

Experiences of adolescents with diabetes *mellitus* from the perspective of the ethics of alterity

Vivência de adolescentes com diabetes *mellitus* na perspectiva da ética da alteridade

Vivencia de adolescentes con diabetes mellitus en la perspectiva de la ética de la otredad

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Abstract

Objective: To learn about the experiences of adolescents with type 1 diabetes *mellitus* from the perspective of the Ethics of Alterity.

Methods: Descriptive-exploratory study with a qualitative approach conducted from February to October 2016, with nine adolescents through focus groups and semi-structured interviews. The data were subjected to thematic analysis, with reflections from the perspective of the Ethics of Alterity.

Results: The following categories were defined: learning of the diagnosis and living with diabetes. Since diagnosis, parents assumed the responsibility for the care of their children, and from the perspective of the Ethics of Alterity, they were present and open to welcome them as the Other. The adolescents were found to be confident individuals with intact self-esteem, despite coping with adversity related to disease management, including dietary restrictions and a lack of insulin pump supplies. Hypoglycemia and hyperglycemia were common events among the adolescents, and the carbohydrate counting method was indicated as an excellent resource for disease acceptance. The independence so desired by adolescents was dependent on their self-care capacity. The adolescents reported maintaining an excellent relationship with relatives, friends and members of the multidisciplinary team, which favored disease acceptance.

Conclusion: Respect for the Alterity of the Other by the Self is crucial in caring relationships with family members, friends, the multidisciplinary team and the State for maintaining the dignity of adolescents with diabetes.

Resumo

Objetivo: Conhecer a vivência de adolescentes com diabetes *mellitus* tipo 1 na perspectiva da Ética da Alteridade.

Métodos: Estudo exploratório-descritivo com abordagem qualitativa realizado de fevereiro a outubro de 2016, com nove adolescentes por meio de grupos focais e entrevistas semiestruturadas. Os dados foram submetidos à análise temática, e as reflexões norteadas na perspectiva da Ética da Alteridade.

Resultados: Foram construídas as seguintes categorias: A descoberta do diagnóstico e convivendo com o diabetes. Desde o diagnóstico, os pais assumiram a responsabilidade pelo cuidado aos filhos, e, na perspectiva da Ética da Alteridade, estiveram presentes e abertos para acolhê-los enquanto Outro. Os adolescentes demonstraram ser pessoas confiantes com autoestima preservada, mesmo diante do enfrentamento de situações adversas que interferem no manejo da doença, dentre elas a restrição da dieta e a falta de insumos. A condição da hipoglicemia e hiperglicemia foram eventos comuns entre eles, e o método de contagem de carboidratos foi apontado como ótimo recurso na aceitabilidade da doença. A independência tão almejada pelos adolescentes esteve condicionada à capacidade de autocuidado. Os adolescentes referiram manter um ótimo relacionamento com a família, amigos e equipe multiprofissional, o que tem favorecido a aceitação da doença.

Conclusão: O respeito à Alteridade do Outro pelo Eu é imperativo nas relações de cuidar implementadas pela família; pelos amigos, pela equipe multiprofissional e pelo Estado, como forma de resgatar a dignidade de adolescentes com diabetes.

Resumen

Objetivo: Conocer la vivencia de adolescentes con diabetes mellitus tipo 1 en la perspectiva de la Ética de la Otredad.

Métodos: Estudio exploratorio-descriptivo, con abordaje cualitativo, realizado de febrero a octubre de 2016, con nueve adolescentes mediante grupos focales y entrevistas semiestructuradas. Datos sometidos a análisis temático, reflexiones orientadas según perspectiva de la Ética de la Otredad.

Resultados: Se construyeron las categorías: Descubrimiento del diagnóstico y convivendo con la diabetes. Desde el diagnóstico, los padres asumieron la responsabilidad del cuidado de sus hijos; en la perspectiva de la Ética de la Otredad, estuvieron presentes y abiertos a acogerlos como Otro. Los adolescentes demostraron ser personas confiadas, con autoestima preservada, incluso enfrentando situaciones adversas que interfieren en el manejo de la enfermedad, como la restricción alimentaria y la falta de insumos. Las condiciones de hipoglucemia e hiperglucemia fueron eventos comunes entre ellos, el método de recuento de carbohidratos fue señalado como óptimo recurso en la aceptabilidad de la enfermedad. La independencia tan deseada por los adolescentes estuvo condicionada a la capacidad de autocuidado. Los adolescentes refirieron mantener óptima relación con la familia, amigos y equipo multiprofesional, lo cual favoreció la aceptación de la enfermedad.

Conclusión: El respeto a la Otredad del Otro del Yo imperativo en las relaciones de cuidado implementadas por familia, amigos, equipo multiprofesional y por el Estado, construyen la forma de rescatar la dignidad de adolescentes diabéticos.

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Introduction

When diabetes is diagnosed in adolescence, in addition to dealing with aspects of this phase, the adolescent must contend with disease and treatment demands. Such psychosocial discomfort has a negative impact on treatment adherence and may compromise quality of life due to the onset of serious acute complications resulting from worsened glycemic control, including the omission of insulin doses.⁽¹⁾

To better address the limitations imposed by diabetes and the new responsibilities resulting from therapeutics, a more careful analysis is necessary to identify ways to raise awareness and to disseminate knowledge among adolescents with type 1 diabetes *mellitus* (DM1) to enable them to take on self-care.⁽²⁾

Living with diabetes requires adolescents, their relatives and friends, in addition to the multidisciplinary team, to share responsibilities in maintaining self-care. The team must adopt a comprehensive, respectful approach that encourages the adolescent and caregiver to make decisions about self-control so that they feel empowered and responsible for the therapy instituted.⁽³⁾

Therefore, healthcare professionals helping adolescents with diabetes must be open to learn about their experiences, and from this perspective, the Ethics of Alterity “is certainly based on the desire to understand the Other, but the relation (of Alterity) surpasses this understanding”⁽⁴⁾ because alterity is fulfilled in the openness to the Other, particularly regarding the Other’s differences, which should be respected.

Accordingly, any preconceived idea of knowing the Other⁽⁵⁾ and being open to new knowledge, which recognizes, in the plurality of adolescents, the singularity of each one and guarantees them the Ethics of Alterity on which humane care is based, must be deconstructed.

Thus, the following question was raised: What are the experiences of adolescents with DM1, considering the Ethics of Alterity by Emanuel Levinas? The objective of this study was to learn about the experiences of adolescents with DM1 from the perspective of the Ethics of Alterity.

The Ethics of Alterity proposed by Levinas is the bonding relationship of the Self with the Other,

but it is not limited to this relationship because it foresees a plurality of relationships that considers the existence of diverse human beings. He proposes an open relationship between the Self and the Other, especially the different Other, who should not therefore be excluded, set aside or discriminated against but instead welcomed and accepted for his or her differences and singularities.⁽⁵⁾

Levinas refers to gaze as perception and meaning and to the Other as the face. “The face imposes on me and I cannot stay deaf to its appeal, or forget it [...]. The presence of the face signifies an irrefutable order—a commandment—that arrests the availability of consciousness”.^(6,7)

Methods

A descriptive-exploratory study with a qualitative approach conducted at the pediatric outpatient clinic of a university hospital in Paraíba, from February to October 2016, with nine adolescents with DM1 who met the following inclusion criteria: aged between 12 and 18 years, diagnosed with DM1 for at least one year and able to express themselves verbally. The exclusion criteria were as follows: adolescents presenting complications requiring hospitalization during the period of data collection.

The study was approved by the Research Ethics Committee under Certificate of Presentation for Ethical Consideration (Certificado de Apresentação para Apreciação Ética – CAAE) 47909515.3.0000.5183 and under Research Ethics Committee (Comitê de Ética em Pesquisa – CEP) Opinion number 1.203.218, considering the guidelines that govern human subject research.

The focus group (FG) was used as the key data collection method and the semi-structured interview as a complementary method. Two FGs were conducted. The first included seven adolescents and proposed an initial experience and reading of a triggering text related to the behavior of an adolescent with diabetes. The guiding question was as follows: What do you think of Rodrigo’s behavior regarding his diet and insulin administration? Five adolescents participated in the second FG, clips from the film

“Adolescendo” were screened and the discussion addressed the experiences of adolescents with diabetes.

Because the number of adolescents able to participate in the subsequent FGs was insufficient, the individual semi-structured interview was chosen as a complementary data collection method. Only one of the nine adolescents was unable to participate in one of the FGs but was interviewed individually. Thus, the data were collected using the data saturation criterion.⁽⁶⁾ Individual interviews were scheduled with five adolescents who had already participated in the FGs, based on the following guiding question: How have you experienced being an adolescent with diabetes? Both FGs and interviews were recorded on a Smartphone, with the adolescents’ consent, and transcribed in full for analysis. A field journal was used to record non-verbal communication expressed by the adolescents during the FGs.

Data were interpreted using thematic analysis guidelines.⁽⁶⁾ All recordings were subjected to extensive readings to conduct the preliminary data organization and systematization. Subsequently, the central thematic units were established, and an interpretive summary was performed with inferences based on the Ethics of Alterity and on relevant literature.

Results

The adolescents who participated in the study ranged in age from 12 to 17 years, and all adolescents had more than 8 years of education. DM was diagnosed at 4 years of age in one adolescent, age 6 in two and from age 9 to 12 in the others. All adolescents were treated with Glargine and Aspart, that is, insulin analogs administered using an insulin pen.

The analysis of reports enabled the construction of the following thematic categories: Learning of the diagnosis and living with diabetes.

Learning of the diagnosis

The diagnosis of DM1 is, in general, confirmed during childhood or puberty, thanks to the parents’ attention to signs and symptoms presented. In general, the diabetes diagnosis is suspected based

on symptoms. *Little ants would always gather in the bathroom when I urinated, and I drank lots of water at night, so my mother began suspecting. When she brought me here to the hospital, my blood glucose was 350 mg/dl (A2).*

At any phase of life, a diagnosis of DM1 is devastating for the family, particularly for the mother, due to the mother-child bond. *When I was little, when my mother found out, I did not know what was going on, and when I saw her crying, I also started to cry because I did not know why she was crying (A9).*

When diabetes is diagnosed during childhood, because of their lack of maturity, children are unable to assess the scale of the problem and the impact it will have on their lives and on their families. Conversely, for mothers, the diagnosis of their child with a chronic disease is a shock, which, sometimes without realizing, they convey to their child, who suffers despite their ignorance.

Living with diabetes

Living with diabetes requires changing self-perceptions and lifestyle. However, because of their lack of maturity, school-age children and adolescents (at puberty) usually have more difficulties in adopting the new dietary and self-care habits: *“I ate things I should not, I stopped taking the medicine (insulin), and then suffered the consequences, feeling sick (A3).* The change in habits, especially dietary habits, is difficult to cope with, primarily during adolescence, when parents make them accountable for managing the disease. In this process of accountability for self-care, adolescents often struggle to fully adhere to the treatment: *I often forget (to take insulin). I am one of “those people”, completely absent-minded, a total space cadet. Sometimes I go to lunch and my father asks: did you check your blood glucose level? I look away to one corner of my eyes, then to the other, and I say, no, to tell you the truth, I do not even know where the device (glucose meter) is (A8).*

When parents understand the need to support their children in managing DM1, assisting them in procedures and in changing lifestyles, diabetes may contribute to improving the health quality of the entire family: *Thanks to my disease, everything changed. Before, we all overate, and after my diagno-*

sis, they began eating with me, avoiding sugar, using sweetener more often, avoiding fried foods and dried meat, eating more salad, all really good. Everyone learned (A2).

The adolescents' behavioral change regarding diabetes management was directly related to maturity and to the trust relationship established with the parents: *Today, I take care of most things, diet, carbohydrate counting, taking insulin, checking the blood glucose levels [...] it has been better than during childhood. I have more responsibility, and with more responsibility, my parents trust me more, I have freedom to do the things I want. The main thing for me was to start taking care of myself, and I also thank my mother for that (A1).*

The difficulty in dealing with diabetes can result in complications such as hypoglycemia: *I was in the street, I began feeling sick, dizzy, and I suddenly began sweating, feeling weak, with blurred vision. My mother rushed to buy candy (chewing gum) and gave it to me, and then I felt normal again (A6).*

Conversely, hyperglycemia was considered a traumatic event that led to a reconsideration of lifestyle habits: *I spent a few days at my aunt's house, skipped a couple of insulin shots, ate sweets, it was New Year's Eve, so my blood glucose levels got too high. [...] the next day, at 5:30 and 6:00 AM I vomited, a black vomit [...]. On New Year's Day, I was hospitalized in the ICU for a week. [...] I said: before, I would do anything; [...] but from today, I will no longer do so, and I started to change (A2).*

It should be noted that despite having family support for care, adolescents cope with other difficulties that are essential for maintaining glycemic control, such as access to insulin pump supplies: *My (insulin pump) supplies are gone. The whole set [...] so I have not been using it for a month, I am waiting for the new supplies to arrive (A1). I could not get insulin, I only got one Lantus (insulin glargine injection). [...] Sometimes (she) neglects to pay a bill in order to buy the drug (A2).*

The condition of living with DM1 was perceived by the adolescents as a "normal" event with no effect on their daily life and routine compared with healthy peers. Those who live with a chronic disease such as diabetes for a long period of time

begin regarding self-care as part of their daily lives. In this condition, adolescents with diabetes see their future similarly to any of their peers, with hope and optimism, because they do not limit their expectations based on their DM1: *I want to take the Military Police Officer Training Course (Curso de Formação de Oficiais – CFO) (A3).* Similar to any individual at this phase of life, adolescents with diabetes have dreams for the future.

Discussion

The literature highlights that a DM1 diagnosis in childhood triggers a traumatic process in the parents that will persist throughout their lives because it involves fears, uncertainties, limitations and concerns, dividing life before and after this event. Parents begin "mourning" for the healthy child, fearing hospitalization and everything it entails, as well as death.⁽⁸⁾

Dealing with a diagnosis of diabetes in childhood or in adolescence may destabilize individuals' lives, and this feeling may accompany them for a longer period of time. The adolescents were angry when they violated the rules established by the parents and by the multidisciplinary team regarding dietary restrictions, which sometimes led to hospitalization for diabetic ketoacidosis. A study has confirmed that adolescents commonly rebel because they have to maintain a restrictive diet and control/monitor their blood glucose several times a day.⁽⁹⁾

Adolescents usually struggle more than children with diabetes in their acceptance of the disease because children depend entirely on their parents, who are responsible for their care regarding dietary restrictions, glucometry and insulin therapy. Conversely, adolescents are forced to take responsibility for themselves, which depending on their maturity, often leads them to rebel against therapy.⁽⁴⁾

Although they have already developed physically, adolescents require the careful monitoring of their parents, who are available to them, while respecting the rhythm of each adolescent regarding self-care autonomy. The adolescent is the Face that calls for care, needy and fragile, whereas the parents

embrace the adolescent, fascinated, and perceive themselves as ethically required to care for him or her. Although adolescents assume self-care, the parents are available to help them during this transition phase. Thus, one study⁽¹⁰⁾ has warned that the emotional state of the adolescent and of the family members must be evaluated to assess the characteristics of their relationship, which may affect self-care actions.

Meetings among adolescents, parents and the multidisciplinary team will allow the identification of adolescents' needs regarding disease management, to support and respect them in their alterity. This process is fundamental to establish a relationship of trust, which helps the adolescents discover new strategies for coping with diabetes. The meeting also allows parents and healthcare professionals to experience their own briefing, broadening the understanding they have of everyday life situations facing adolescents. In the face-to-face meeting with the Other, the Human Being finds himself or herself "in front of the Other"⁽¹¹⁾ who seeks care.

Corroborating the findings of this research, a study has shown that the main way to manage diabetes and to change the adolescent's eating habits is by expanding these changes to all family members.⁽¹²⁾ In this condition, care relationships are strengthened, overcoming the adversities imposed by the disease.⁽¹³⁾

In agreement with the literature, disease acceptance problems affect adolescents and their families because they must live with an incurable disease.⁽¹⁴⁾ Thus, the healthcare professional must consider the parents (Human Being) of children with diabetes (Other) as infinitely accountable for them, reminding them of their fragility, of their essential suffering, albeit without subjugating them for not recognizing their alterity.⁽⁵⁾

Although the healthcare team has the ability to identify health needs, these needs do not always correspond to those reported by adolescents. This phenomenon occurs when the healthcare team is insensitive to the Alterity of the Other (adolescent), specifically the adolescent with diabetes, failing to embrace the singularity of the Other. Conversely, the healthcare team believes it has the authority to

demand standard behavior from the Other. The Other is not in the same sphere of the Self (team); the relationship with the Other is not object knowledge but instead transcends any pre-established knowledge of the Self and reveals the asymmetry of the relationship between the Self and the Other.⁽⁷⁾

However, respect for the Alterity of the Other surpasses knowledge of the Self about the Other. During a healthcare meeting, the healthcare professional should be open to the Other who requires care in a relationship of equality and respect for his or her condition and self-perception in the context of the disease and surrounding world. Healthcare professionals must not assume that their scientific knowledge allows them to make therapeutic decisions alone. Establishing a therapeutic relationship that will help the patient manage the disease requires a merging of horizons.⁽¹⁵⁾ Hence, the multidisciplinary team must respect the Alterity of the Other regarding his or her choices, which may not necessarily be the choices of the team. Embracing the Face will certainly foster the essence of the Other,⁽¹⁶⁾ developing in him or her accountability for their own health.

The responsibility of the family and multidisciplinary team for the Other must be extended to the State, for which neglect of the health of adolescents with diabetes violates their rights as citizens.^(17,18) This neglect contrasts with the position of the parents of this study, who, despite their low income, strive to buy the necessary supplies to control their children's blood glucose. In addition to burdening the finances of the family because the supplies are quite expensive, the lack of these supplies may further aggravate the health status of their child. Levinas highlights the accountability of the Human Being (State) to the Other (adolescent), emphasizing the asymmetrical relationship between them. Therefore, power over the Other should be replaced by ethics and justice.⁽¹⁹⁾

The difficulty associated with public authorities in regularly providing the necessary supplies for blood glucose control may compromise the health and quality of life of adolescents with diabetes and of their families, particularly low-income families who cannot afford these supplies. To minimize the

problems resulting from this situation, families have become true pilgrims in search of the resources necessary to maintain the survival of their children. Levinas highlights the accountability of the Human Being (State) to the Other (adolescent), emphasizing the asymmetrical relationship between them. Therefore, power over the Other should be replaced by ethics and justice.⁽¹⁹⁾

Justice must be based on the principle of responsibility to be considered authentic. “Justice, society, the state and its institutions (...) nothing is outside of the control of the responsibility of the one for the other. (...), the State, politics, techniques, work are at every moment on the point of (...) weighing on their own account”. If health institutions, the state and politics act on their own based on their own laws, they will be committing an injustice because they will lose sight of their responsibility to the Other.⁽²⁰⁾

The adolescents in this study, despite experiencing difficulties inherent to diabetes care, such as a lack of supplies, were found to be confident, “normal” people, perhaps because they had lived a long time with the disease, regarding it as part of their daily life. Furthermore, the parents’ help in therapeutics and the way that they perceived the condition and conveyed it to the adolescent with diabetes, avoiding distinguishing between him or her and the siblings, positively contributed to this coping. A study⁽²¹⁾ aimed at understanding how adolescents with DM1 experience living with the disease and how they cope with this situation in daily life obtained similar results showing that some adolescents, initially, did not regard the disease as something normal, but over time learned how to manage it, incorporating diabetes into their daily routine and thus becoming normal while living with the disease. However, other adolescents remained “stuck” in the difficulties imposed by the disease, which caused a lot of suffering.

The limitations of this study are directly related to the qualitative approach, which disregards the number of participants but instead focuses on values, phenomena, events and meanings in the context in which they are inserted. Therefore, further research studies should be conducted using other types of approaches.

Conclusion

Learning about the experiences of adolescents with diabetes from the perspective of the Ethics of Alterity advocated by Levinas makes it possible to extend care to adolescents who have a different perception of themselves, of others and of the world that surrounds them. Thinking of a new way of caring for and of relating to the Other opens the possibility to construct Ethics of Alterity in healthcare, expanding the autonomy of the adolescent in disease management. To learn about the new, we must get rid of old paradigms and walk with the Other in an egalitarian relationship, seeking new ways for adolescents with diabetes to live their lives to the fullest extent as captains of their own destiny.

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Collaborations

Cruz DSM, Silva KL, Souza JTB, Nóbrega MML, Reichert APS, Marques DKA and Collet N designed the study, analyzed and interpreted the data, wrote the article and approved the final version of the manuscript before submission for publication.

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