

LIVING WITH DIABETES: THE EXPERIENCE AS IT IS TOLD BY CHILDREN¹

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Diabetes mellitus is a chronic disease that demands adaptation in the psychological, social and physical sphere. This study aimed to understand the experiences of children with the disease. Symbolic Interactionism and Grounded Theory were used as a theoretical and methodological reference framework, respectively. We interviewed children in the age group between 7 and 14 years old. A total of 7 topics were identified in the collected data, which were: "Experiencing something unexpected", "Facing a harsh reality", "Being afraid of what is happening", "Living under control", "Trying to adapt to a new reality", "Maturing with this close relationship" and "Seeing this disease from a different angle". Living with diabetes is something these children are confronted with daily from the very moment it is diagnosed, having to live with a restricted diet, insulin therapy and life style changes, facts that bring about feelings that range from fear to insecurity, to revolt, to acceptance and adaptation.

DESCRIPTORS: child; diabetes mellitus; life change events

VIVIENDO CON LA DIABETES: LA EXPERIENCIA RELATADA POR NIÑOS

La diabetes mellitus es una enfermedad crónica que exige adaptación en los ámbitos psicológico, social y físico. El presente trabajo tuvo como objetivo comprender la experiencia del niño viviendo con la enfermedad. Los referenciales teórico y metodológico utilizados fueron el Interaccionismo Simbólico y la Teoría Fundamentada en los Datos, respectivamente. Entrevistamos niños con las edades de 7 hasta 14 años. Un total de 7 temas fueron identificados en los datos recopilados, siendo ellos: "Viviendo algo inesperado", "Enfrentando una dura realidad", "Sintiendo miedo sobre lo que está pasando", "Viviendo bajo control", "Intentando adaptarse a la nueva realidad", "Madurando con la convivencia", "Mirando la enfermedad de una manera diferente". La vivencia con la diabetes es algo que el niño enfrenta cada día, desde el momento del diagnóstico, teniendo limitaciones en la dieta, la inserción de la insulino terapia, el cambio en el estilo de vida, hechos esos que desencadenan sentimientos que oscilan entre miedo, inseguridad, indignación y adaptación.

DESCRIPTORES: niño; diabetes mellitas; acontecimientos que cambian la vida

VIVENDO COM O DIABETES: A EXPERIÊNCIA CONTADA PELA CRIANÇA

O diabetes mellitus como uma doença crônica exige adaptação nos âmbitos psicológico, social e físico. Este estudo tem por objetivo compreender a experiência da criança na vivência com a doença. Os referenciais teórico e metodológico utilizados foram o Interacionismo Simbólico e a Teoria Fundamentada nos Dados, respectivamente. Entrevistou-se 12 crianças na faixa etária entre 7 e 14 anos. Um total de 7 temas foram identificados nos dados coletados, sendo eles: "Vivendo algo inesperado", "Enfrentando uma dura realidade", "Tendo medo do que está acontecendo", "Vivendo sob controle", "Tentando adaptar-se à nova realidade", "Amadurecendo com a convivência", "Olhando para a doença de um jeito diferente". A vivência com o diabetes é algo que a criança enfrenta a cada dia, desde o momento do diagnóstico, tendo limitações na dieta, a inserção da insulino terapia, a mudança no estilo de vida, fatos esses que desencadeiam sentimentos que oscilam entre medo, insegurança, revolta, aceitação e adaptação.

DESCRIPTORES: criança; diabetes mellitus; acontecimentos que mudam a vida

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INTRODUCTION

A chronic disease is that which “requires constant medical follow-up and control treatment. It may be minimized or it may persevere throughout the individual’s entire life, constantly affecting the individual’s daily routine and activities because of hospitalization, completion of exams, medical follow-up or even due to domiciliary permanence⁽¹⁾”.

According to the Health Ministry, “diabetes is a chronic hyperglycemic state, succeeded by chronic and acute complications, which may include organ damage, dysfunction or collapse, especially of the kidneys, nerves, heart and blood vessels. It is a common disease of growing frequency. It is estimated that in 1995 it reached 4% of the adult population worldwide and that by 2025, it will reach proportions of 5,4%”. In Brazil, there are approximately 5 million diabetics, out of which roughly 300 thousands are minors under 15 years of age. *Diabetes mellitus* type 1 is one of the most common chronic childhood diseases and is among those that most demands psychological, social and physical adaptation of children as well as of the family⁽²⁾.

Thus, moments of advance and regression are seen in family relations, all of which take up time and energy, with the possibility of reducing privacy as well as provoking social and emotional isolation⁽³⁾.

It is well-known that limitations undergone by children with diabetes are countless and can set-off many emotions such as, fear and insecurity, and attitudes that go from conformism to self-care, all of which are experienced for long periods of time⁽⁴⁾. Furthermore, emotions created in children facing this chronic disease are similar to emotions experienced at any age range, among which, one can perceive denial, minimization of disease, anger and frustration due to limitation of the pathology, depressing symptoms, guilt, search for impossible solutions, among others⁽⁵⁾. Depression has a significantly high percentage among adolescent with mellitus diabetes type 1⁽⁶⁾ and depression problems, as well as self-esteem distress, have a negative impact in diabetes adaptation and control of this pathology⁽⁷⁾.

It is believed that understanding how children, under their own perspective, live and experience this disease, will offer assistance towards a nursing practice that will enable nurses to help children and their families along the long health-illness process.

OBJECTIVE

Understanding children’s experience undergoing diabetes.

MATERIALS AND METHODS

Theoretical reference

With the interest of understanding, the nature of interactions and the social dynamics that involves the individual at a deeper level, Symbolic Interactionism was chosen as theoretical reference for this work.

Symbolic Interactionism values, above all, the significance human beings attribute to their experiences. In agreement with such reference people are submitted to constant change in interactions, which at the same time, do not become limited to what happens only among them, but reaches into what occurs inside the person. Thus, the person interacts behaving, perceiving, interpreting, acting again, which makes the person actor and reactor in the process, becoming unpredictable and active in the world⁽⁸⁾.

Methodological reference

Grounded Theory, which follows the premises of Symbolic Interactionism, is the data analysis method chosen for the present paper.

Grounded Theory was developed by the American sociologists *Barney Glaser and Anselm Strauss*⁽⁹⁾ and is a qualitative research method aimed at discovering new concepts and theories by means of data from reality, rather than testing already existing data. The information obtained by data collection is constantly analyzed and it is up to the researcher to understand the meaning of such data, from which a new theory appears.

It is important to emphasize that the data collected are comparatively and continuously analyzed, enabling the researcher to understand its meanings, which is at the same time derived from social interaction, from the participant’s perspective.

Research development

All methodological procedures followed standards established by Resolution number 196/96,

which deals with Research Norms Involving Human Beings. The research project was approved by the University's Research Ethics Committee and afterwards an active search began for children in doctor's office, Specialized Centers, the Pediatrics Unit of a mid-sized hospital of a city in the interior of the State of São Paulo, as well as the participants indicating other children to participate. Telephone contact was established with those responsible for the children, at which time the research proposal and its objective was explained. Data collection was performed from September of 2001 to July 2002. Interviews, as well as taping, were done with the children's acceptance and consent and also with formal written parent authorization. The instrument of data collection in this research was the semi-structured interview, where the question presented was: **"what is it like for you to live with diabetes?"**

After the initial question, the interview was directed at comprehending the child's experience, that is, what was it like discovering he/she had diabetes, the changes that came after the diagnosis, how such changes were confronted, what was the experience like and the feelings that permeated that experience. The data were grouped according to the similarity of meanings, and this began to originate the categories. The interviews stopped when the reports did not show any new experiences.

RESULTS

The sample group of this investigation was composed of 11 children aged from 7 to 12, and a 14-year old adolescent, indicated by one of the families who demonstrated interest in participating in the study. That is the reason "children" is used to denominate the participants of the interview, since the great majority were children. 9 of the participants were of the feminine gender and 3 of the masculine gender. The time of diagnosis of the pathology in this group varied from 1 to 7 years, being that 8 children discovered the illness during school years.

A total of 7 themes were identified in the collected data. They were: **"Experiencing something unexpected"**, **"Facing a harsh reality"**, **"Being afraid of what is happening"**, **"Living under control"**, **"Trying to adapt to a new reality"**, **"Maturing with this experience"**, **"Looking at this illness differently"**.

The themes are made-up of categories and sub-categories according to meaning.

Experiencing something unexpected

Here the children relate how the illness was discovered, how diabetes became part of their lives. Afterwards they begin to live with something that was unexpected... The children then describe the course of discovering the illness, how their body felt different and noticed that something was going on.

It was like this... I was feeling really bad. I kept on fainting, I felt bad, limp, dizzy, and I trembled (Interview 7).

Afterwards they underwent medical consultations, exams, and at times hospitalization, something that generates moments of expectations and anguish. Then the children received the news that they had diabetes, which not only conveyed the result, but carried the impact of knowing that they were sick. And above all, knowing that they now have a disease they know little of and do not know what it means. It is a sad moment, a moment of hurt. They are emotionally shaken. They are afraid, angry, feeling bad about the whole thing. They feel they are threading on thin ice.

(...)I was confused; I didn't know what diabetes was... Why couldn't I eat cake or drink tea or milk? Then I asked the nurse to explain it to me, but she explained it in a way I couldn't understand. (Interview 4).

I suffered a lot at that time. It all happened so quickly. (Interview 7).

Facing a harsh reality

Relates the difficulties children went through at the beginning of the experience with diabetes: the body they knew before is not the same, the impact of everything they could do before and no longer can, hospitalizations and feelings related to this, such as revolt and loneliness, beginning to understand the illness after it is discovered. They talk about the barriers and limitations regarding the diet, insulin application, as well as the daily struggle with themselves, the feeling of always being tested.

Ah, hold back, resist candies. That is the only really hard thing for me. Using insulin everyday is also hard (Interview 3).

For my entire life, I always liked sweets and candies (Interview 8).

The children begin to recognize body language as a result of self-knowledge gained throughout time. They already know the meaning of a headache, or wanting to go to the bathroom all the time or drinking water.

Oh darn body. When the diabetes goes up, my body aches, my back hurts, I feel really tired. (Interview 2).

When it is high I feel like going to the bathroom all the time, always drinking water (...). Today I feel bad. Yesterday and last night I went to the bathroom a lot. I have gone to the bathroom 4 times since last night (Interview 2).

Decompensations do not always generate noticeable symptoms.

I don't feel it. At the beginning I felt. I shook and felt hungry. Not now, if I'm feeling bad someone else notices it because I start to look really pale and colorless. If nobody sees it, neither do I (Interview 12)

Such harsh reality brings in new situations to their day-to-day life. They are up against things they do not understand, such as why the restrictions, the possible causes of the disease, the need to become aware of his/her own body, of the instability of such a disease.

Well, generally the doctors and people that know this illness and the therapists, they told, A. once that my diabetes is emotional, but I don't really know what is emotional diabetes (Interview 4).

I have no idea... It stops to function... I don't understand why my pancreas don't function anymore (Interview 8).

I think it comes from the blood. My dad has diabetes, it dangerous to catch diabetes (...) I guess it's a "type" of blood (...) It's dangerous to catch it because she (mother) has a relative with diabetes also. If there isn't a relative with it, then it doesn't happen (Interview 2).

As a result, children realize that they cannot do what they could do before.

Oh, I used to ride bicycle and run a lot. Not anymore, I get tired really fast. It's tiring, you know? Sometimes, when I ride a bicycle my legs go limp, then I stop. Running also. I used to run a lot. Now I have to run slower... I can't run, I don't have as much energy as I used to. I get tired (Interview 6)

Before, I used to go everywhere and could do things. Now I can't anymore (Interview 2).

Yesterday I wanted to go out with my friends, but my mom didn't let me because my diabetes was altered (Interview 3).

Revolt is a common feeling among children that live with diabetes, which can happen right after diagnosis as well as with lengthy follow-up. They can become impatient and angry with the insulin and lose

their temper with the treatment, the diet, of not being able to eat candies and sweets. Also, they might want to leave aside the treatment because they cannot stand any of it any longer.

And when I was fed up with diabetes, I didn't want to take insulin, anything sweet that came my way I would eat and I said: 'This isn't going to harm me, this is just something made up by my head. I don't have this'. I would eat sweets, I wouldn't eat right before going to school, I wouldn't eat dinner at home, I wouldn't eat anything during the day. (Interview 4).

Being afraid of what is happening

This topic brings forth much of what anguishes children living with diabetes. They know it is a disease without cure, but at times they doubt it. They live with the ghost of death and with doubts, among which, so much information about the disease and what to believe.

We are afraid of dying, those of us who have diabetes. Because some people with diabetes have died. If you eat too much candy... (Interview 5).

If I'm in doubt about eating or not eating, I know that if I can eat then it won't be bad for me. If I can't eat it and I do, I guess it can be harmful for me. Then, I prefer to know first, to clear my doubts (Interview 4).

Children also live with the fear of prejudice, of isolation from other people, which is the reason they do not tell most people they have diabetes.

I don't know. I guess... people don't really know what it is many times. Then you have to keep on explaining, they keep on asking things; but it was mostly like that at the very beginning, not so much anymore. But I try not to talk about it. That way those who already know are aware, but I try not to talk about it to anyone... I think it's better that way (Interview 8).

There is only one person who knows, but I told him not to talk about to anyone. (Interview 2).

Also living with the fear of having an incurable disease that will exist throughout every relationship, that will be there daily for the rest of their lives life, regardless of their wishes. It means having a disease where the only thing to do is take care of themselves, because everything depends on this control, not on the cure.

Oh, it's really hard. To know that I'll have to live with this for the rest of my life, not eating sweets, I'm getting used to this, it's almost 3 years now. I'm adapting... (Interview 7).

Today there isn't a cure. I have medication and all, but until now I'm not really sure. For now I'll have this for a long time... (Interview 8).

Living under control

This topic comprises the categories related to the child's attempt at getting used to a new life. It is where he talks about the control of the disease in its different scopes, from the diet to doing exercises; control which is in regards to monitoring the disease and life by a set of rules.

It's just that I don't like to walk (...) Like, there is physical education at school, then I do it. Except that at home, I don't do it much. Like, to walk by myself, well then I don't do it (interview 8).

Also, having to take insulin everyday, something children dislike doing, but know it is necessary. Moreover, and often, to face daily the fear of the needle or of applying it the wrong way.

Well, at the beginning I didn't want to. I cried every time I had to apply insulin, I didn't like to do it. But now, you know, I know I have to, so I do it (Interview 6).

The only thing I dislike is to take insulin, sometimes it leaves a mark when it hits a vein, it bursts, then it leaves a bruise. And I don't like to do it in the belly because it leaves little bumps... (Interview 8).

It also describes the difficulty of not being able to eat sweets, something they loved, as well as their anxiety, fears and what extends through such experience, as for example, the feeling of guilt for not controlling that longing.

Sometimes I see someone eating candies and I think: 'Oh, I used to love that, now I can't eat it anymore'. Then I get this craving (Interview 4).

...Because I can't eat sweets, that's all. I used to only worry about sweets (...) And I guess I only think about candies, not too much with my health (...) I can't get over that craving (Interview 8).

Trying to adapt to the new reality

The children demonstrate the motion in search of adequacy in the experience of living with diabetes. In this case, they try to not think much about it because they become sad and so try to move on and simply view diabetes as a disease they have to live with.

Oh, before, I didn't accept having diabetes, I thought it was the worst thing in the world. Then I stopped to think a little and I said: 'Gosh, there are a person that don't have a leg, who move around in a wheel chair and that is a lot worse'. A person who knows that in a few years or a few days won't be here anymore (Interview 4).

Then I try to do my own things, even forget about it, I try to study, amuse myself... (Interview 7).

Thus, they undergo treatments and seek professional help. Often, even believing in things they are not sure about, but something that relieves the suffering.

My mom and I went to therapy. I already stopped. It was last year, and the year before that, every Tuesday (...) It was like talking about everything, you know? And it lasted about an hour, an hour and a half, just talking. Then at the end she asked me to draw or play a game, you know, to see if the kid could tell more later (Interview 10).

Maturing with the experience

At this stage, children with diabetes begin to not fight with themselves everyday, that is, with their desires, with their fears, their commitments and needs. They face all of it as something that is part of them, and since they have to accept it, they try to do it the best way possible. As children say, "you get used to it" with all of it.

I continued to go out. To Cancun, to Abasc, to the mall. I guess you end up getting used to it (Interview 7).

Also, realizing that not accepting it will only make the experience with the disease become harder and will not help in any way.

Oh well, I guess that resisting won't help at all. Maybe it will just make things worse (...) Then I started to not being so upset with people and with diabetes (Interview 4).

I have to accept it and that's it (Interview 3).

The children continue trying to adapt to the new needs, learning to live without sweets, to control the amount of certain foods and to choose other foods, to apply insulin, to take care of their body. Ultimately, to take care of themselves, as if this were not a bad thing, but something necessary for their well being.

I have good control of my food... At 10 o'clock I eat a fruit, then I have lunch at 11:30... (Interview 4).

Oh, they say that I have to take really good care of my feet. I wash them, I dry in between the toes, I let my mom clip my toenails so they won't inflame (Interview 8).

At this stage children demonstrate the need to understand the disease which goes beyond the physical and biological limits: it is to look at God for answers to such questions, putting him as a conductor of everything that happens in the lives of people. Thus, it is better to accept it, because they believe that God knows what he does and if He chose them, it is because they can overcome all of it.

Oh, maybe a fact that touched me is that it had to happen one way or another (...) He (God) maybe made it happen to show me something (...) So, if it had to happen with me, it did and I have only to accept it and know how to control it (Interview 4).

I can't say: 'I don't want to have diabetes, I'm not going to'. Who orders it is God, He knows what he is doing, you know? It has to be that way (Interview 10).

Viewing the disease in a different way

This deals with the children's change of perception about the disease and about themselves. They begin to have attitudes they did not have before. All of this contributes to living better and feeling happier about themselves and others. They accept they have diabetes and are not ashamed of it.

Oh, it doesn't matter talking about it, does it? My friends know it, the entire class knows it, I guess (Interview 8).

They know it. So the teacher lets me go and drink water. The teacher doesn't let the kids go out and drink too much water, only me. They asked her why, then the teacher told then I had diabetes (Interview 9).

A factor that helps at having a better perspective of the disease is knowing that others also have this disease, they are not the only ones who have diabetes, it did not only happen to them. Furthermore, in living with diabetes there are other people who participate, who are concerned, and who help.

It's cool to know everyone worries about me. I also get worried about them when something happens, you know? That's cool... (Interview 10).

The day I found out, my grandma spent R\$ 100,00 on things for me. She brought the things home for me (Interview 6).

Then the children begin to perceive themselves similar to others, no longer as a person who has an incurable disease. It is to perceive that it is not because they have diabetes that they are different from other people. They feel the same as their friends and schoolmates who do not have the disease. This means that diabetes does not alter their way of being and the possibility of being happy and being able to live as other people do.

Oh, I don't think there's much difference. If I'm with 5 teens and they treat me the same, I won't care because I'll feel the same as them (Interview 3).

Everybody is the same as everybody, nobody should be treated different (Interview 3).

(...) At least I'd like to be treated the same as everyone else. I'd like to at least feel the same as other people (Interview 4).

DISCUSSION OF THE RESULTS

Based on the results in the present work, it can be seen that children living with diabetes go through many stages. The moment of the diagnosis seems to be very strong for them. It is when diabetes seems to change their entire life and they wonder: "why with me?". Very often children try to blame people and things, trying to find justification for the fact. Fear, despair, insecurity and even revolt are feelings that children clearly relate. Thus, it is agreed on that "when a person is stricken with a disease with chronic characteristics, this person encounters changes in his lifestyle, which are brought on by certain restrictions resulting from the actual pathology, the therapeutical requirements and the clinical control, besides the possibility of recurrent hospitalizations"⁽¹⁰⁾.

A strong characteristic of this group of children was the before and after comparison when the disease was discovered, focusing on the immediate lack of freedom: to eat what they want, to go out of the house without having to worry with insulin or having to feel afraid of feeling bad, to run and play. They notice that their body is no longer the same. Living with diabetes causes deep transformations in their world, needing to learn to live with certain limitations, situations and new routines. Children and adolescents with diabetes have their ordinary lives modified, and each new phase of living with diabetes has its own characteristics that require strength, change of habits, adaptation attitudes⁽¹¹⁾. Therefore, adaptation to a chronic disease at childhood is a complex process that involves external and internal factors, which are also influenced by age and growth⁽¹²⁾.

In view of Symbolic Interactionism, it can be seen that living with diabetes also depends on social interactions that are part of children's lives. Food restriction, for example, is far more difficult when children are interacting with others who do not share of this situation.

One can notice, by reading the accounts given by children that the meanings attributed to the experience modify with the passing of time. The more time passes, the more adapted they are to treatment and awareness of the disease.

It is believed that hearing out children and giving them the opportunity to talk about their illness and feelings is important for their self-esteem. The authors compared children and adolescents with diabetes mellitus type 1 to a control group concerning

self-image and self-esteem. It was detected that children and adolescents with diabetes showed low self-esteem and a poor self-image when compared to the control group⁽¹³⁾. Therefore, to listen to them does not exhaust the extent of help given to children with diabetes. It is important to understand their behavior, their fears and anguishes and give them support in the many scopes of such an experience, which first comprises the physical, the emotional and the social part. Therefore, the need to be educated by a multi-professional team specialized in this area becomes evident.

It has been agreed on that it is not an easy task, since education must be viewed under different aspects, among them the different beliefs, values and myths⁽¹⁴⁾.

However, keeping the children in view, it is worth emphasizing that the central point should not be only the diagnosis. That is, it is not enough to view them as someone who has diabetes, but also comprehend the complexity of their experience in the different ambits of their existence, since they are biopsychosocial beings, including the family aspect. A study investigating conflicts of adolescent with metillus diabetes with their parents⁽¹⁵⁾ demonstrated that the perception of the adolescents regarding the parent's preoccupation, intrusive and repressing behavior, as well as their focus is in the future, contrary to the adolescents, whose focus is in the present. These are the aspects that are strongest in managing *diabetes mellitus* type 1.

Therefore it should be considered that to minister assistance to children with diabetes it means going beyond blood glucose control and cares with

the food and physical exercises. Assistance foresees hearing them out and understanding their actions and behaviors, their escapes and fears, their way of dealing with diabetes, as well as how they confront it.

FINAL CONSIDERATIONS

Nursing should be present throughout the entire process, assisting, guiding and intervening in accordance to the child's needs. From the moment of diagnosis and the beginning of living with the pathology, the children's emotional shock can be worsened by the fact they do not know what it means to have diabetes and what implications it will have in their everyday lives. Some of the children's accounts show such suffering very clearly and therefore, how important it becomes that the professionals that are rendering assistance, including the nursing staff, explain, guide and reassure them, never forgetting to take into consideration their development, using understandable language.

During the process of maturing and adaptation to the new needs, the nurse can promote emotional support, assessing difficulties and searching for ways to deliver this, as well as educating in order to prevent complications.

Furthermore, considering the children's need of living the present and the parent's looking at the future, the professional nurse can make himself present by helping the main participants of this experience to find equilibrium, at first seeming divergent, but that somehow must converge for the success of the treatment.

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