Self-management of diabetes in adolescence: experience of Portuguese young adults and their parents

Autogestão do diabetes na adolescência: experiência de jovens adultos e pais portugueses
Autogestión de la diabetes en la adolescencia: experiencias de jóvenes adultos y padres portugueses

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Abstract

Objective: To identify the factors that facilitate or hinder the construction of autonomy in adolescence through the experience of young adults with type-1 diabetes and their parents.

Methods: This was a qualitative, descriptive, and exploratory study. Two focus group interviews were conducted: one with nine young adults who were experts in managing their illness and the other with seven parents. Thematic and categorical content analysis was used for data analysis, with particularities of a focus group interview and the use of the NVIVO 12 software.

Results: Two major categories and ten subcategories related to factors that facilitated (support systems, knowledge, diet, insulin pump, early responsibility for managing therapy, and characteristics of young people) and hindered (therapeutic regimen, stigma, attitude of health professionals, characteristics of young people, and knowledge) the development of autonomy in disease management emerged.

Conclusion: Autonomy in the management of diabetes involves several challenges for adolescents, which requires adaptation of attitudes and interventions by professionals. In addition to the traditional management of the health condition, addressing issues related to the socialization of adolescents is essential, looking for innovative strategies that promote coping and quality of life. The results of this study make it possible to reflect on the therapeutic relationship with adolescents, emphasizing the importance of individualizing care and innovative responses to their specific needs.

Resumo

Objetivo: Identificar os fatores que facilitam ou dificultam a construção da autonomia na adolescência através da experiência de jovens adultos com diabetes tipo 1 e seus pais.

Métodos: Estudo de natureza qualitativa, descritiva e exploratória. Foram realizadas duas entrevistas de grupo focal, uma com nove jovens adultos peritos na gestão de sua doença e outra com sete pais. Para análise dos dados, foram usados análise de conteúdo temática e categorial, com particularidades de entrevista de grupo focal, e recurso ao *software* NVIVO 12.

Resultados: Emergiram duas grandes categorias e dez subcategorias relativas aos fatores que facilitaram (sistemas de suporte, conhecimentos, alimentação, bomba de insulina, responsabilização precoce pela gestão da terapêutica, características dos jovens), e dificultaram (regime terapêutico, estigma, atitude dos profissionais de saúde, características dos jovens, conhecimento) o desenvolvimento da autonomia na gestão da doença.

Conclusão: A autonomia na gestão do diabetes envolve vários desafios aos adolescentes, o que requer adequação de atitudes e intervenções de profissionais. Além da gestão tradicional da condição de saúde, é

essencial abordar temas relacionados com a socialização dos adolescentes, procurando estratégias inovadoras que promovam o *coping* e a qualidade de vida. Os resultados deste estudo possibilitam refletir sobre a relação terapêutica com os adolescentes, salientando a importância de individualizar cuidados e respostas inovadoras às suas necessidades específicas.

Resumen

Objetivo: Identificar los factores que facilitan o dificultan la construcción de la autonomía en la adolescencia a través de la experiencia de jóvenes adultos con diabetes tipo 1 y sus padres.

Métodos: Estudio de naturaleza cualitativa, descriptiva y exploratoria. Se realizaron dos entrevistas de grupo focal, una con nueve jóvenes adultos expertos en la gestión de su enfermedad y otra con siete padres. Para el análisis de datos se utilizó el análisis de contenido temático y categorial, con particularidades de entrevista de grupo focal y recurso del *software* NVIVO 12.

Resultados: Surgieron dos grandes categorías y diez subcategorías relativas a los factores que facilitaron el desarrollo de la autonomía en la gestión de la enfermedad (sistemas de apoyo, conocimientos, alimentación, bomba de insulina, responsabilización temprana de la gestión de la terapéutica, características de los jóvenes) y los que la dificultaron (régimen terapéutico, estigma, actitudes de los profesionales de la salud, características de los jóvenes, conocimientos).

Conclusión: La autonomía en la gestión de la diabetes incluye muchos desafíos para los adolescentes, lo que requiere adaptación de actitudes e intervenciones de profesionales. Además de la gestión tradicional del estado de salud, es esencial abordar temas relacionados con la socialización de los adolescentes y buscar estrategias innovadoras que promuevan el *coping* y la calidad de vida. Los resultados de este estudio permiten reflexionar sobre la relación terapéutica con los adolescentes y destacar la importancia de individualizar los cuidados y las respuestas innovadoras para sus necesidades específicas.

Introduction

Type-1 Diabetes m*ellitus* (T1D) is the most common form of diabetes in children and young people. The global prevalence of T1D has been increasing by 3-4% per year.[1] Poor long-term metabolic control can lead to serious health conditions such as neuropathy, nephropathy, retinopathy, etc.[2] Investing in health promotion interventions and responsibility for self-management of illness during adolescence is essential for good metabolic control in adult life.[3,4]

In adolescence, the search for identity and the desire for autonomy guide the decisions and behavior of adolescents. This phase of development is an opportunity to adopt healthy behaviors and lifestyles, with benefits not only in adolescence but also in adulthood.[5]

In physiological terms, puberty decreases the effectiveness of insulin, implying a need for more demanding glycemic control.[6] Other characteristic factors associated with metabolic deterioration in adolescence include the following: irregular meal and exercices pattens, poor adherence to treatment regimens, eating disorders, and risky behaviors.[7] This period of life makes controlling this chronic condition a complex challenge, giving rise to feelings of revolt and resistance to adequate management of their condition in adolescents; this demands special attention from health professionals regarding their monitoring and intervention for autonomy.

Health policies increasingly seek to make young people with chronic conditions responsible for autonomy in their self-care, highlighting the role of health professionals in the training process.[8,9] The term "Self-management" implies that the individual himself is autonomous and responsible for the daily care and management of his chronic condition.[10]

Effective self-management behaviors improve health outcomes and quality of life, reducing complications, recurrences to health services, and associated costs.[11] When clients who are experts in managing their illness are recognized as partners in care delivery rather than simply users of health services, a partnership can help professionals make better decisions. In this context, young adults who are experts in the management of T1D and their parents are an unavoidable source of information for developing intervention programs for autonomous and effective management of the disease aimed at adolescents.[12] The lived experiences will allow identifying the intrinsic and extrinsic factors for adolescents, which may be barriers or facilitators in the development of competencies for self-management of their T1D.[13]

Therefore, the objective of this study was to identify the factors that facilitate or hinder the construction of autonomy in adolescence through the experience of young adults with T1D and their parents.

Knowing the experience of young people experts in the management of their disease, as well as

that of their parents, will allow identifying possible gaps that can be filled through an intervention program adapted to the real needs of adolescents, thus allowing to improve the quality of life of children and adolescents with T1D.

Methods

This was a descriptive and exploratory study of a qualitative nature. Two groups, young adults with T1D (Y; ages: 23-35 years; n=9) and parents (P; n=7) participated in this study. Being a young adult expert in T1D management and parents of these young adults were the inclusion criteria. The initial recruitment was done through a reference institution for the treatment of patients with diabetes in Portugal, which facilitated the first access to the participants and supported the authors in conducting the theoretical sampling; the snowball sampling technique was used for the following accessions.

The focus group was used as a data collection technique.[14,15] The interviews of both groups were carried out simultaneously in two separate meeting rooms at the university, being moderated by the principal researchers with experience in using this technique. The interviews had a mean duration of 85 min and were recorded on video. Only the participants, the moderator researcher and the moderator assistant were present. The *corpus* of the analysis resulted from the full transcription of the interviews, which was carried out by the researchers, including the field notes made by the assistant during the interview. The principal investigator was the custodian of the data during the time necessary to conclude the study.[16]

As summarizing and validating the content with the participants would be impossible, a summary was made and then sent to all participants (November 2022) to validate its content; all participants responded positively.[14,15]

An interview guide was prepared to collect data based on a similar study adapted to T1D [17] with the following questions: "In your opinion, what does it mean for a young person with T1D to be autonomous? What is your opinion about your process of building autonomy in managing T1D in adolescence? What made it difficult? What made it easier? What do you suggest facilitating the process of building the autonomy of adolescents with T1D?". The interview concluded with an open-ended question, allowing participants to add anything they felt was important. The interviews took place without incident and the questions were deepened until data redundancy was reached. Thematic and categorical content analysis,[14] with particularities of focal group interview,[15] and the NVIVO 12 software were used in the data analysis.

In the "coding" phase, we seek to ensure the scientific rigor of internal consistency through the agreement of researchers and judges in the interpretation of data. The dubious or contradictory information detected in the participants' discourse was clarified with themselves by telephone contact. To ensure the reliability of results, all coding carried out involving the registration units organized into categories, subcategories, and indicators was discussed with the respective judges.

The analysis grid was inductively (re)built, supporting the global analysis of data. A between-group analysis was performed whenever there was justification in terms of discrepancy and/or divergence about the results.

The present study was approved by the Ethics Committee of the Protective Association of Diabetics in Portugal. All ethical procedures required in the Declaration of Helsinki were fulfilled. The informed, free, and clarified consent was requested from young adults with T1D and their parents, and they were informed of the purpose and objectives of the study.

Results

As for the characterization of the sample, table 1 shows that the mean age of young adults was 29.6 years and the age at diagnosis ranged from 7 to 19 years; this means that the participants referred to the process of building autonomy in the management of T1D recent and simultaneously with a distance that allows them to have a more reflective and critical look at their experience.

Table 1. Characteristics of participants

	Mean Ages (min.-max.)	Sex		Literary abilities				Age* (max-min)	Method **	
		M	F	Basic	1st Cycle	2nd Cycle	3rd Cycle		Pen	Pump
Young adults	29.6 (23-35)	4	5		5	3	1	14 (7-19)	4	5
Parents	64.7 (54-73)	-	-	2	5	-	-	-	-	-

*Age when the diagnosis was received; ** Method used to administer insulin

Two dimensions stood out in the results: Autonomy in T1D management and Development of T1D self-management skills, each with categories and subcategories, according to the analysis grid shown in chart 1.

Chart 1. Analysis of autonomy in the development of skills for self-management of type-1 diabetes *mellitus* (T1D)

Dimensions	Categories	Subcategories
Autonomy in the management of T1D	Concepts	Self-determination
		Self-care
		Independence
Development of skills for self-management of T1D	Facilitating factors	Support systems
		Knowledge about T1D
		Food
		Insulin pump
		Responsibility for (early) therapeutic management
		Characteristics of young adults
		Maintenance of life routines and/or activities
	Hindering factors	Management of the therapeutic regimen
		Discriminatory attitudes and/or stigma
		Attitude of health professionals
		Characteristics of young adults
		Knowledge about T1D

Autonomy in the management of T1D
Concept of autonomy
Table 2 shows that for both groups the concept is related to self-determination and accountability in decision-making on T1D management: *"(…) I want to be the one to decide everything by myself (…)" (Y1)*. Following independence, the participants defined themselves as persons who do not depend on others: *"I want to do it by myself and not be dependent on someone giving me the injection" (Y4)*. These results agree with Proot's concept of autonomy,[18] including the three recommended dimensions: self-determination, independence, and self-care.

Development of T1D Self-Management Skills
As for the dimension of development of skills for self-management of T1D, the factors that facilitated and hindered this process and suggestions for

Table 2. Concepts of autonomy in the management of type-1 diabetes *mellitus* (T1D)

Subcategories	Young adults n(freq.)	Parents n(freq.)
Self-determination	5(54)	6(29)
Independence	3(16)	5(13)
Self-care	1(1)	5(11)

improving it emerged as categories (Table 3). As for the facilitating factors of this process, six subcategories emerged: support systems, knowledge about T1D, insulin pump, accountability for therapeutic management, food, and characteristics of young people and their routines.

Facilitating factors
The support systems are a relevant factor. We emphasize the support given by peers with T1D in formal and informal groups of young adults in summer camps: *"(…) I saw how the older ones did it and I wanted to be just like them (…)" (Y1)*. As well as the health professional experts in T1D: *"(…) having a multidisciplinary team who knows how to talk about everything!" (P4)*. Parental support also appears significantly for both groups: *"My facilitating person (…) is my mother. She showed me the way" (Y1)*. The support young adults found in the whole school community was also important: *"… Diabetes appeared to me and the whole structure of the school, teachers and assistants, everyone got together (…) with a person specialized in Diabetes; they realized what it was, how they had to act with me, how it was done" (Y4)*.

The knowledge related to T1D was evidenced with greater emphasis by the group of parents: *"[the] fact that this was giving in science on the heights (…) she understood how her pancreas worked and what diabetes was, and that made it easier" (P5)*, considering a prerequisite to conquer their autonomy *"Nobody is autonomous without knowledge" (Y2)*. The insulin pump (Continuous Subcutaneous Insulin Infusion

[CSII]) was undoubtedly a facilitator in the development of skills for self-management of T1D in both groups, although the adaptation process is a troubled phase and a considerable challenge for young adults: *"The pump was God in heaven and the bomb on earth, (...) it was a miracle at home" (P3).*

The early responsibility of children or adolescents for the management of the therapeutic regimen was recognized as an important contribution: *"(...) I clearly remember my mother saying on the heights - (...), Diabetes is a disease that you are the one who has it, therefore you are the one who has to deal with it." (Y4); "all the responsibility went basically to his hands (...)" (P2).* In the great majority of these young people, diagnosis of T1D occurred during adolescence and the characteristics associated with this stage of development, such as the search for independence and autonomy, emerged as a facilitating factor: *"the time of adolescence which is the age par excellence in which autonomy is worked on" (P7); "14 years old is my best age (…) I want to do things by myself" (Y1).*

Hindering factors

As for the factors that hampered the development of skills for self-management of T1D, they are presented in table 3, where five subcategories emerge: the complexity of the therapeutic regimen and difficulties in its management; discriminatory attitudes; attitudes of health professionals; adolescent characteristics; and lack of knowledge about T1D.

As for the management of the therapeutic regimen, food management stands out as the most difficult component to manage, especially the difficulty in counting carbohydrates associated with poor food labeling, followed by the unpredictability in managing the daily activities, namely the school schedules and transport used for travel.

The fear of needles was referred to as a significant difficulty in the self-administration of insulin with the pen: *"The fear of needles is what complicated things a bit. (...)" (Y4).*

The negative impact of discriminatory attitudes on the adolescents' self-esteem and their relationship with the disease was mentioned by both groups: *"...she started not wanting to go to school (…)*

(P6). However, the experience was bad, to the point that some parents didn't want their children to go out with it because they caught it" (P6): "You're a drug addict, you're injecting" (Y2). Both groups emphasized that the attitudes of health professionals are decisive in adherence to the therapeutic regimen. The lack of flexibility and empathy for the concrete difficulties in managing the therapeutic regimen and rigidity in complying with this regime, place "a great weight" on the mistakes made; *"sometimes, doctors transmit some panic (…) (Y2); "Often, health professionals are very square; they are very attached to books" (Y5).* The young adults' characteristics also emerged as difficulties associated with the process of adapting to the disease, managing frustration, and blaming when their effort is not successful: *"I think the most difficult thing is to manage frustration (...)" (Y6).* Stress, anxiety, and changes associated with menstruation at the hormonal level were also highlighted by the young women: *"It is enough to be a little more anxious, to have menstruation, and there is immediately a lack of control" (Y4).*

Table 3. Facilitating and hindering factors in the development of autonomy to manage type-1 diabetes mellitus (T1D)

Categories	Subcategories	Young adults n(freq.)	Parents n(freq.)
Facilitating factors	Support systems	7(144)	5(60)
	Knowledge about T1D	5(19)	6(47)
	Insulin pump	3(18)	3(24)
	Responsibility for the management of therapy (early)	4(10)	4(17)
	Characteristics of teenagers	4(6)	3(10)
	Routine maintenance		2(12)
Hindering factors	Management of therapy	9(83)	6(22)
	Discriminatory attitudes or Stigma	5(29)	6(37)
	Attitude of health professionals	9(28)	1(3)
	Characteristics of teenagers	5(21)	4(8)
	Deficit of knowledge about T1D		5(8)

To improve the process of building autonomy in the management of T1D, most young people suggested that health professionals provide more activities in less controlled environments, highlighting summer camps, supervised sports practice, and meetings with reference peers with T1D. They suggested that professionals adopt more flexible attitudes and greater permeability to less conventional solutions, supporting them without judging,

and advising them to undergo training in the area of communication and therapeutic relationships. They added that one should invest in training on T1D, aimed not only at professionals but at the entire school community, especially cooks, to provide prior information on the nutritional value of meals. They also suggested that information on the nutritional value of foods should be mandatory in commercial establishments.

Discussion

Autonomy in managing T1D entails several challenges for adolescents and both groups highlighted self-determination as an important assumption. The young adults essentially referred to decision-making, *i.e.*, the capacity to analyze alternatives and possible consequences of the decision in the long, medium, and short terms. At this stage of development, gaining independence requires knowledge, skills, and experience to decide on disease management; such dimensions also emerged in another study with adolescents aged 16-18 years.[19] The development of autonomy in the self-management of the chronic condition was perceived by the participants as a natural process in adolescence, a troubled period that implies feeling proud of achievements, but also taking responsibility for the mistakes made. These results reflect previous studies, in which it was inferred that responsibility for self-care is part of the expectations of adolescents with T1D; however, this process is also frightening as it represents managing the overload of activities necessary to manage the disease and the expectations of themselves, parents, and professionals.[19,20]

In agreement with the results of previous studies, support systems stand out as facilitating factors in the process of autonomy among adolescents.[8,9,21] They highlighted the influence of peers with T1D associated with the awareness that they are not unique, and that there are others with the same problems and difficulties. Our results agree with previous studies, in which peers are recognized as important behavior models, and sharing experiences allows learning to solve problems with repercus-

sions on their self-efficacy.[9,19,21,22] The difficulty in dealing with the frustration related to the ineffectiveness of their performance was evidenced in the present study, suggesting that health professionals should attend to these experiences instead of focusing only on the results. This idea was also presented in other studies which underlined that adolescents identify allies and people who show empathy, reinforcing the importance of individualization and the availability of mental health resources.[23,24]

Parental support is a facilitator when it is based on mutual collaboration and trust. The parents referred to the importance of a relationship of trust with their children in the management of the disease, suggesting that supervision and support are key elements, emphasizing the importance of the relationship between parents and children and the gradual responsibility of adolescents with parental support and supervision.[24,25] Our results agree with those of previous studies and expert recommendations, highlighting the influence of the quality of this relationship and shared responsibility on adherence to the therapeutic regimen.[7,13,25]

On the one hand, health professionals who are experts in T1D appear in this study as a meaningful support system that transmits confidence to adolescents. On the other hand, they appear as a barrier when they demonstrate rigidity in the approach related to non-compliance, attributing a great weight to the mistakes made and the respective consequences on their future health.[23] Most suggestions of the participants of this study fall on the professionals. The participants suggested that the empathetic and interested attitude of the professionals allows for establishing a relationship of trust,[23] agreeing with the review by Figueiredo *et al.*[13] who underlined the idea that health services should be perceived as a safe place for adolescents to express their doubts, fears, and difficulties. In this context, adolescents also highlighted the need to be supported without value judgments,[26] adding that they can choose their preferred professionals would be a facilitator.[24]

Both the responsibility to make the environment safe and enabling and educating their students about T1D and treatment falls on schools

as a fundamental support system.[13,27] Disease management activities were also the target of stigma and discrimination attitudes; this result agrees with recent studies that recommend awareness actions on T1D not only in schools but also in society in general.[24]

The need to perform complex calculations and the lack of information on the nutritional value of commercially available foods and school canteens are also difficulties present in the results of other studies.[28,29]

Although the technology in the blood glucose regulation and subcutaneous insulin infusion systems used by children show encouraging clinical results and excellent contributions to the development of autonomy in the management of T1D, they do not eliminate the need for daily adjustments and support in the associated difficulties [20,30] especially in the adaptation process.[20,23]

It is important to mention some limitations that may help to interpret results and guide future investigations. Although this study was a robust discussion of the development of autonomy in adolescents, it involved only two focus groups. The limited cultural diversity among the participants may have been a limitation of this present study, since the development of autonomy can be influenced by different cultures, eating habits, etc.

Conclusion

Our results inform the practice of care to facilitate the construction of autonomy for adolescents with T1D through the experiences lived by participants. They enable health professionals to reflect on the importance of the quality of the therapeutic relationship with adolescents, individualized care, and innovative responses to the needs of adolescents with T1D. Through the voices of these young adults and their parents, challenges emerge for professionals who go beyond the traditional management of the health condition, calling for the need to use innovative strategies to improve the quality of life of children and adolescents with T1D.

Collaborations

MIDC, Vinagre MG, Colaço SI, Flora MC, Paixão MJG, Figueiredo IC e Dingle MC contributed to the design of the study, analysis and interpretation of data, writing of the manuscript, critical review of relevant intellectual content, and approval of the final version to be published.

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