



EXPERIENCES OF DIABETIC ADOLESCENTS: A PHENOMENOLOGICAL APPROACH

VIVÊNCIAS DE ADOLESCENTES COM DIABETES: UMA ABORDAGEM FENOMENOLÓGICA VIVENCIAS DE ADOLESCENTES CON DIABETES: UM ENFOQUE FENOMENOLÓGICO

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ABSTRACT

Objective: to unveil the feelings and the meaning of being an adolescent with diabetes mellitus type 1. **Method:** qualitative study with phenomenological approach carried out through open interviews with seven adolescents diagnosed with diabetes mellitus type 1. Data were analyzed following the steps: full transcript of testimonies, successive readings, extraction of units of meaning and finally, categorization. **Results:** four categories and two sub-categories emerged after analysis: Category 1. Experiencing the impact of diagnosis; Category 2. Being an adolescent with DM; Category 3. The daily routine of being an adolescent with DM; and Category 4. Being an adolescent with DM: impasse between maternal control and loss of autonomy. **Conclusion:** it was evident that teenagers adapt well to the chronic condition, but they have difficulties in coping with the implications of the disease even with the passing of time. **Descriptors:** Nursing; Adolescent; Diabetes Mellitus.

RESUMO

Objetivo: desvelar os sentimentos e o significado de ser adolescente com diabetes mellitus tipo 1. **Método:** estudo qualitativo, com abordagem fenomenológica, por meio de entrevistas abertas, com sete adolescentes com diabetes mellitus tipo 1. Os dados foram analisados seguindo as etapas: transcrição na íntegra dos depoimentos, leituras sucessivas, extração das unidades de significado e, por fim, a categorização. **Resultados:** após a análise, emergiram quatro categorias e duas subcategorias: Categoria 1. Vivenciando o impacto do diagnóstico; Categoria 2. Ser adolescente com DM; Categoria 3. O dia a dia de ser adolescente com DM; e Categoria 4. Ser adolescente com DM: impasse entre o controle materno e a perda da autonomia. **Conclusão:** evidenciou-se que os adolescentes se adaptam bem a condição crônica, porém, apresentam dificuldades no enfrentamento diante das implicações da doença mesmo com o passar do tempo. **Descritores:** Enfermagem; Adolescente; Diabetes Mellitus.

RESUMEN

Objetivo: desvelar los sentimientos y el significado de ser adolescente con diabetes mellitus tipo 1. **Método:** estudio cualitativo, con enfoque fenomenológica, por medio de entrevistas abiertas, con siete adolescentes con diabetes mellitus tipo 1. Los datos fueron analizados siguiendo las etapas: transcripción en su íntegra de las declaraciones, lecturas sucesivas, extracción de las unidades de significado y, por fin, la categorización. **Resultados:** después del análisis, surgieron cuatro categorías y dos subcategorías: Categoría 1. Vivenciando el impacto del diagnóstico; Categoría 2. Ser adolescente con DM; Categoría 3. El día a día de ser adolescente con DM; y Categoría 4. Ser adolescente con DM: obstáculo entre el control materno y la pérdida de la autonomía. **Conclusión:** se evidenció que los adolescentes se adaptan bien a condiciones crónica, pero, presentan dificultades en el enfrentamiento frente a las implicaciones de la enfermedad mismo con el pasar del tiempo. **Descriptores:** Enfermería; Adolescente; Diabetes Mellitus.

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INTRODUCTION

Diabetes Mellitus (DM) is a metabolic disorder characterized by a deficiency in the pancreatic beta cells resulting in partial or complete failure of insulin secretion. The clinical picture is characterized by metabolic disorders and episodes of hyperglycemia.¹

The considerable increase in the rates of incidence and prevalence of diabetes mellitus has been a cause of concern for public health. Worldwide, estimates suggest that 285 million people are affected by this disease, and Brazil is the fifth country with the highest number of cases.²

Diabetes mellitus is characterized by the destruction of the cells responsible for pancreatic insulin production, causing a failure or suppression of production. It affects people at all ages, but is mostly prevalent in children and young adults. Treatment by daily administration of insulin is required when this type of diabetes is diagnosed.³

Polyuria, polydipsia and weight loss are typical symptoms of diabetes mellitus presented in the majority of children and adolescents. Symptoms may progress to diabetic ketoacidosis, dehydration and metabolic acidosis.⁴

Adolescence is considered a phase of major changes, marked by the development of biological, psychological and social spheres. The transition to this phase is complex and many become susceptible to many changes, what may be manifested by different psychological and behavioural damages.⁵

Chronic situations impose the need for continuous monitoring of treatment. At this stage, of being adolescent, these difficulties become more apparent upon being concurrent with physical and emotional changes. Whereas the teenager seeks an independent identity, the diagnosis of DM may represent a limiting condition in the point of view of the teenager.⁷

Adolescents affected by this disease have to be limited to diets and daily insulin shots, since their immaturity makes it difficult to comply with the new condition of life. In addition, stressful situations cause hormonal changes that can increase the rate of glucose in blood. In this context, the teenager is forced to use the long-awaited independence of his/her actions to control the health-disease process.⁷

Adolescents face even feelings of exclusion and low self-esteem that easily engages patients with chronic diseases and, therefore, they need to receive a better attention from

the family and the health team. It is necessary to understand the meaning of being a teenager and living with a chronic disease like diabetes, because only when there is the understanding of these feelings, the nursing staff will be able to offer assistance with better efficacy. Thus, it is believed that this study provided evidence that health professionals are able to carry out actions of prevention and health promotion for this population and their families. This study aimed to reveal the feelings and meanings of being an adolescent and having diabetes mellitus.

METHOD

Qualitative study on light of the slope of phenomenology^{8,9} with seven adolescents with DM registered in the Drug Distribution Center, residents in a municipality of southern Minas Gerais. Researchers had access to the list of adolescents registered in this institution and this made possible to obtain contacts. After gaining access to list, adolescents or those responsible for them were contacted through phone calls and, this way, interviews were scheduled at a place and time convenient to the participants.

Whereas qualitative research with phenomenological approach is not based on numerical criteria but it is determined by saturation of information given by participants, there was not a predetermined number of participants. Seven interviews were conducted and participants were named A1, A2, A3, A4, A5, A6 and A7, thus ensuring the anonymity of respondents.

The production of data was carried out between the months of April and May 2015 through open individual interviews recorded, and based on the guiding question "How is it for you being a teenager and having diabetes mellitus?" Data were analyzed following the steps: full transcript of testimonies, successive readings, extraction of units of meaning and finally, categorization.

After analysis, four categories and two sub-categories emerged: Category 1 - Experiencing the impact of diagnosis; Category 2 - Being an adolescent with DM; Category 3 - The daily routine of being an adolescent with DM; Category 4 - Being an adolescent with DM: impasse between maternal control and loss of autonomy.

To meet the ethical aspects, the study had the project approved by the Research Ethics Committee of UNIFAL-MG and approved by the CAAE Protocol nº: 40212914.8.0000.5142.

RESULTS AND DISCUSSION

Category 1 - ♦ Experiencing the impact of diagnosis

The diagnosis of DM in childhood causes feeling of discomfort and uncertainty in families because of the level of permanent care and irreversible changes that this will bring to daily life. At first, the impact affects specially parents and those responsible for the child.¹⁰

The family unit is primarily responsible for the child and its development. In this sense, the family presence is indispensable after the definition of diagnosis because childhood is a phase where the person has not yet developed a conscience to understand what means to have a chronic condition and what this involves.¹¹ In this study, all participants were diagnosed in childhood, as it is unveiled in the statements:

I found out I had diabetes when I was eight. I did not feel anything, it was only my grandmother that took me to "measure" and it was high. My mother was suspicious because I was going too often to the bathroom. (A1)

[...] I discovered when I was five. I heard the doctor talking to my father, but at the time I did not feel anything because I did not know what that was. Over time, people speak so much, that you slowly realize what is this that you have. (A2)

[...] When we found out, I remember I went to the gym with my mom and they were measuring blood pressure and glucose. She asked to check mine, and it was already in 300. We soon thought because my father and paternal grandmother are diabetic. I was drinking a lot of water, going to the bathroom a lot, but as my mother works all day long she had not noticed. And I did not know, I did not have much knowledge about that. (A5)

The diagnosis comes unexpectedly and imposes an uncertain future for the child. The lack of knowledge of pathology, at first, does not cause inconvenience to the individual. But when the person comes to understand the chronic condition, the difficulty to accept is explicit,¹² as unveil the speeches of the adolescents in this study:

[...] When we got home my mother told me it was forever. I was very sad. Today I understand better than when I was a kid. (A4)

[...] Wow! I cried a lot when I finally understood. That was very difficult. (A5)

[...] I remember I was seven when I discovered I had diabetes. For me it was just fine, you know? I remember I lost weight too, unlike many diabetic, I had loss

of appetite. At the time I didn't realise what it was. (A6)

[...] It was long time ago, when I discovered the diabetes, I was 6, I am 13 now. After one year or two, I came to understand that I had diabetes. My mother and doctor were the ones who explained to me what it was. They told that diabetes was a disease that affected the pancreas. (A7)

Study participants had the diagnosis of DM completed in childhood. The interpretation of the statements shows that the lack of information and psychological immaturity make it difficult to them understand the permanent condition that they will be subjected. But even after several years, some participants remember the time the disease was diagnosed, and this shows that the news was a landmark in childhood. The impact comes over time, when they begin to understand the chronic disease, with demonstrations of crying, mainly in girls who participated in this study. Also, we understand that girl's reports are more extensive permeated by feelings and emotions, while reports of boys are more objective and brief.

Category 2 - ♦ Being an adolescent with diabetes mellitus

Children have less difficulty to accept the DM than teenagers and this is because, while child, the person is entirely under family care and as adolescent, the person is required to acquire maturity and take responsibility for the needs imposed by the disease.¹³

Adolescence is characterized by physical, biological and psychosocial changes. The onset of cognitive and emotional development is accompanied by responsibilities that involve making decisions that will reflect in the future. It is the time when a new world is being discovered, one where feelings and new experiences are part of the daily life. A teenager with diabetes need to reconcile this phase with their chronic condition and limitations imposed by it.¹⁴

Feelings like anger and frustration were seized in the speeches of the participants:

[...] From time to time, I feel angry because I have the disease. You want to be healthy, no more diabetes. You have to be making blood tests and I'm afraid of these. (A1)

[...] Diabetes is a disease that ... how can I say? Sugar, you eat too much sugar, it rises, you do not eat, it goes down, then you have to ponder. This disease, you can live normally as everyone else, but you need to have a diet. There are rules, it's hard to obey. (A2)

[...] Damn diabetes that got in my way, came to keep me from doing things I like. I

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feel sad for having this disease. I get angry. (A3)

[...] It is very complicated to have diabetes, I get very sad when I think that I have it and I keep thinking how it would be like if I had not this disease. I did not want to, but now I have to get used to it, because it is for life. (A4)

Emotional, psychological and affective aspects and family relations directly influence the glycemic control from the moment of the onset of the disease until the course of adulthood. The "being diabetic" throughout the stages of life develop different ways to cope with their problems. Thus, children, adolescents and adults react differently to a chronic condition.

Category 3 - ♦ The daily routine of being an adolescent with diabetes mellitus

Many difficulties are imposed to adolescents with DM and these must be understood in order to achieve good metabolic control. There are several changes in their daily lives, especially in eating habits and living routines, what turn out to propitiate them a great learning experience, especially with respect to the management of insulin as shown by A1:

[...] My life has changed, and now I cannot eat sweet things anymore and I have to apply insulin. (A1)

Nutritional therapy and diet control are essential to success in the treatment of diabetes, as they have as main objective to keep blood glucose levels as much close to normal as possible. Despite of being so important, it is a common obstacle faced by people with diabetes and their families because the disease causes a change for the entire household. Food becomes a major reason due to the lack of adherence to treatment.¹⁵

The greatest difficulty with the new routine is this food restructuring. Some foods are excluded or restricted, others are modified and some even inserted. This change involves not only the patient but the whole family unit, as this facilitates the compliance with the diet.¹²

Food must be controlled and is of fundamental importance for the prevention of injuries and further complications. The study participants report their difficulties in dealing with dietary restrictions in their daily lives:

[...] The diet is the most difficult part of diabetes, because we want to eat, and we cannot. I following in part, I have breakfast, lunch and have dinner, but I also have some sweet after lunch. When I was a kid, my

mother controlled the food and I obeyed. Now that I grew up, I do not obey so much, it is not so easy for her to control me. (A2)

[...] I don't like that disease because I cannot eat sweets and is very hard to do without it. I want to eat what I used to eat before diabetes. My mother has changed with me after we found out, she doesn't allow me to eat anymore. At school when there is rice pudding they just give me a little bit on my plate, it makes me want to eat more. (A3)

[...] Here at home sugar doesn't exist anymore, because when there was sugar, I would eat it. So, my mom stopped buying. Everyone here at home started also making diet. (A5)

There has been a conflict between the desire to eat and the food restrictions imposed by the disease,⁷ as complements A5:

[...] I think the diet is the hardest part of diabetes, I don't get used. Before that, I was not of the kind that eats much sugar, I was always ok with that. But now that I cannot eat, I feel like I want it badly. There are days when I have to eat, really. I make mistakes. I can't follow the diet perfectly.

In order to prevent complications of diabetes, nutritional education along with adherence to insulin treatment in addition to daily physical activity are necessary. Diet plan aims at glycemic control, and one of the strategies often used by patients with DM is carbohydrate counting, an individualized and effective way to succeed in metabolic control, but that has difficult adherence though.¹⁶

The main responsible for the increase in postprandial glucose are carbohydrates. For this reason, it is very important to count the total amount consumed in each meal. Depending on the amount of carbohydrates consumed, insulin doses are adjusted. This method must be performed under the guidance and monitoring of professional nutritionists,¹⁷ as it is possible to grasp in the testimonies:

[...] I do count the carbohydrates that I eat, and I've been doing insulin application to prevent it to get high. From time to time I eat when I go to a birthday party, but everything is controlled, it is not possible to avoid everything. I avoid eating too many sweets, for not rise rates, but sometimes I can't resist. (A1)

[...] I find it difficult to control the amount, because I like to eat a lot. And it is very difficult to control because every "so many" grams of carbohydrate I have to take one unit of insulin. (A4)

[...] I went to the nutritionist along with my doctor and now we do carbohydrate counting because the Humalog (insulin) I do according to what I eat, and NPH not, there

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is that exact dose. But it is so, I have dinner, do the counting of carbohydrates and take the Humalog according to what I eat. (A5)

[...] Sometimes, it's like, that thing that you want to eat sweets, but I do that control by carbohydrate counting, so I have a little more freedom. I apply insulin according to what I eat. (A6)

Adolescents with DM type 1 are susceptible to events such as diabetic ketoacidosis. Thus, in order to preventing it, they become insulin dependent. Many respondents denied difficulties related to the disease due to their being "used to" their condition because of the elapsed time between diagnosis and the present day. But others see the condition with more difficulty, particularly with respect to changes in food habits and especially the dependence on insulin.¹⁴

In this study, the difficulty that participants have not only with learning how to handle insulin but also with reconciling their routines with the application of insulin was expressed through verbal reports:

[...] I take insulin and apply myself. Once out of the hospital I was afraid of my grandmother making the application of insulin and causing me pain, so I myself started to apply it. I apply insulin in the morning to make effect all day long, and also at night. Before breakfast, lunch and dinner I apply Humalog. (A1)

[...] I think the hardest part is to apply insulin, it's worse than the diet, because it hurts a little. I found it very difficult to learn to apply, actually I'm still learning. (A4)

[...] At first, my father was the one who applied insulin to me, but then I was applying myself. I started with twice a day, now I do three. I take in the morning after breakfast, after lunch and at night. (A5)

[...] What I find the hardest part is not injecting insulin, but this dependence of it, all that I eat, I have to take insulin. Then I have to get out of the place I am, because even knowing that everyone knows, I cannot inject it in front of everyone, then have to leave school, leave the table at meal time and, things like this. (A6)

[...] I find it difficult to take the insulin when the shot goes in the same place It hurts. The diet, it's kinda easy, it's just eat right, at the right times. (A7)

Nursing professionals are of great importance in this context, because in addition of being able to teach the insulin delivery technique, they clarify the sites and rotation of these sites. It is important, therefore, that the nurse be attentive to the demands and concerns of these adolescents and their families.¹⁸ Much more than the look

English/Portuguese

J Nurs UFPE on line., Recife, 10(Suppl. 2):805-13, Feb., 2016

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of the pathology, it is necessary to understand that this is a being who is in a phase of change and that requires a full and focused attention to their real needs for care. All questions and concerns should be addressed in consultations and longitudinal care should be supported by all the professionals who serve this adolescent and his family.

Category 4 - ♦ Being an adolescent with diabetes: impasse between maternal control and loss of autonomy

The DM alters the adolescent's perspective in relation to the formation of their autonomy and identity. A chronic condition such as this disease significantly changes the reality, as it leads the individual to adjust its eating habits as well as imposes the need for exercise and requires daily shots of insulin several times a day.¹⁹

In the present study, the testimonials show that these impositions lead the teenager to be more dependent on mothers. And in turn, the mothers as the main responsible for their children remain with permanent concerns after diagnosis. They abdicate their own appointments in order to assume the therapeutic procedures and glycemic control, living in function of the sickness of the child.²⁰

[...] I had no difficulty to learn how to inject the insulin, but it is my mother who prepares the syringe for me to not make a mistake... When you it is low, I can feel it, and I complain with my mother. (A1)

[...] The day that my mother is at home she gives me the shot of insulin, if she is not, I do it myself. I do not go out without it, at least with one best man I have. (E2)

In a study conducted in 2014 by researchers of this article, which dealt with experiences of mothers with diabetic children also showed a strong commitment with the treatment and, above all, it became clear that they judged themselves responsible by the treatment and its implications to the daily routine of the family.²¹ The speeches collected portray the relationship of dependency between adolescents and their caregivers.

[...] When I'm not feeling well I say: mom I have to eat because I'm not well. My mother taught me to measure blood glucose, but the insulin is she the one who gives me. When I go to somewhere, my mother or my father come with me. (E3)

[...] She (the mother) has always given me the shots, but now she taught me and a few months ago I started to do it myself. I prepare everything, but I always show her to see if it is right, but she has to check it. (A4)

[...] My mother was always the most present, since I found out. She was

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fundamental, because she always took care of everything for me. Supermarket, medication ... all I want is always her. (A5)

[...] The image I have is of my mother getting here at home with a friend of hers all weepy and then I learned that I could not eat sugar ... My mother has always been very present, so much so that the doctor said like this to her, he would not keep me in the hospital because she knew my mother would take care of me. She put me to sleep with her, she used to wake up at dawn to measure blood sugar, give me insulin. Until today, it is my mom who gives me insulin in the morning, because there are many units. (A6)

[...] My mom helps me, like my guardian angel, who helped me with everything. (A7)

Socially, mothers take responsibility for household care, so when the child falls ill, they blame themselves and feel despair that lead them to offset these feelings in the most intense care for children. They form a protective barrier, assuming all control of the treatment and of the impositions of the disease. When the transition from childhood to adolescence happens, it is more difficult for mothers to motivate their children to assume responsibility for their own care and the teenager faces the challenge of untying of maternal control.

It is noteworthy that the family balance between care and autonomy of the adolescent is extremely important in fighting the disease, in order to reduce unfavourable aspects and assist in recovery, thus ensuring that the subject adapts to the possible negative events of the disease.

In addition to maternal care, the nursing staff, especially the nurse, has a key role in coping with the chronic condition of the teenager, as referenced by A3: "[...] The FHP nurse came here and taught me and my mother to how to give the shot of insulin and measure blood sugar".

Adolescence is marked by profound changes in the physical and emotional sense, and this makes it difficult to accept the impositions of a chronic condition at this phase. An effective strategy in addressing the adaptation and acceptance of the disease is the redefinition of stressful situations caused by diabetes.²² It is extremely important that nurses be involved in this process.

To experience the context of a chronic condition is a complex process that involves not only the adolescents, but also families and their caregivers. It must be fundamentally guided by a team trained to meet the physical and emotional needs. It is necessary to establish and maintain the motivation that

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allows the adolescent to face the disease, respecting his/her growth and chronological development and considering the social constraints of family and friends at various stages of development.²³

The importance of the multidisciplinary team in the process of acceptance, adaptation and monitoring adolescent with chronic disease is evident. The actions of health professionals, especially nurses, should contribute to the prevention, promotion and control of the diabetes, as these aid in teaching and learning, promoting the necessary changes and proper compliance.²⁴

It is essential that nurses know the reality of adolescents and their families considering its perceptions and expectations. Giving voice to this public will make possible to them to relate their experiences, what may facilitate adherence to treatment and motivate them to self-care as well as to the adoption of new lifestyles required by the chronic condition.²⁵

CONCLUSION

This study unveiled that the biopsychosocial changes faced by adolescents are intensified when they are forced to live with a chronic condition. Participants were diagnosed with DM in childhood, as well showed no difficulty in dealing with this moment, because they did not understand at the time what was a chronic disease and the implications that this would bring to life.

Difficulties with handling insulin are common in the daily life of a teenager who lives with DM, but this was not considered the main difficulty to be faced. The majority of respondents cited the change in eating habits as the biggest obstacle raised by the disease. They admitted that they often do not respect the diet as they should, even being aware of the possible complications.

The mother figure has the role of supporter in this context, and sometimes has the role of the person depriving the adolescent of some autonomy. It is necessary that health professionals follow as closely as possible the transition of care to adolescents and their families. Incentive for autonomy and self-care is extremely important in this phase of life, so that adolescents may move forward and gradually experience more independence and confidence while to carrying out their own care. Health education is an excellent alternative to achieve self-care.

Changes in living habits affect not only the interviewed, but the entire family unit. We believe that the approach used in this study allowed us to understand how a teenager

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experiences a chronic condition. The study fosters a reflection on the part of nurses and other health professionals about their practice held with this audience. The act of recognize the individuality and perception of each being is part of a humanized care and favours less unequal and authoritarian relations, favouring the establishment of a rapport and trust between professionals and adolescents.

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Submission: 2015/06/25

Accepted: 2016/01/20

Published: 2016/02/15

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