the moment they are experiencing. Crises and other stressful situations are moments that make them more fragile and increase their chance of trying new treatments. This reinforces that biomedicine is not considered the single valid knowledge that founds their choices. There are different possible itineraries, which are always strongly linked to the process of living with countless alternative choices<sup>(13)</sup>.

#### - Family participation

The chronic disease is incorporated into people's life process. Families are a fundamental part in this process, especially for adolescents, since the choices they make regarding healthcare and treatments are influenced by the family, who takes the role of a caregiver.

Many parents consider the moment of diagnosis as a moment of crisis. They change their relationships with their children in order to compensate them for the limitations imposed by the disease. For some parents, their child becomes special, "pampered" and is never left alone. This could also affect the adolescent's social interaction, especially because they consider themselves different and limit their world to the people around them. There is a family readjustment that makes it possible to accept and understand the diagnosis, as well as the recommendations for healthcare and treatment.

Participants always perceive the family as part of the process of caring for and treating the adolescent with diabetes mellitus.

- The evaluation of the performed treatment and care procedures

In the attempt to control the disease and to live better, adolescents and their relatives turn to several types of care and/or treatments, either simultaneously or successively in the different subsystems. Hence, the adolescent visits a doctor, a spiritualist center and takes some sort of tea, integrating these care procedures and treatments in different ways, which does not mean the need to abandon one care or treatment in order to start a new one. Each situation is evaluated within its specificity, considering different elements that involve their lives at that specific moment.

Adolescents and their relatives evaluate not only the care and treatment they receive, but also the way people indicate these care procedures and treatments. They emphasize the dialogue as essential, as it includes the possibility of their saying what they think, feel and how they perceive the disease.

Another fundamental aspect of the evaluation is treatment effectiveness. Insulin and diet are at the top of the evaluation, acknowledged as what really helps to control diabetes, despite all implications addressed.

Most adolescents evaluate insulin application as an unpleasant sensation, in spite of being considered indispensable for diabetes treatment, and refer to the idea of suffering and pain. However, eventually, they evaluate this treatment as beneficial, because the fear of hospitalization, complications and worsening surpasses the fear of the "pricks".

Another aspect considered in the care and treatment evaluation is the excessive cost of some treatments. This could make them unfeasible, or mobilize patients and relatives to search for strategies to perform them. Participants recognize that the Single Health System (SHS) facilitates their following treatment, due to the distribution of insulin, syringes, needles and tapes to measure glycemia.

Over time, adolescents and their relatives select the care procedures and treatments they consider most appropriate for their characteristics and needs, always considering the outcomes, the cultural aspects involved, as well as how easy it is to access these care procedures and treatments<sup>(2-9)</sup>.

The pathway in the three subsystems

It was observed that the therapeutic itinerary of adolescents and relatives first occurred in the Family Subsystem. Next, simultaneously, in the Popular and Professional Subsystems, with a prevalence of one or the other in certain moments, without removing the Family Subsystem from the moments of making decision, evaluating and performing some of the care procedures.

Some care procedures and treatments associated with the Popular and Family Subsystems are performed regardless of the glycemia result. These include: prayers, visits to spiritualist centers and to healers. They consider that these alternatives bring consolation, give them a chance to open up, pass on positive thoughts and give hope, increasing their inner strength. In the Popular Subsystem, cost is referred to as an important factor, since they are considered cheaper and of easy access to all. These practices remind them of the past and include a symbolic value. They were used by their ancestors, by older people, and diffused among them from generation to generation. In addition, the practices of these Subsystems use a language that is familiar to these people, comforting them and providing them with a more horizontal relationship. Many people influence their decisions about care procedures and treatments to be performed. The people who get most involved are relatives, neighbors, friends and community members, especially those who in some way also experience diabetes.

The Professional Subsystem was the most valued and with the greatest amount of practices. This situation might be associated with the fact that people consider diabetes as a "doctor's disease"; that is, it depends on medical diagnosis to be recognized. Based on this diagnosis, the disease starts to affect various aspects of the person's life, beyond changes in organism structure and functioning<sup>(2)</sup>.

Another factor that contributes to the prevalence of the Professional Subsystem was acknowledging insulin as an essential treatment. One cannot disregard the strong influence of biomedicine in our society, which attempts to impose that its principles are the only valuable and effective ones, using the media and other strategies to outshine any other practice.

## FINAL CONSIDERATIONS

We observed that the way people interpret the origin, importance and effect of the disease on their behaviors and relationships will affect their decisions when searching for care and treatment.

The therapeutic itinerary initiates with the perception that something is not right. That perception is caused by physical manifestations that interfere in the adolescents' everyday life. At this moment, adolescents and their families start to think about what could be causing these manifestations, take the risk of making some kind of "diagnosis" and then start their search for care and treatment.

They usually choose alternatives that make sense to them; choices that are anchored in their previous socially constructed experiences, which are always temporary and under constant evaluation. There is no single path to follow. There are multiple

possibilities, and their personal interpretations regarding their experience could always bring a new perspective. Believing that it is always possible to live better with their health condition is what provides them with encouragement and the energy they need to continue their quest.

In conclusion, we emphasize that understanding the therapeutic itinerary of adolescents with diabetes and their relatives contributes to a more humanized professional approach, and helps professionals to stop founding their actions exclusively on their knowledge and make some room for the experiences and perceptions of those who live with the disease. When healthcare professionals improve their understanding about what people do to search for care and treatment, as well as why they do that, they become more open and available to establish new exchanges in a more horizontal relationship, permeated by respect.

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