

"BEING TRANSFORMED BY ILLNESS": ADOLESCENTS' DIABETES EXPERIENCE

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This research aimed to understand the experience of adolescents to live with a chronic illness like diabetes mellitus type 1. Symbolic Interactionism and Grounded Theory were both used as theoretical and methodological frameworks respectively. The results allowed us to know the adolescents' perceptions about their experience in living with diabetes through three themes: Knowing the diabetes diagnosis; Being transformed by illness and Being a sharp life. The adolescents in this study were resilient people because they became stronger in spite of the illness, being transformed. In this way, the resilient adolescent is capable of healing his/her wounds, being in charge of his/her own life and having a full life.

DESCRIPTORS: adolescent; diabetes mellitus type 1; pediatric nursing

"SIENDO TRANSFORMADO POR LA ENFERMEDAD": LA VIVENCIA DEL ADOLESCENTE CON DIABETES

El objetivo de esta investigación es comprender la experiencia del adolescente que sufre una enfermedad crónica como la diabetes. Utilizamos el Interaccionismo Simbólico y la Teoría Fundamentada en los Datos como referenciales teórico y metodológico respectivamente. Los resultados nos han permitido conocer la percepción del adolescente sobre su experiencia y vivencia con la diabetes a partir de tres temas: "Recibiendo el Diagnóstico de Diabetes", "Siendo transformado por la Enfermedad" y "Llevando una vida puntiaguda". Los adolescentes de este estudio son personas resilientes porque han logrado no solamente convivir con la diabetes sino convertirse en más fuertes: siendo transformadas. Así, el adolescente resiliente es capaz de curarse de sus propias heridas, dirigir su vida y vivir plenamente.

DESCRIPTORES: adolescente; diabetes mellitus tipo 1; enfermería pediátrica

"SENDO TRANSFORMADO PELA DOENÇA": A VIVÊNCIA DO ADOLESCENTE COM DIABETES

Esta pesquisa objetivou compreender a experiência do adolescente em ter uma doença crônica como o diabetes tipo 1. Utilizou-se o Interacionismo Simbólico e a Teoria Fundamentada nos Dados como referenciais teórico e metodológico respectivamente. Os resultados permitiram conhecer a percepção do adolescente sobre a sua experiência e vivência com o diabetes a partir de três temas: "recebendo o diagnóstico de diabetes", "sendo transformado pela doença" e "sendo uma vida pontiaguda". Os adolescentes deste estudo são pessoas resilientes por conseguirem não só conviver com o diabetes, mas tornarem-se mais fortalecidas: sendo transformadas. Desse modo, o adolescente resiliente é capaz de curar-se de suas próprias feridas, dirigir sua vida e viver plenamente.

DESCRIPTORES: adolescente; diabetes mellitus tipo 1; enfermagem pediátrica

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INTRODUCTION

When children with a chronic disease enter adolescence, they not only need to deal with the issues regarding their age, which alone are stressful, but still live with the irreversible changes and effects caused by illness⁽¹⁻²⁾.

Adolescents with type 1 diabetes mellitus experience characteristics specific to adolescence just as well, like living the present, not thinking about the future, believing they are invulnerable to bad events and to further consequences of inappropriate present behaviors, and wanting to show autonomy during confrontations with parents and teachers. In addition, there is also the fact that metabolic control during adolescence tends to deteriorate due to the decline in insulin production until reaching zero, to hormonal changes characteristic of that age associated with insulin resistance, greater risk of hypoglycemia, and due to the difficulty to follow the proposed treatment. Thus, children and adolescents' adjustment to the situation is a complex process that involves internal and external factors, which influence adolescents' responses and adjustment to the illness situation⁽³⁻⁵⁾.

Among the range of studies concerning children and adolescents with type 1 diabetes mellitus, few seek to understand adolescents' experience from their statements regarding the illness. Adolescents are able to describe how they deal with the illness, what the difficulties are and the costs implied by the illness situation to adolescents and their families. However, they can also identify aspects that are rewarding and bring benefits⁽⁶⁻⁷⁾.

Only two studies in our context attempted to learn about the experience of having diabetes from the subject's perspective. One of these studies was performed with children. It interviewed school children, with ages ranging between 7 and 12 years, and one 14 year-old teenager. Despite not having complete language knowledge, they were able to express themselves through statements regarding the illness, reporting their experience, fears, difficulties and wishes related to the illness situation, and others specific to their age⁽⁸⁻⁹⁾.

Regarding adolescents with diabetes, little is known about their experience, except for the fact that many do not reach the established standards of good metabolic control. It is necessary to know and understand the reality and meaning adolescents assign to their daily experience of the illness situation, how

they deal with difficulties and correct decisions, so that interventions can be proposed to truly help adolescents to correctly follow the treatment, improving their prognosis and consequently preserving their quality of life. Hence, this exploratory qualitative study was proposed, with the following purpose:

- to understand how adolescents with type 1 diabetes mellitus experience their disease.

THEORETICAL AND METHODOLOGICAL FRAMEWORK

The theoretical framework adopted in this study was Symbolic Interactionism, because it allows for understanding the meaning that individuals assign to the experienced interactions. Symbolic Interactionism is a theory about human behavior, based on the premise that human experience is measured by interpretation⁽¹⁰⁾. From this perspective, adolescents are considered "experts" in describing their illness situation. Through their report, it can be understood what meaning adolescents with type 1 diabetes mellitus assign to the interventions they experience every day.

Interpretive research methods are appropriate for this kind of research. Thus, the Grounded Theory was chosen as the methodological framework, since it is one of the most representative methods of the groups and has Symbolic Interactionism as its theoretical framework⁽¹¹⁾.

Seven adolescents took part in this study; three girls and four boys, with ages between 12 and 18 years. The adolescents had been followed at the outpatient clinic of a teaching hospital in the city of Sao Paulo, and diagnosed with type 1 diabetes mellitus for at least one year. The one-year period after diagnosis was established so that adolescents had enough time to recover from the impact of being diagnosed and had the experience of living with the illness. After being approved by the Institutional Review Board, eligible adolescents were invited to take part in the study and their mothers or guardians were asked to authorize their participation. Participants were informed about the purpose of the study and signed the Free and Informed Consent Form. They were assured about anonymity and confidentiality regarding the collected information.

Data were collected from October 2003 to June 2004 through semi-structured interviews, held

in a private room to guarantee confidentiality, privacy, and the quality of the recording on cassette tapes. The following guiding question was used: "Tell me what it is like to have an illness like diabetes." Other questions were added to obtain clarifications about the data and support their experience of having a chronic disease like type 1 diabetes mellitus. Interviews took approximately one hour.

The first step in processing the subjects' statements was the detailed transcription of the tape recordings. Next, the codes, which are the basic analysis units, were extracted. Open coding refers to the part of analysis that specifically concerns naming and categorizing the phenomenon through exhaustive data examination. During open coding, data were "broken" into small phrases, examined, compared for similarities and differences, and questions about the codes were asked, related to the phenomenon contained in the data. Through this process, the phenomenon is questioned or explored, thus allowing for new discoveries. These two analytical procedures are essential for coding the data: "making comparisons" and "making questions" regarding each incident, event, and other aspects of the phenomenon. The coded data were grouped by phenomenon similarity. This process of grouping concepts regarding the same phenomenon is called categorization. One category is saturated when it is no longer possible to add new data, or when no further representative aspects emerge⁽¹²⁾.

This method allows researchers to manage the data. Moreover, it is a constant construction. Therefore, it permits to interrupt data analysis at any moment and report the findings, presenting the theory, the phenomenon or a category⁽¹³⁾.

In the present study, according to the proposed objective, data analysis resulted in themes and categories that explained the adolescents' experience of type 1 diabetes mellitus.

RESULTS

Data analysis, through three themes, permitted understanding adolescents' view about their experience of living with type 1 diabetes mellitus. The facts, for most adolescents, are interpreted "today", that is, considering what the events are and what they

mean at the moment they occur, and not by the consequences they may bring in the future. Hence, their behavior seems uncommitted and irresponsible, since no priority is given to preventing diabetes complications. Although it is difficult for health professionals in general to understand and accept this behavior, it is rather common in adolescence. To adolescents, the future seems far and intangible, so they are simply unable to measure the consequences of their actions.

There are also adolescents who manage to live better with diabetes and follow the prescribed treatment. These adolescents seem naturally disciplined and methodical in their routine, and are thus able to keep the regularity demanded by the treatment.

The three themes that portray the different aspects of the experience of adolescents with type 1 diabetes are presented below: "Receiving the diabetes diagnosis", "Being transformed by illness", and "Being a prickly life".

Theme I: "receiving the diabetes diagnosis"

I think I didn't even know for sure what it was, when I was told like, I don't know, I think I didn't "get it" immediately, only later, I guess, over time. So, I was sad, first because I would have to eat less, which was pretty hard.

This theme presented adolescents' experience during the diagnosis period. Although the interview did not emphasize diagnosis, adolescents usually begin their statements by reporting that moment, at least briefly. This moment is a mark in the life of children/adolescents* who were old enough at that moment to remember what happened. The narration covers the period from the first symptoms to the first hospitalization, when diagnosis occurred, through three categories: *Presenting signs and symptoms*; *Experiencing the impact of diagnosis*; and *Learning about diabetes*.

Adolescents remember the event and compare it to what they now know about diabetes. They report that it was only after being discharged from the hospital due to the first decompensation that they actually realized they would have to live with daily restrictions, insulin therapy and blood glucose monitoring. Awareness of having diabetes and its complications, in general, "take a while" to make sense to children/adolescents.

*We will use the expression child/adolescent to indicate that, in some cases, the adolescent is remembering facts from his/her childhood and that, in others, (s)he is referring to recent facts from adolescence.

Since the beginning, children/adolescents understand that the family has also been affected by the illness situation. The family, however, is aware of the severity of the child/adolescent's condition, because there usually exists a previous notion about the disease or there are other family members with diabetes.

Theme II: "Being transformed by the disease"

That illness is for life... I don't even say it is a disease because, to me, having a disease means you go to the doctor, he tells you what your problem is, you take the medication and you get better. Not diabetes, you don't get better, you control it.

This theme reveals the experience of living with a chronic disease. The perception of having diabetes is gradual and children begin to elaborate their experience within what is possible at their age. Adolescents, however, are able to analyze their experience as *being difficult at the beginning* when compared with the present moment. They are also able to characterize their behaviors toward diabetes when they were younger, associating them with current ones, in their adolescence. They conclude that, today, they are better prepared, and that it is therefore easier to live with diabetes.

In some cases, adolescents may not recall the moment of diagnosis because they were too young and not old enough to understand the event. However, they remember the fact, *recognizing, for the first time, that they have diabetes*, a disease that requires daily care.

Adolescents notice they are being transformed in many ways. There is physical transformation, and sometimes weight loss is significant. If adolescents were overweight, weight loss is seen as something positive. It improves self-image and, thus, helps to deal with the situation. When adolescents think about their feelings toward diabetes, they *notice they are different, although they feel normal*. The feeling is of awkwardness, because diabetes makes them different from their friends. However, they have the same wishes, expectations, pleasures and sorrows as their peers.

Adolescents also notice, more and more, that the care regarding diabetes can be part of their daily life. Hence, they start to organize their time in a way that they can care for themselves with no harms to their lives and their teenager activities.

In this sense, by recalling the phases they experienced since the diagnosis, adolescents *become aware that the disease is forever*, they cannot ignore

that diabetes is now part of their lives, and that the disease is inside them.

Some adolescents, by living with diabetes, notice *the benefits they have from the disease*, they see that they gained something. They actually state that they "do not regret having diabetes", that today they have a better physical condition than before being diagnosed. Adolescents also state the family union that was established after the diagnosis, weight loss and improvements to physical and health conditions. They understand that, whether they want it or not, they have to live with diabetes, and they notice that life with diabetes can be good, provided that the disease is under control.

The transformation that takes place in children/adolescents' life is not based only on the situation brought about by illness. Some situations are very difficult and painful. However, they have to learn how to live with the situation, using their own coping strategies and abilities.

Adolescents know that the whole family was shocked by the diagnosis. *They notice changes in the family*. Food habits change, as well as family dynamics and relationships, in order to incorporate the illness into the family's routine.

Relationships between families in this group of adolescents with diabetes did not seem dysfunctional. Parents and siblings do not treat adolescents differently because they have diabetes. Rather, adolescents participate in family life with their own roles, rights and responsibilities. That is, they have *good family relationships*.

Along with their development, as they acquire more independence and autonomy, adolescents start to go out with friends, and, in some cases, they start working, *having a pleasant life*. Hence, when going out without another family member, they are concerned about taking along all the material needed for insulin therapy and blood glucose monitoring.

Having diabetes does not interfere with adolescents' friendships. All participants reported they have a group of close friends, who they can talk to about diabetes. Friends provide support by accepting adolescents with diabetes in the group, treating them as if not having the disease and, at the same time, worrying about their feeling sick.

Theme III: Being a "prickly life"

'Big time' suffering. You have to prick yourself all the time. A prickly life, right? Pretty bad, drawing blood. Drawing

blood was the worst thing. And I remember that, when I was supposed to monitor, there was a big needle. Then, "wham" in my finger. Ouch. And the serum ... I just wouldn't let them put it in, I would put on a show, I remember.

Adolescents with diabetes often go through periods of more difficulty regarding glucose control due to the hormonal changes that occur in this age, and/or not following the treatment. Some adolescents, despite being diagnosed with diabetes very young, living with the illness situation and treatment every day, like with insulin therapy, do not feel they are prepared already to perform it. They *are afraid* the needle might break or that they may shake so much they will end up getting hurt. This situation can make it more difficult for adolescents to reach their independence from their parents because they cannot go out and be responsible for their self-applied insulin shot.

First hospitalization generally occurs at the first diabetic decompensation, at the same time as diagnosis is made. If children/adolescents were old enough to understand what was going on at that moment, they usually had sad memories of *being hospitalized*. They recall the situation very clearly, of how bad the overall sickness was, of how the family was worried, and about hearing people comment on how sick they were, that even their parents thought they were going to die.

In general, adolescents have two forms of dealing with the signs and symptoms of being sick, but with one common outcome. Some adolescents, *when feeling sick*, think about other possibilities besides diabetes, like having a cold or a drop in blood pressure, if their glucose was normal in the routine monitoring. However, others report they always think about diabetes. Nevertheless, even when adolescents believe that their feeling sick is not caused by diabetes, they perform capillary glucose monitoring. After monitoring, there are only two possibilities: treat hyperglycemia or hypoglycemia through measures taught by the health team, or, when glucose is normal, take the necessary measures to identify and solve the cause of the problem.

As they grow up and become more mature, adolescents are able to better understand diabetes-related issues. They are able to understand the illness situation, but there are days when rationalizing does not help as a coping strategy. They become discouraged and think that they might not feel as well as they thought they would in this respect, *not accepting the disease 100%*.

Noticing that emotions affect diabetes is the perception that adolescents have of their experience of living with the disease situation; of how emotions can interfere in everyday life, through changes in their mood and spirit and, in some cases, even in glucose levels.

There is currently much information regarding diabetes. However, adolescents still see themselves *dealing with other people's lack of knowledge about diabetes*, since many people are unaware of essential information regarding the disease. Hence, they do not like to talk with these people, because they have to give too many explanations about the disease and its treatment, in addition to often believing that people feel pity, which annoys the adolescents.

DISCUSSION

The present study results show, through three themes, adolescents' perception about their experience and living with diabetes. The first theme "*Receiving the diabetes diagnosis*" portrays the period surrounding diagnosis, which is important for children/adolescents who recall the hospitalization, the exams, and the impact it had in their lives⁽¹⁴⁾.

The second theme, "*Being transformed by the disease*", reveals how adolescents notice and deal with the disease very naturally, believing that the fact of having the disease does not make them less able or qualified to get the best out of their lives. The categories *Noticing they are different, though feeling normal; Getting benefits from the disease* and *Living a pleasant life* show how adolescents are able to face the situations and challenges brought about by the disease and their life, and to stay focused on the advantages and benefits diabetes brought to their own as well as their family's life.

The behavior of the adolescents who took part in this study confirms a new tendency in terms of how coping with chronic illnesses is understood. Generally, when considering chronic illnesses, it is supposed that the illness imposes a heavy weight and burden on one's life. This concept has been reviewed and new studies have presented contributions, showing a different view on that experience. Hence, living with a chronic disease is also understood as something that improves the quality and adds meaning to one's life. It means that, without the advent of diabetes, individuals would not be what they are today; the disease situation transformed their life with diabetes into a positive experience with a rewarding outcome⁽¹⁵⁾.

By allowing themselves to be transformed by the illness situation – diabetes, the adolescents in this study reveal an intrinsic characteristic, that is, inner personal strength. This characteristic is defined as resilience or the ability to overcome adversities and rise stronger and with more problem-solving resources. It is an active resistance and growth process in response to crises and challenges. This approach is based on the principles that individuals' strengths are reinforced through collaborative efforts to deal with sudden crises and enduring adversity⁽¹⁶⁻¹⁷⁾.

Thus, it is observed that the adolescents who participated in this study have this characteristic. They are resilient because they are not only able to live with diabetes, but also surpass the risk of becoming discouraged and suffered people. They know how to deal with a chronic illness like diabetes, and become stronger despite their suffering; they were transformed. It is wrong to presume that resilient people do not suffer. In fact, they suffer a lot, but are able to assign a meaning to their suffering, which makes them move ahead⁽¹⁶⁻¹⁷⁾.

Suffering does not turn resilient people into human beings full of self-consideration, who feels sorry for themselves or enraged towards everything and everyone because things did not turn out as expected and they have a chronic illness like diabetes. On the contrary, they transform this suffering, which could be unbearable, into the strength that moves them to grow and live a normal adolescent life. Hence, resilient adolescents are capable of curing their own wounds, manage and fully live their life.

The third theme "*Being a prickly life*" portrays the difficulties adolescents sometimes face regarding the disease situation, understanding that life with a disease like diabetes is a life that injures, penetrates and hurts. This moment portrays the suffering and the difficulties that surpass their internal and external resources; moments in which the illness situation was the main setting in the adolescents' lives. These periods are understood as phases in which adolescents are more physically and/or emotionally fragile, but can be reverted through coping strategies, and support

from the family and the health team, in order to overcome difficulties and problems, as well as to strengthen adolescents⁽¹⁸⁻¹⁹⁾.

The themes should not be understood as phases of a process, but as important non-sequential moments of adolescents' experience with type 1 diabetes. Understanding how adolescents deal with diabetes and knowing how to identify which phase they are experiencing is essential for the health team to propose interventions that are truly efficacious in delivering care to adolescents with type 1 diabetes. Resilient adolescents need others to acknowledge their effort to grow through, and not despite diabetes. It encourages the transformation in their lives. Adolescents experiencing the "prickly life" should receive support to overcome that moment and come back stronger.

FINAL CONSIDERATIONS

This study shows the perception, comprehension and meanings participant adolescents assigned to the experience of having type 1 diabetes; hence, the obtained results cannot be generalized. Nonetheless, it is considered that the open interviews allowed them to express their opinions regarding the aspects and nuances of their experience, which would be lost if questionnaires or more structured formats had been used.

The knowledge learned in this study can help health teams to have insights about adolescents' experience of having type 1 diabetes.

Further studies should be performed in order to better understand other aspects of the experience, like what coping strategies adolescents use to live with the disease situation; how to assess, promote or develop adolescent resilience toward the illness situation; what resources can be mobilized, since the treatment is rigorous and demands certain instruments for its control. These and other questions, as well as intervention proposals, should be studied to help adolescents find a place for diabetes in their lives, as opposed to living exclusively for diabetes.

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