ARTIGO ORIGINAL

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ADOLESCENTS RESILIENCE WITH TYPE 1 DIABETES MELLITUS

RESILIÊNCIA DE ADOLESCENTES COM DIABETES MELLITUS TIPO 1

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ABSTRACT

Objective: to analyze the resilience of adolescents diagnosed with DM1 treated at an endocrine pediatric clinic. Method: This is an exploratory, descriptive study with a qualitative approach. The study was carried out with 16 adolescents diagnosed with DM1 treated at the Pediatric Endocrinology Clinic of a Regional University Hospital in northwestern Paraná. Potential participants were then contacted by phone and invited to participate in the study. The Scale Resilience was used to measure levels of positive psychosocial adaptation in the face of diabetes. Results: scores were found in the range of 114 to 149, showing that they have a high level of resilience according to the scale used. Conclusion: such knowledge, about the resilience developed by these adolescents in relation to DM1, can offer elements that allow a more adequate approach with these young people, contributing to the improvement of the quality of care. Thus, when planning adolescent care, based on the identification of weaknesses and real needs of this clientele, it is essential to the effectiveness of health promotion actions.

Keywords: Type 1 Diabetes *Mellitus*; Adolescent; Health education.

RESUMO

Objetivo: analisar a resiliência de adolescentes com diagnóstico de DM1 atendidos em ambulatório de endócrina pediatria. Método: Trata-se de uma pesquisa exploratória, descritiva, de abordagem qualitativa. O estudo foi realizado com 16 adolescentes diagnosticados com DM1 atendidos no Ambulatório de Endocrinologia Pediátrica de um Hospital Universitário Regional do noroeste do Paraná. Os potenciais participantes foram então contatados por telefone e convidados a participar do estudo. Utilizou-se a Escala de Resiliência para medir níveis de adaptação psicossocial positiva em face ao diabetes. Resultados: encontrou-se escores na faixa de 114 a 149, denotando que eles apresentam um alto nível de resiliência de acordo com a escala utilizada. Conclusão: tal conhecimento, acerca da resiliência desenvolvida por estes adolescentes frente ao DM1, pode oferecer elementos que permitam uma abordagem mais adequada junto a estes jovens, contribuindo para a melhoraria da qualidade da assistência. Assim, ao se planejar o cuidado ao adolescente, pautado na identificação de fragilidades e necessidades reais desta clientela é elemento essencial à efetividade das ações de promoção de saúde.

Palavras-chave: Diabetes mellitus tipo 1; Adolescente; Educação em saúde.

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INTRODUCTION

Type 1 Diabetes Mellitus (DM1) is characterized by insulin deficiency due to the destruction of pancreatic beta cells. This process occurs as a result of an autoimmune mechanism, although there are cases in which the disease happens by another mechanism, constituting the idiopathic form of DM1. This typology accounts for 5% to 10% of diabetes cases[1]. This form of the disease is one of the most prevalent among chronic childhood diseases, affecting approximately 2/3 of all cases of diabetes in children[2].

In Brazil, it is estimated that there are approximately 88,000 people with DM1, which places the country in the third position in the world with the highest number of people affected by the disease, second only to the United States and India[1]. The numbers of DM1 carriers are increasing, in Brazil, there are 9,600 new cases per year, and worldwide about 70,000 new casesper year[2-3].

Considering that the onset of diabetes, even in adulthood, triggers many difficulties, when it occurs in adolescence, a phase itself marked by transformations that make it somewhat troubled, the process of acceptance of diagnosis and therapeutic conduction can become even more painful[4].

The most difficult situations imposed by the disease are related to sudden changes in daily routine, which include from changing eating habits, to the adoption of insulin therapy, in addition to the need for frequent medical follow-up[5].

The impact of chronic disease in adolescence may be even more harmful, considering the fact that at no point in life is the individual being so vulnerable to emotional stress, due to the intense biological changes in progress. Moreover, it is a milestone in the process of developing the being, since it is constituted in the period for the establishment of a personal identity, with a view to achieving the independence of the family and focused on the planning of goals for adulthood[6-7].

It can be said, therefore, that adolescence is a period marked by physical, emotional, social and cognitive changes. Adolescents with DM1, in turn, may have this perspective of the future reduced, and shaken by lower independence in relation to other individuals of the same age. This forced dependence and physical impairment can generate conflicts between parents and children, due to the absence or lack of understanding of both parties[7-8].

In this perspective, it is necessary that these individuals find a way to face the impacts of DM1, developing mechanisms that help them overcome the problems inherent to this condition[9].

This form of coping composes the mechanism of resilience, which means the ability to overcome adverse conditions, that is,

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they are skills that the individual develops to face situations in a positive way[10].

Thus, considering the context of coping and adapting living to DM1, it is assumed that resilient adolescents are able to seek help and develop ways to deal with these changes in their life routines, together with the people of their conviviality and trust[9-10].

Based on these assumptions, and considering the need to better understand how adolescents face the challenges of living with diabetes, this investigation aimed to analyze the resilience of adolescents diagnosed with DM1 treated in pediatric endocrine outpatient clinics.

METHOD

This is an exploratory, descriptive, qualitative research. The study was conducted with 16 adolescents diagnosed with DM1 enrolled in the Pediatric Endocrinology Outpatient Clinic of a Regional University Hospital in northwestern Paraná. All the adolescents enrolled with the beginning of treatment in 2015 were surveyed, totaling 21 adolescents registered in that period, however, the reduction in the number was because they could not contact them or because they did not accept to participate in the study. The interviews took place at home in 8 municipalities in the northwest of the State of Paraná in the second half of 2015. It is a public teaching hospital that treats patients through the Unified Health System (SUS).

The inclusion criteria defined in the study were adolescents registered with the pediatric endocrinology outpatient clinic with diagnosis of DM1; between 10 and 19 years, which is the milestone of adolescence[11] .

For the selection of adolescents, a survey of the number of adolescents enrolled in the pediatric endocrine outpatient clinic was conducted, according to the inclusion criteria established. The potential participants were then contacted by telephone and invited to participate in the study. After acceptance, interviews were conducted according to previously scheduled times and locations, as well as resilience assessments through the application of the instrument itself.

The Resilience Scale developed by Wagnild & Young, already culturally validated and available in Brazil[12], is one of the few instruments used to measure levels of positive psychosocial adaptation in the face of important life events. It has 25 items described positively, with *likert responses*, ranging from 1 (totally disagree) to 7 (totally agree). The scores of the scale range from 25, which mean low resilience, to 175 points, which translates as high resilience. Thus, the higher the values, the higher the level of resilience of the evaluated individual[12].

The results were interpreted according to the specification of the instrument and analyzed in the light of the national and international literature on the theme in question. The anonymity of the participants

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was guaranteed through the adoption of code names.

Thus, and considering the theme in question, these codenames were inspired by characters present in the book "The Diary of Anne Frank". The character who gives the book its name, based on true history, is a 13-year-old teenager of Jewish origin who described her life in a diary from 1942 to 1944. In the context of World War II, these years were the time when the teenager remained hidden in an annex of the house, along with her family and four other Jews, due to Hitler's persecution of hispeople.

Thus, some analogies can be established between the adolescents in the study and the character of the book. Thus, in common appear the coping processes experienced by Anne Frank in the contexts of adversity of the Second World War, which involved the drastic change of her life routine, the need for sudden adaptations, with deprivations of food and social interaction[13].

Both those responsible for the adolescents and the adolescents themselves confirmed their consent to participate by signing the Informed Consent. The approach of the collaborators of the study occurred after authorization from the institution and service to which the participants were linked. The present study was approved by the Standing Committee on Ethics in Research Involving Human Beings, under opinion number 350,108 and CAAE: 17652413.8.0000.0104.

RESULTS AND DISCUSSIONS

The study included 16 adolescents, 11 pre-adolescents aged 10 to 14 years and five adolescents aged between 15 and 19 years. Of this total, five were female and 11 were male. Regarding the age at which they were diagnosed, three had their diagnosis in preschool age, five in the school phase, and eight in adolescence, evidencing the late diagnosis in most of the cases studied.

The discovery of the diagnosis of DM1 needs to be carried out quickly, since children are not attentive to changes in their body, due to physiological immaturity, causing the diagnosis to arise through a diabetic ketoacidosis, which may lead to complications in the child's recovery[14].

Regarding the evaluation of resilience in the 16 adolescents, scores ranging from 114 to 149 were found, denoting that they have a high level of resilience according to the scale used. Regarding the distribution of adolescent resilience levels by value range, three were between 114-119, 11 between 121-139 and two between 142-149. The profile of young people who scored the lowest degree of resilience is described below:

Margot is 13 years old, female and had her diagnosis signed at the age of 9. It presented the lowest degree of resilience among the total of 16 adolescents participating in the study, totaling 114 points. He also says that he cannot accept the diagnosis, often

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expressing anger at the disease. This revolt translates into behaviors of lack of discipline with diet and low treatment adhering. The following report expresses well the feelings of the adolescent in relation to the disease:

> *[...] I don't accept the diagnosis, it's that shit, you can't live with it and I can't eat everything I want[...]* (Margot).

The denial of the disease is a complicating factor of treatment, because it causes non-adherence to health follow-up, as well as negligence in the proposed therapy, resulting not only in the decompensation of the disease, but also the reduction of quality of life, which can generate feelings of anxiety and depression[15].

Understanding the disease facilitates acceptance of the disease, therefore, it is up to health professionals, especially nurses, to develop health education strategies aimed at clarifying and empowering diabetic children and adolescents, so that when they unseethe disease, they become actors of their own therapy [10].

Albert, a 15-year-old male, scored 119 points in the assessment of his resilience. The adolescent was diagnosed at 13 years of age, not presenting behaviors of revolt in relation to his condition. However, he presents himself as a shy young man, of few words, and who works from Tuesday to Sunday as a fairman. He has no friends among the neighborhood, considering that he resides in a predominantly industrial area. He says he has friends at school, has no neighbor, because he lives in an industrialized area, has school friends, but he doesn't usually attend their homes.

As for leisure, he mentions leaving little for such activities, at most every 2 months, since he does not usually leave without his family, attending only the gym. Regarding the greatest difficulty related to their condition, the adolescent reported:

> *[...] The greatest difficulty are the times: eating time, time to apply insulin [...]* (Albert).

The adaptation of adolescents to DM1 is complex, since adolescence alone is already a time of great biopsychosocial changes, therefore, the support of family members, friends and health professionals are of paramount importance in adapting to the disease. Individualized orientation is essential to facilitate the daily life of adolescents, because knowing their routine makes it possible to perform a therapeutic plan that fits the routine, favoring the maintenance of their quality of life[16-17].

Joseph, a 16-year-old male, scored 119 points. The diagnosis of DM1 occurred at 10 years of age. The mother refers to her son as a child who has always been very agitated, "stressed", which led to the need for the use of ritalin and propanil. In 2013 Joseph lost his father in a work accident, which led the teenager to a period of isolation, in which he

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did not talk to anyone and did not leave the house. Joseph reports having only one friend whose house he usually frequents to play on the computer. The other friendships and contacts are established only in a virtual way. According to the mother, the son is playing day and night. In addition, he dropped out of school while attending the 7th grade of elementary school, because he claimed not to support the noise of the younger children with whom he studied. When referring to the disease, the adolescent expressed the negative view of his condition:

> *[...] Diabetes is not a disease, it is a pest[...]* (Joseph).

The perception about the disease as a plague is a clear sign of disgust and disagreement with the disease, where it is clear the decrease in the quality of life of the adolescent. Coping with the disease must be done through the empowerment of children and adolescents through the knowledge of the disease, therefore, the importance of professional action in health is again emphasized, since it is only from this that the patient's perception can change[5-6].

Visualization is something very important and powerful in the lives of adolescents, so it should be used to show the adolescent that it is possible to have a normal life, even with the disease, evidencing success cases of people from the same health unit and even famous people, because the visualization that it is possible to live normally can empower adolescents in the face of the disease [18].

The other adolescents, with degrees of intermediate resilience to the borderline values found in the study, and who scored between 121 and 139 on the scale, presented similar profiles. When commenting on their daily lives, they also reported experiencing some difficulties with the disease, but have strong ties with their families and friends, usually attend school, and do not manifest feelings of anger regarding their condition or regarding their daily lives.

The acceptance of the disease provides higher rates of resilience in adolescents, which facilitates the management of the disease, also functioning as a protective factor for future serious changes, such as diabetic ketoacidosis, since they know and accept their limits[9].

The highest degree of resilience 149 points found in the studied group was presented by a 17-year-old. The teenager had his diagnosis at the age of 13. In addition to DM1, the mother reported the diagnosis of microcephaly. Due to the limitations of the adolescent, the resilience scale was applied in an explanatory way, and with the mother's intermediation, which helped in the recognition of the answers as affirmative or negative to each of the items of the instrument.

During the mediated interview, the adolescent demonstrated to understand the limitations in relation to food, as well as the

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understanding that the intake of certain foods could bring future consequences. However, this did not prevent him from sometimes eating such food on the sly.

The home of the teenager and his family is quite humble. Because the father is an alcoholic, the sustenance of the house is the responsibility of the mother who works as a day laborer. Thus, and in view of the mother's work, the application/administration of insulin is under the responsibility of the adolescent himself, who administers the drug previously prepared by the mother, who leaves home in the morning, returning from work only in the late afternoon.

Despite all the adversities experienced, the adolescent who has mainly maternal support, demonstrates to overcome in a very positive way the difficulties of his daily life. When asked about the disease, Leo reported that his greatest fear is losing his mother because, in his absence, he will take care of him?

Leo is an example of resilience, which, despite all the family, economic, and health difficulties (microcephaly and DM1), has achieved, together with its support network, achieving quality of life.

When adolescents transcend the barriers imposed by life, he also transcends the fears of the disease, which is treated properly, but without the burden of suffering that is often embedded in the act of diagnosis. When this occurs, the adolescent's quality of life is preserved, in addition to strengthening the bonds between them and health professionals, which are the contacts that will help in the conduction of DM[10].

The second highest resilience score was achieved by Max with 142 points, ten years of age, male, diagnosed with DM1 at seven years. He presents a shy boy and quite involved with the church, in which he performs various activities. The parents are separated, and the teenager does not maintain a good relationship with the father. When it comes to leisure, he says he goes out every weekend to go for a walk and play with his cousins. The mother also reported that Max had consultations with the psychologist, due to the learning regression observed after the diagnosis. There are also references to a marked improvement of Max after starting psychological follow-up.

Max has many friends who help with his illness. His mother even reports that at a school party, the friend asked his mother not to bring cake because of Max's DM1. By such observation the sweets were then replaced by fruits.

Thus, since resilience is understood as the ability of the person to respond to the demands, situations, complexities of his daily life in a positive way, it can be said that the adversities faced along the journey in the life cycle, results in the development of a quality of the individual in rebalancing in the face of difficulties[14].

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During the application of the resilience scale, there was a manifestation on the part of the adolescents that the greatest difficulty faced by them, especially at the time of diagnosis and extended to the present day, was related to food, the need for rigid discipline, and to the adhering to routine and treatment. The following are the impressions of the adolescents in relation to DM1, organized through the main themes addressed during the interaction with the researchers.

DM in adolescence: daily difficulties

The daily difficulties of adolescents with DM1 are evident in the reports of adolescents and their guardians:

> *[...] she is to eat a lot of hidden things, and the problem of Margot is that she eats and does not tell me that she ate, and when I measure her daughter is very high [...]* (Margot's mother).

> *[...] I do not tell because I do not like to take insulin, I know I have to take, I know I go wrong [...]* (Margot).

> *[...] Having DM I is kind of bad, kind of good... bad because I can not eat sweet, good because it does not fatten [...]* (Petter).

> *[...] he is in a very decompensated phase, it is difficult, it is resistant* (Petter's mother).

> *I don't like the Nutritionist, she fights with me because I eat just a little flour and I don't count the carbohydrates [...] I get nervous, because I have this disease [...] I feel trapped, I feel a lot of anger!!! [...]* (Anne).

> *[...] when I fight with her, she says, 'you talk like that because you don't know how bad it is to have diabetes* (Anne's mother).

Although having adequate eating habits is necessary for diabetes control, treatment and food control are not always easy, as it requires changes in routines and eating patterns, requiring the involvement and effective participation of family and friends[17].

Food, in addition to carrying cultural traits of families, is still surrounded by social meanings, since food unites people around the table to celebrate and share moments. Food has a much greater meaning than merely physiological nutrition, therefore, when adolescents are deprived of socialization by the most common environment, they feel deprived of acting as members of that community[1].

Therefore, it is of paramount importance to know about the disease by adolescents and also their families and friends, because the preparation of recipes for diabetics, where everyone will share the same food, provides the inclusion of these in the group. Knowing viable substitutions of food also helps in the creation of food awareness, assisting in the control of DM1[1,6].

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School and social relations in the life context of adolescents with DM1

Regarding schooling, it was observed that among the 16 adolescents only one no longer attended school, and another had already completed high school, and only worked at the time of the interviews. Regarding the absences of adolescents, they attributed them to routine consultations, when scheduled in a period that is coincident with the classes. No faults were mentioned due to other aspects of the disease or treatment.

The school is where adolescents spend most of the day, thus forming not only formal education, but also collaborating in the social education of adolescents, therefore, the school in partnership with primary health care should raise students' awareness about chronic non-communicable diseases such as diabetes, in addition to maintaining a healthy menu for children[19].

The partnership between the school and health services are strong allies in the propagation of knowledge about their own health, besides generating an environment open to discussions, providing diabetic adolescents with a break of taboos due to the disease, promoting social inclusion and assisting in the maintenance of the student in school[10,20].

The participants also reported having strong bonds of friendship, revealing the concern of friends regarding the routine of life and disease control, as well as a good relationship with family and neighborhood. There were no reports of relationship difficulties motivated by DM.

> *[...] I have several friends, I go to their house, play station game, play ball, eat popcorn, yet we do not know how to make brigadeiro (laughs) [...] When I go to get something I can't eat, my cousin talks; that you can't eat, that you can't drink[...] The others do not, is curious only [...]* (Otto).

> *[...] They come home. [...] They're curious, they're afraid, they ask if I do it every day, if it hurts, if I don't feel anything. [...] If there's anything really sweet about the school snack, they tell me not to eat too much or my diabetes will go up[...].* (Van Dan).

> *[...] For me, they want my good, only, I think I know how to take care of myself, when I go to the house, every once in a while, each other and always mom makes that delicious food and I exaggerate a little, ... there they: Dussel... manera!... only I don't accept it, because, like, let me be happy, I know I'm going to get sick[...]* (Dussel).

Social support can minimize the psychological suffering of adolescents who go through a moment of fragility and conflict when encountering chronic disease. In this phase, in addition to family ties, friends assume a role of great importance, especially in the sense of experiencing the protection and acceptance of their group, which has a positive impact on the development of their personality[14]. This is because the circle of

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friends has great influence on the lives of adolescents, representing important support in the emotional, spiritual, material, social and evenschool tasks fields [10].

The limitations of this study are due to the difficulty at the time of the approach of adolescents, who did not answer telephone contact or did not agree to participate in the research, however, because it is an extremely important problem both in epidemiological terms, but especially with regard to their social and psychoemotional implications, the present study made it possible to reflect on the importance of greater investments in the process of monitoring these individuals and their families , with a view to making such confrontations lighter and with fewer sequelae for all involved.

CONCLUSION

The present study disescorted some of the experiences by adolescents and their families in living with the disease, describing the development of resilient behaviors in this population, in light of the particular perceptions of these individuals and their families in the daily life of chronic disease.

Thus, feelings of revolt, and behaviors of non-treatment, sometimes express the sum of two experiences that, in isolation, already impose on individuals the need to build adaptation mechanisms. The double challenge, therefore, is how to deal with the experience of "getting sick" along with the experience of "falling ill" from a chronic problem such as DM1.

In this walk, it is possible to perceive the configuration of some strengths, resulting from the resilience mechanisms developed by these young people, as able by the high scores achieved. Another notorious aspect is the essential role played by the family network and friends, for the process of adaptation and acceptance of the disease by these adolescents.

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