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Inclusive Education for Students with Type 1 Diabetes in Spain: Reality or Utopia?

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The presence, participation and learning of children with Type 1 Diabetes is not ensured in Spanish classrooms due to the existence of barriers of various origins. The aim of the present research is to understand the inclusive vision of diabetes at school through the voice of people involved in the schooling process and to analyse the educational reality of students with Type 1 Diabetes, examining both the barriers to inclusion and the opportunities for its achievement. Qualitative and phenomenological research was used, obtaining data through in-depth interviews with parents of children living with Type 1 Diabetes and their teachers, all residing in the province of Segovia, in the Autonomous Community of Castilla y León (Spain). The obtained results allow us to visualise some experiences of families and teachers based on the onset of the disease (diagnosis) and the facilitating elements and barriers perceived at school. The complexity of the disease often hinders the integration of sufferers in schools. Barriers include the lack of diabetic training, the scarcity of resources and support, and inadequate coordination between administrations. On the other hand, the importance of the school nurse, collaboration between families, professionals, health professionals and teachers, and the involvement of teachers in the care of students are highlighted. Access to inclusive education for students with Type 1 Diabetes depends on the attitude and involvement of teachers.

Keywords: inclusive education, primary school teacher, chronic diseases, diabetes, school nurse

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Inkluzivno izobraževanje učencev s sladkorno boleznijo tipa 1 v Španiji: realnost ali utopija

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Prisotnost, sodelovanje in učenje pri otrocih s sladkorno boleznijo tipa 1 pri pouku v Španiji niso zagotovljeni zaradi ovir različnega izvora. Namen te raziskave je razumeti inkluzivno vizijo sladkorne bolezni v šoli skozi glas ljudi, vključenih v šolski proces, in analizirati izobraževalno realnost učencev s sladkorno boleznijo tipa 1, pri čemer je treba preučiti ovire pri inkluziji pa tudi možnosti za njeno doseganje. Uporabljena je bila kvalitativna in fenomenološka raziskava, pri čemer so bili podatki pridobljeni s poglobljenimi intervjuji s starši otrok s sladkorno boleznijo tipa 1 in z njihovimi učitelji, vsi s prebivališčem v pokrajini Segovia v avtonomni skupnosti Kastilja in León (Španija). Pridobljeni izsledki nam omogočajo vizualizacijo nekaterih izkušenj družin in učiteljev glede na začetek bolezni (diagnozo) ter olajševalne elemente in ovire, ki jih zaznavajo v šoli. Kompleksnost bolezni pogosto ovira vključevanje obolelih v šolah. Ovire vključujejo pomanjkanje usposabljanja za sladkorne bolnike, pomanjkanje sredstev in podpore ter neustrezno usklajevanje med upravnimi skupinami. Po drugi strani pa so poudarjeni: pomen šolske medicinske sestre, sodelovanje med družinami, strokovnjaki, zdravstvenimi delavci in učitelji ter vključenost učiteljev v skrb za učence. Dostop do inkluzivnega izobraževanja za učence s sladkorno boleznijo tipa 1 je odvisen od odnosa in vključenosti učiteljev.

Ključne besede: inkluzivno izobraževanje, osnovnošolski učitelj, kronične bolezni, sladkorna bolezen, šolska medicinska sestra

Introduction

Education is a universal right that requires legal, moral and ethical responsibilities (UNESCO, 2014), but not all people are currently guaranteed this right. According to the PISA report (Ministerio de Educación, Formación Profesional y Deportes, 2022), the socioeconomic level of families and their involvement in the education of their children (Bunijevac, 2017) continues to condition learning, as does the availability of healthcare.

More than seven decades ago, the Universal Declaration of Human Rights (United Nations General Assembly, 1948) included universal access to school, which eventually became the right to education for all in the Convention on the Rights of the Child (United Nations General Assembly, 1989) and the Convention on the Rights of Persons with Disabilities (United Nations, 2006). As Echeita (2016) reminds us, inclusive education is not an option, but a right. At this point, it is necessary to clarify the fact that inclusive education encompasses a wide range of activities, processes and strategies aimed at ensuring the universal right to equitable and quality education for all (Arnaiz, 2012). It is an educational perspective in which the diversity of students is understood as richness (Booth et al., 2011), which is why it must accommodate and value all of their particularities and consider them as fundamental to the correct development of the teaching-learning process (Torres-Cladera et al., 2021). This creates a challenge, especially for schools, which, according to Echeita (2016), have two essential tasks. The first is to recognise the multiple barriers in education policies, cultures and practices that currently limit or impede students' presence, participation and learning. Schools need to review and reflect deeply on their institutional programmes and educational projects through this analytical lens. The second task is to transform these barriers into facilitators in order to ensure education that is equitably responsive and accommodating to the diversity of learners, their educational needs and their interests.

This context makes it clear that inclusive education is a challenge for current education systems, as it requires providing personalised attention taking into account the social, cultural and personal conditions of each learner (Delgado et al., 2022). Despite this, we continue to experience situations in which the presence, participation and learning of all students in educational centres is not guaranteed. The educational inclusion of students affected by Type 1 Diabetes (T1DM) is a clear example of this.

T1D

T1D belongs to a group of diseases (Diabetes Mellitus) characterised by "hyperglycemia resulting from defects in insulin secretion and/or action" (Alfaro et al., 2000, p. 33). It is an autoimmune disease that destroys pancreatic β-cells, making it impossible to secrete insulin. The most common chronic endocrinological pathology in the paediatric age group (Gómez, et al., 2020; Pinelli, et al., 2011), T1D is characterised by a pre-onset symptomatology that causes the child to have a constant need to drink, urinate and eat, together with blood glucose equal to or higher than 200 mg/dl (11.1 mmol/l) at any time of the day, or basal blood glucose equal to or higher than 126 mg/dl (7. 0 mmol/l), or blood glucose equal to or greater than 200 mg/dl (11.1 mmol/l) at two hours during an oral glucose tolerance test (blood glucose curve with 75 g of glucose) (Barrio et al., 2020). Although all of these symptoms are visible, the existing lack of knowledge about T1D causes the diagnosis to be later than desired (Bodas et al., 2008).

After diagnosis, we have to deal with a chronic disease, i.e., a disease that cannot be cured but can be treated, using glucose controls and subcutaneous insulin injections (Carral et al., 2018). It is therefore necessary to be aware of the main imbalances in DM1: hyperglycaemia where there is a high blood glucose level (above 180 mg/dl) and hypoglycaemia where there is a low blood glucose level (below 70 mg/dl) (American Diabetes Association, 2012). It is important to recognise and detect the symptomatology of both imbalances in order to act effectively and early to avoid acute complications (Gómez et al., 2020). In DM1, lack of adherence to treatment and failure to control blood glucose can lead to a significant long-term loss of quality of life (de Pablo, 2014). Children diagnosed at an early age are at an increased risk of complications due to the nature of the disease and the difficulties in achieving good glycaemic control at this age (Pinelli et al., 2011). Adequate treatment requires intensive monitoring 24 hours a day, 365 days a year.

Schooling of students with T1D

Schooling is one of the fundamental pillars in the full development of children, particularly in situations in which they are faced with an illness (Gómez & Espino, 2012). If we add to this the fact that education is a universal right (UNESCO, 2014), we must defend the premise that the school life of students with T1D cannot be differentiated from that of other students (Ordoño et al., 2016). However, due to the complex nature and treatment of the disease, on numerous occasions, difficulties arise when it comes to the school integration of these students (Barrio et al., 2020).

Armas and Fernández (2022) argue that T1D cannot hinder educational inclusion, regardless of the age of onset. They also explain the importance of returning to normality as soon as possible and recall that, in this normality, the educational centre is a fundamental element for children and adolescents. Thus, guaranteeing that students with T1D receive the necessary care to ensure their well-being in the educational centre has become one of the educational challenges of the twenty-first century (Carral et al., 2018), as the ideal of homogenisation and the concept of 'normalisation' continue to be established in classrooms, leading to educational marginalisation and exclusion (Santos-Guerra, 2002). We seem to forget that "equality does not apply indiscriminately to any type of diversity or inequality" (Santos-Guerra, 2002).

Along these lines, we have found that, in recent decades, there has been a significant proliferation of studies that focus on investigating the phenomena of inequity, marginalisation and educational exclusion (Plá, 2015). This is due to the fact that international agreements are failing to guarantee the right to inclusive education (Echeita, 2016) and that, on the contrary, marginalisation and educational exclusion have become normalised in society (Plá, 2015). When we talk about educational exclusion, we mean any phenomenon in which the access or participation of all people in the educational process is set aside, denied or restricted. It can be understood as a synonym for oppression, such that the voices of these people are not heard, let alone considered.

All of this converges in educational inequality (Gajardo-Espinoza et al., 2023). Inequality that, according to Gajardo-Espinoza et al. (2023), is imposed on society, so that although all people are born with the same rights, their characteristics, circumstances and personal interests group them into 'categories'. This is the case of students with T1D and their respective families, a group that is denied or restricted access to and/or participation in many of the activities that take place in schools, which means that, at present, these students are being denied their right to education.

Students with T1D, who, like other children, spend a third of their day in school, should be able to achieve the same level of diabetes control during their school day. This would mean that these children could incorporate continuous glucose monitoring, insulin injections and meal planning at school, as well as their right to participate fully and safely in all school activities (Muntaner et al., 2014). All of this implies a rigorous diabetes education that enables them to understand how, when and how much they should eat, how, when and how much insulin to administer, how long they should wait, and so on (García et al., 2008). As can be seen, disease management is demanding and unsuitable for younger students, as it requires interpretations and logical-mathematical calculations that are beyond their abilities.

It is difficult for these students to attend excursions, participate in sports activities or attend unplanned or modified school meals (Cousins, 2014). In other words, these children are presented with daily barriers that make it difficult or impossible for them to attend and participate in the daily activities of the school day, so they are being denied their right to an inclusive education that allows them to develop to their full potential.

In this context, we present qualitative research whose main objective is to make visible the educational reality of students diagnosed with T1D from an inclusive perspective. For this purpose, we propose a study with a phenomenological approach that gives voice to a group of people involved in the schooling process of these students: teachers and families.

Accordingly, we propose the following specific objectives:

To understand the inclusive vision of diabetes at school through the voice of the people involved in the schooling process: teachers and families.

To analyse the concept of inclusion, understood as a right, with regard to the educational reality of students with T1D, detecting both the barriers to inclusion and the opportunities to achieve it.

Method

Participants

The sampling method was based on convenience. The participants in the study included two female teachers in middle adulthood (40–50 years old). At the time of the interview, Teacher 1 (ED1) was teaching in the third year of early childhood education, while Teacher 2 (ED2) was teaching in the second year of primary education. The first teacher had 19 years of teaching experience, while the second had 23 years. Both teachers had taught students with chronic illnesses such as asthma or diabetes.

The family members included seven middle-aged individuals (35–50 years old): four women and three men. Two of the women worked in the service sector, while the rest of the interviewees were employed in the manufacturing industry. All of the participants in the study signed an informed consent form, ensuring that their sociodemographic data would remain confidential for the research. Finally, in order to verify that the participants had a child diagnosed with T1D, all of them were obliged to belong to or take part in the activities of the Segovia Diabetes Association. The respondents had to meet the criteria reflected in Table 1.

Table 1

Eligibility criteria for the interviewees

Families	Education professionals
The parent has a child with T1D.	The teacher teaches in early childhood education or in the first years of primary education.
The onset of diabetes in the child occurred in the province of Segovia when the child was between the ages of 0 and 6 years.	The teacher works in educational centres in the province of Segovia.
The child is in school.	The teacher has had students with T1D in the classroom.
The parent belongs to the Segovia Diabetes Association.	

Note. Own elaboration

In October 2021, we launched a public invitation to participate in the study, explaining the main purpose and the eligibility criteria to be met by the participants. On the same day that the proposal was shared, more than a dozen families showed their gratitude and interest in participating in the project, but not all of them met the required characteristics (see Table 1). For this reason, only four mothers and three fathers were selected to participate in the study.

After selecting the participants, we contacted them by phone to ask about their preferences regarding the schedule, date and location for the interview (see Table 2). Additionally, we informed them that before proceeding with the interview, they needed to sign an informed consent form outlining the purpose of the research and the ethical criteria, and ensuring their anonymity.

During the interviews, the families provided us with information about teachers who had worked with students with T1D, which enabled us to make contact with the two teachers who participated in the research.

Instruments

The scripts designed for families (Appendix 1) and teachers (Appendix 2) were based on reading and analyses carried out during a previous systematised review (Cáceres-Iglesias et al., 2023), reading of and reflection on press reports, and the participation of the researchers in networks of families living with T1D.

With all of this in mind, we drew up an outline of the topics that we considered necessary to discuss with the participants in our research, while reiterating the need to let the research do the talking.

Research design

The study has a qualitative character and a phenomenological approach that allowed us to investigate the experiences of the people involved in the schooling of students with T1D and to understand the inclusive and exclusive measures that have shaped their reality.

The semi-structured interview (Flick, 2015) was used as the main method for obtaining data on the experience of each of the participants in reference to a key moment (phenomenon): the diabetic onset. This is equivalent to the diagnosis of the disease, often associated with typical symptoms: polyuria (excessive urination), polydipsia (excessive thirst), polyphagia (excessive appetite) and weight loss (Sesmilo, 2021).

Following ethical standards in educational research, prior to conducting the interviews, the participants were informed of the research objectives and conditions of participation, and their informed consent was obtained. In order to protect their identity, the data were anonymised.

According to Massot et al. (2004), "The interview is a technique whose objective is to obtain oral and personalized information about events experienced and subjective aspects of the person" (p. 336). In our research, the data collected form a narrative that establishes the basis for understanding the socio-educational reality of the participants from a phenomenological perspective, which emphasises the need to construct first-person accounts in order to understand a phenomenon (Yin, 2014).

All of the interviews were carried out in a comfortable environment, close and convenient for the interviewees (Gómez et al., 2006). The interviews were recorded using an audio recording device, with each interviewee being informed when the recording began and ended. This process allowed for the subsequent transcription of the data in order to proceed with the analysis. Table 2 shows the data for each person interviewed.

Table 2

Place, date, time and coding of the interviews

Interviewee	Location	Date	Schedule	Duration	Coding
Family 1	At home	07/02/2022	19:00h	2.5 hours	EFM1 EFP1
Family 2	At their workplace	08/02/2022	19:30h	2 hours	EFM2 EFP2
Family 3	At home	14/02/2022	17:30h	2.5 hours	EFM3 EFP3

Interviewee	Location	Date	Schedule	Duration	Coding
Family 4	At the researcher's home	24/02/2022	18:30h	1.5 hours	EFM4
Teacher 1	In a park	01/07/2022	19:00h	2 hours	ED1
Teacher 2	In a cafeteria	02/09/2022	18:00h	1.5 hours	ED2

Note. Data collected from the research.

The data analysis proceeded using an open category system, which was also used to analyse the data collected through the documentary analysis, the systematised review and the interviews. According to Rodríguez et al. (1996), the design of an open category system allows the information to be classified and catalogued in thematic units (Table 3).

We conducted a thematic analysis that required inductive coding of all of the information obtained, based on the method of Andréu (2002) and using the qualitative analysis software Atlas Ti. 9.0.

Table 3

Coding system, categories and subcategories

Categories	Subcategories
Roles/actors	Families Children Health professionals Education professionals Educational administration
Socio-educational paradigm	Educational inclusion Educational integration Health education
Results	Inclusive measures (facilitators) Exclusionary measures (barriers)
Recommendations/limitations	Public policies Training actions Educational practices Professional actions Need for interrelation Impact of interpersonal relationships
Impact	Impact of programmes Policy impact

Note. Prepared by the authors.

In the present article, we examine three questions (subcategories) in particular: 1) How does the story begin? 2) What measures facilitate schooling? (inclusive measures or facilitators) 3) What factors hinder or deny access to inclusive education? (exclusionary measures or barriers).

Results

This section aims to present the experiences of the participating families and teachers, using excerpts from the interviews. It focuses on the three subcategories mentioned above: 1) How does the story begin? (the onset); 2) What measures facilitate schooling? (inclusive measures or facilitators); 3) What factors hinder or deny access to inclusive education? (exclusionary measures or barriers). The results are therefore structured in two sections: 1) experiences and perceptions of the teachers, and 2) experiences and perceptions of the families. Both sections are organised into the three aforementioned subcategories.

Experiences and perceptions of teachers

The onset: The beginning of the story

As explained in the introductory section, T1D is distinguished by a prodromal phase in which the child exhibits persistent thirst, frequent urination and increased appetite. Although these symptoms are readily observable, limited awareness of T1D often results in a delayed diagnosis.

The people who usually notice this symptomatology are:

> The families (…). After the diagnosis, at school they start to piece things together retroactively. Maybe you have already noticed things, like the bathroom situation, but since it's preschool, where children have the freedom to go to the bathroom, it's harder to see. After the onset, you become more aware (EDI).

The moment of the onset produces uncertainty due to a lack of knowledge and the limited information to which one has access:

> When the two of them experienced their onset, I didn't have as much knowledge as I do now. Then it was how, where we read, what information we had (...) Then, because of the hospitalisation issue, at that time, we had first aid training and so on (...) We tried to inform ourselves, through other schools that had similar cases (...) It caused us, above all, a lot of uncertainty about how to act in this regard, because no one had information on the subject (ED1).

In this example, the child experienced the onset when she was already in school, but this is not always the case. There are cases in which the child experiences his or her onset as a baby, which means that he or she is not in school at the time of the onset. There are also cases in which the onset takes place in another school or with other teachers. An example of this is recalled in the following dialogue:

> I found out when they gave me the information, but the child already had the disease in infancy. Besides, I found out that (...) they had to admit him some time, so I was already on alert because somehow I had to prevent this from happening, that is, I had to have information to prevent this, that's for sure (ED1).

This example allows us to understand how important it is to learn about disease and metabolic control, since diabetes is a life. But who is responsible for the metabolic control of children in early childhood education?

> I believe that (...) we teachers have that responsibility. I have always said it: we work with children; each one has his or her own characteristics, and we must work on that (...) Reality cannot be ignored, so you must consider that you are, in the end, like a mother, and then you do what you would like them to do with your children, that's what I think because being a teacher is all that (ED2).

Inclusive measures: Difficulties and limitations

In terms of schools in Castilla y León, is there sufficient educational support?

> I don't think so, because, in Castilla y León in the educational field, I think we need the figure of a nurse (...) I have worked in Madrid (...) and we had a nurse for all kinds of disorders, illnesses, etc. So, the figure of a psychologist, not a counsellor who diagnoses, but a psychologist who addresses these concerns, and a nurse or a nurse who can intervene at a particular time, would be great (ED2).

This lack of educational support generates stress and uncertainty:

> We don't know what to hold on to with the nurse issue there, we are waiting to see what they tell us (ED1).

At this point, the figure of the school nurse emerges, a resource that seems to be essential for the educational inclusion of students with T1D:

> For me, the most important thing would be the resource of the nurse, because it would relieve us, I think, a lot, but if that were not possible, some kind of protocol (ED1).

This may lead one to think that the figure of the school nurse in schools would guarantee the educational inclusion of these students; however, the research participants do not entirely agree:

> I can't affirm that the figure of the school nurse guarantees the educational inclusion of these students, since it would be necessary to redefine the role that this professional should play beforehand. It's necessary for this person to be involved in the care required by these students, not only in the care of their pathology, but also in their social and emotional care (...) We, the families, oversee caring for our daughters and sons 24 hours a day and 365 days a year (EFM1).

On the other hand, we must mention the non-existence of protocols. Although it is true that there are several protocols and action and orientation guides in Spain, Castilla y León is the exception that proves the rule. In this community, there is no protocol that deals with students diagnosed with T1D; there is only a document that deals in just one page with the urgent care of a diabetic student. Consequently, teachers in Castilla y León are calling for a protocol to help them, or in their own words:

> There should be a regulated guide on how to act in certain cases, because children are at school all morning. So, it is not unusual for something to happen, so I miss that guide, to be honest (ED1).

Another point to be addressed in this section is the support of the teaching team. T1D requires cooperation between the different administrations involved in the schooling process of students with T1D. If we focus on the educational centres themselves, we have observed how the management of T1D falls exclusively to the families or to the 'goodwill' of the teaching staff. At this point, we wanted to know how the rest of the teachers are involved. The families have different perspectives in this regard:

> Yes, I feel supported before and now. I have never been made to feel that it is only my problem, so I feel supported by the teaching staff. That way, no problem (ED1).
>
> Honestly, I don't feel supported, because I have seen things that I didn't like. Seeing my student's file pinned on a corkboard, without giving it importance (...) are details that supported me, yes, of course, but it was me, above all, so if I was not there, there was no one, so that support was fictitious, because the reality was different. So, I felt alone (ED2).

This conversation reflects feelings that could describe many families. A sense of anguish and loneliness:

> Although no one is indispensable, the fact that a school does not worry about having more than one person trained in case something unforeseen happens seems to me to be a blunder (...) That's what I felt, that's how clear it is (ED2).
>
> At this point, is there any support from the Provincial Educational Department? No, they don't give you anything. So, why knock on that door, if it is going to be a waste of time. On the issue of the nurse, we have no choice, but let's see where they come out, asking for reports and so on (ED1).

All of this causes generalised discomfort among the teachers, so the cooperation is non-existent:

> They haven't even shown up. For them, they are all numbers, so there's no problem for them. The problems that the students have should be solved by the teachers, because if not, I don't understand why they don't have a nurse there (ED2).

Exclusionary measures

Regarding the measures that make the educational inclusion of students with T1D difficult or impossible, what difficulties or limitations exist for teachers?

> Two things: first, the lack of knowledge about diabetes and, second, the difficulties that you encounter that do not depend on you, that is, dealing with the administration for things that complicate your life, such as when the electricity goes out and, of course, without electricity, the glucagon goes out. In the end, you register the mail to cure yourself, but that is not the solution (...) They are issues that touch you directly and no matter how much you get involved, you get frustrated (ED1).

In addition to this reality, there are other barriers, such as the scarcity of training and information, and the lack of mandatory action.

> I consider it necessary to have more information and more teacher training, I don't say in all pathologies, but if a sociological study is made of which are the most common cases in schools (...) it should be mandatory because if it is voluntary, nobody is going to go (...) on the other hand, what I've mentioned about the nurse, as well as material related to the subject, because there are more and more diverse pathologies, so it will be necessary to keep up to date (ED2).

In the absence of regulations governing the incorporation of healthcare personnel in schools, and due to the lack of public policies to guarantee care, the absence of coherent and updated protocols, and the scarcity of training and information, everything depends on the assigned teacher that the family has:

> And it's very sad, but that's how it is; it really depends on who you get, for sure (ED2).

Family experiences

The onset: The beginning the story

The onset or diagnosis of the disease becomes a turning point that can be approached in two different ways: through acceptance or through resignation. We find families that, in the face of adversity, deny the situation, collapse and try to focus on distractors, but some families gather strength to forge family resilience:

> We didn't believe it, because, besides, in our family, there was no one who previously had diabetes (EFM1).
>
> It can't be true! (...) it seemed incredible to me, you can't tell me that you have done a finger prick, and that's it, you know she has diabetes (EFM3).
>
> At first I didn't want to believe it, I thought they were wrong, and that it had a cure, so I was willing to do anything to cure her (EFM1).
>
> We even did real nonsense and barbarities for our daughter to be cured (...) I would have gone to seven witches if it had been necessary (EFM2).

Distractors, which have a greater presence than would be desired, have a negative impact on psychological factors:

> I went to the Social Security psychologist and more than anything, he told me that if I was like that now that I had just started, how would I be when my daughter had complications. So, I hung up the phone directly and I didn't want to hear from her again, so I looked for another one, whom I paid for out of my own pocket (EFM3).

Economic:

> We got in touch with a person in Madrid to whom we paid a lot of money, and with a healer who was in America and who assured us that he had cured many people with diabetes. We were about to make the transfer and go (...) I had a very bad time, and I was crying all day, I did nothing but cry and look for the cure (EFM2).

> And social:
> Nothing has ever been the same (EFM2).
> I have never gone out at night again (EFM4).

As can be observed, these distractors become excluding situations that cause the beginnings to be turbulent first "when you hear what a diabetic onset is" (EFP2) and when you think about "when does it pass?" (EFM2) or "is this cured?" (EFM4) and you receive a negative answer: "it's a chronic disease" (EFM3), "this is for life" (EFP2). "That's when you get the first cold water" (FSM2).

Despite all of this and all of the exclusionary situations we have described – loss of money, loss of self-confidence, and even loss of health – the families hope that "something will change, that something will happen, maybe there has been a mistake, maybe there was a failure or why not, maybe there's a cure" (EFM3).

This feeling of hope is unwavering in those early days.

> It's a situation of living in a different reality, as if you were waking up from a dream (...) You always try to put yourself in her place or say why doesn't it happen to me? Why does it happen to her? Why does it have to happen? There's no reason to look for a culprit, because most of the time there isn't one (EFP2).

All of these questions provoke certain feelings: "sad and bad, (...) but I am a strong person, and I said to myself: this is what it is, and we have to move forward" (EFM4). At that moment, the families show resilience: "The onset was a shock" (EFM1), but "after the first month, we started to talk to the medical teams to be discharged" (EFM2); "because the sooner we are in our habitat and in our place, the sooner we can start our whole new life" (EFP3):

> We wanted to leave because it was already becoming unbearable for the child in the hospital (...) If she is not going to be cured, discharge us now! And they told us: but you must learn, this can be learned by living! and I told her: teach me how to give insulin, teach me how to do the dilutions, teach me now (EFP2).

Inclusive measures

The principles of normalisation, individualisation and inclusion, as well as the preventive and promotional role of the family, demand new forms of intervention. The present research has consistently reflected the fact that families need to promote their health, to reinforce their resilience and their socialising capacity, because "the more natural everything is, the better" (EFP2).

First, we must understand that promoting the health of the family implies satisfying the biological needs of all its members, for which it is necessary to foster social skills, and promote self-control and the ability to cope with problems. How can this be achieved?

> I think that (the child) has been pricked by almost everyone in her closest environment, we treat it very naturally (...) The way to treat the disease is to show naturalness in the treatments and administration of medications. The child is also seeing it as something normal (...) I am in a restaurant and you get up and she is sitting in the chair, and we act normally (EFP2).

There is also the idea that the tutor should be a family figure, in order to analyse the context and intervene by building a family-school relationship that satisfies family needs and reinforces their capacities. This figure is forged from the first day, with trust, respect, love and commitment: "I believe that parents have to make an effort to reassure and give confidence to the teacher. It is a joint effort" (EFP2).

> I remember that in the first interview (...) she (the teacher) was the first one to say: hey, I prefer that, instead of having to be there, that if you call reception, they call me and so on, I prefer to have a direct line. Maybe if she sees that I haven't said anything and she sees that the girl is at 80, falling, she asks me, should I give her a juice? (EFM2).
>
> On the one hand, the more natural everything is, the better. It's a serious disease, of course, if certain measures aren't taken, which you're not obliged to do because you are a teacher, there's one thing she's clear about, you are a teacher, and she says, I am dedicated to teaching them. And I dedicate myself to taking care, it's my responsibility, to teach and to take care (EFM2).

At the end of the day, all of this is teaching that is part of the daily life of all these students.

Exclusionary measures: Difficulties and limitations

Exclusionary measures are barriers that limit or prevent some people from participating in an activity or social benefit. Children with T1D and their respective families must face these barriers daily. At this point, we would like to detail some of them in the family experiences:

> Since the school doesn't offer any solutions, you must fend for yourself. The first year I stopped working (...) I went to school at recess and before

> lunch. And of course, I was always on the lookout. Then, as I found a lady who could do it for me, paying for it, I was free to work (EFM4).
>
> We don't have economic possibilities, and we can't be without work for either of us. We need both salaries, and we can't stop working to take care of our daughter. I think that, for me, is the biggest difficulty (EFP1).
>
> I feel that people often don't put themselves in our shoes (EFM3).
>
> You know what happens? At the rate she's going, at the age of 9, she's going to prick herself. And they play (...) with the trump card that the family is always there for their child (...) and they know that someday it will stop being a problem because the girl will grow up and you won't be bothering her anymore, and I think, they don't see this as a problem (EFP3).

In addition to these barriers, there are other issues that cause discomfort, stress and frustration, as there are everyday situations that change dramatically after the onset of the disease. Some examples of this can be time and work availability, and the use of a cell phone:

> I (...) have to be available at work (...) I can no longer conceive that it used to happen to me, I would forget my phone, nothing would happen, but, however, now, imagine (EFM3).
>
> We're totally dependent (...) you're always on the cell phone, even at night when we have the routine, but (...) well, that's the way it is (EFM4).

At this point, it is possible to address those exclusionary situations in which it is assumed that it is the students who 'decide' to exclude themselves:

> I have always felt bad, always. It's a horrible moment, when that happens, when you see that, for example, others eat even though they know that there are gluten-free foods (...) Some mothers did bring her (the child) something, an Aquarius, or maybe they bought her something gluten-free. Then, I told her: whatever they give you, don't eat it, bring it to her, thank her and that's it (EFM4).

All of the above can be summarised as follows: "In conclusion, we could say that we have many limitations, but we've become accustomed to living with them" (EFM4).

Discussion

T1D is a complex condition that requires rigorous treatment (insulin injections, carbohydrate intake, etc.). This poses challenges for the school integration of students with T1D (Barrio et al., 2020). In this regard, the present study highlights the fear, misinformation and concern that this condition generates among teachers and families, particularly in the initial months. These feelings often result in situations where students diagnosed with diabetes are unable to participate in activities such as field trips, extracurricular events, etc. However, it is well established that schooling is essential for the full development of all students, especially those with disabilities (Gómez & Espino, 2012). Moreover, it is important to remember that education is a fundamental right (UNESCO, 2014), and the educational inclusion of students with T1D must therefore be defended. This notion is supported by Armas and Fernández (2022), who emphasise the importance of returning to normalcy as soon as possible. In this regard, the present study reveals that students with diabetes are enrolled in mainstream classrooms; however, there are situations where teachers request the direct involvement of families to ensure student participation in activities.

Several studies indicate that inclusive education remains a challenge for schools (Booth et al., 2011; Gajardo-Espinoza et al., 2023; Muntaner et al., 2014; Plá, 2015; Torres-Cladera et al., 2021; UNESCO, 2014). According to Echeita (2016), schools face two primary tasks: identifying educational, cultural and political barriers that hinder student inclusion, and transforming these barriers into facilitators. In line with this assertion, the interviews conducted for the present study reveal two predominant themes: exclusionary barriers and inclusive facilitators.

Among the exclusionary barriers, the one that is most frequently mentioned during the interviews is the lack of diabetes-related training. Teachers report that their limited knowledge comes primarily from families or self-training, as there is no direct contact with healthcare institutions. Families, on the other hand, state that while the initial training received in hospitals provides a basis, it is insufficient, and they advocate for ongoing training opportunities to reinforce their learning. These exclusionary barriers are also documented in studies by Flinn (2016), Iken et al. (2023) and St. Leger (2014). Another widely mentioned exclusionary factor is the lack of resources, support systems, programmes and/or public policies (Cousins, 2014; Flinn, 2016; Watt, 2015). The present study highlights the obligatory involvement of families in many school-proposed activities due to the absence of necessary resources or support mechanisms to ensure the participation of students with diabetes. Lastly, the study points to the non-existent relationship between educational and healthcare administrations (Cáceres-Iglesias, 2023; Muntaner et al., 2014; Watt, 2015), as emphasised by the interviewed teachers and families, who assert that there is no collaboration between schools and healthcare centres.

Regarding facilitators or inclusive measures, most studies and analysed narratives underscore the need for school nurses in educational institutions (Bodas et al., 2008; Muntaner et al., 2014). The interviews conducted for the present study demonstrate a unanimous consensus in favour of this measure as a key facilitator for achieving effective educational inclusion. Researchers such as Bunijevac (2017), Cousins (2014), Flinn (2016), and Musgrave and Levy (2020), argue that the presence of a school nurse would significantly enhance the inclusion of students with T1D by benefiting both teachers and families, while also normalising the daily experiences of these students (Bunijevac, 2017; Cousins, 2014; Flinn, 2016; Musgrave & Levy, 2020). This role is internationally recognised as essential in the care of students with chronic illnesses, particularly those with T1D (Kudlová & Skarupská, 2021; Marks et al., 2021; Uhm & Choi, 2022).

Regarding interprofessional collaboration as an inclusive measure, Wood and Kaufman (2012) argue that when families, healthcare professionals and teachers work collaboratively, they create a network that facilitates the educational inclusion of students with T1D by addressing their educational, emotional and health needs. Although this level of collaboration was not evident in the present study, families who have successfully established close communication and continuous dialogue with their child's teacher corroborate the benefits of such coordination. Conversely, families who have not experienced such teacher involvement report frequent instances of exclusion.

Finally, teacher involvement must be addressed as an inclusive measure. Studies such as those by Cousins (2014) and Smith et al. (2012) support the notion that teachers should be actively involved in the care of students with chronic conditions, as this responsibility is integral to their role as educators. In alignment with this perspective, one family in our study shared that their child's teacher stated during the first meeting that she felt a moral and ethical duty to learn how to care for her student, just as she does for the rest of the class. However, other families report that this is not always the case, as some teachers argue that their responsibilities are limited to teaching rather than caregiving.

In summary, after analysing the educational context of students with T1D, it is evident that the barriers they face daily are similar to those identified in previous studies conducted in different countries: inadequate diabetes training for teachers (Iken et al., 2023; Kudlová & Skarupská, 2021); lack of individualised diabetes management plans (Iken et al., 2023); deficiencies in policies and regulations, particularly the absence of school nurses in educational institutions (Muntaner et al., 2014; Uhm & Choi, 2023); and regional disparities in the availability of school nurses (Marks et al., 2021). These barriers severely hinder equal access to education for students with T1D in Spain.

Conclusions

The aim of the present study was to understand the inclusive vision of diabetes in schools through the voices of those involved in the educational process: teachers and families. Overall, the study reveals an exclusionary educational reality for children with T1D. Teachers advocate for inclusive education, but in practice, due to a lack of training and support, they do not feel equipped to realise this right for students with T1D. On the other hand, families have normalised the exclusionary situations their children face and have assumed sole responsibility for their care.

Another objective of the research was to identify the barriers to the educational inclusion of students with T1D. In this regard, the following results can be drawn:

- Teachers report a lack of knowledge about the disease, insufficient training on its care, and a lack of general protocols from the administration. Additionally, teachers feel isolated and powerless to provide an inclusive response to students with T1D.
- Families have assumed all of the responsibilities related to the care of children with T1D, ranging from economic to psychological aspects.

The main limitations of the research are related to the difficulty of generalising from a limited number of participants and the scarce research conducted on the inclusion of students with diabetes in schools, which impedes the development of deeper discussions (Cáceres-Iglesias et al., 2023). Future research should increase the number of participants in order to give voice to other profiles related to the schooling of students with diabetes; integrate mixed methods to compare qualitative and quantitative data; investigate regional inequalities in the availability of school nurses; compare the protocols developed by each Spanish autonomous community or other countries for the care of students with T1D; and analyse the coordination mechanisms between health and education institutions.

The developed study proposes taking clear actions to address the highlighted problem, such as:

- Proposing awareness-raising actions, such as courses and talks for the involved communities (schools, health centres, educational administration) in order to promote the appreciation of students with chronic illnesses such as T1D.
- Promoting actions that effectively bring families and schools together, such as working groups both in-person and online, constant communication and collaborative projects.
- Recognising the school nurse as a necessary and educational member within school communities through the creation of new educational and administrative policies.

Ethical statement

The research study was approved by "Comité de ética de la investigación con medicamentos del área de salud de Valladolid" [Valladolid Health Area Ethics Committee on Research on Medicinal Products].

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APPENDIX 1:
Interview guidelines family interviews

We will begin the interview as this disease always begins, with the onset.

a) How was the onset (feelings, how did you accept it)?
- Who trained you in diabetes education and did you find it difficult?
- During that period of hospitalisation, did any other patient with the disease or any DBT3 family visit you?
- If so, did the visit help you?
- If not, would it have helped you if someone in the same conditions as you had visited you?

b) In terms of social relationships, what things have changed?
- Keep playing as usual
- The child behaves the same way
- Your immediate environment is aware of the child's illness.

c) Regarding the school relationship, let's start with that first interview/meeting with the school tutor. How did it go?
- Received diabetology training
- You saw him willing to train, interested and eager to support this new situation.
- You came out of the interview encouraged and strengthened.

d) How did your child's classmates take this new situation?
- What is the degree of integration with colleagues?
- And how did the teachers act?
- And what is the degree of integration with teachers?

e) With respect to school activities, can your child access any activity?
- If the activity is within the school, do the teaching staff have the necessary diabetes education?
- If it is an extracurricular activity, does the instructor who teaches the activity have diabetes education to be able to act in case of need?

f) How has having diabetes impacted your child academically?

g) Do you think there are enough social supports and resources?
- If the answer is no, in the absence of these social resources, who do

you turn to when you need some kind of help?
- What social resources do you think could improve your child's quality of life?

h) What difficulties and limitations do you encounter?
- What has been the biggest change you have had to make as a family?

i) How do you see the onset now? What would you say to A frightened family that has just experienced its onset?

j) To conclude, I would like you to tell me an anecdote or episode you have experienced in the school environment.

And finally, let's talk about the uncertain future that makes us think so much...

k) How do you imagine all of this in ten years?

APPENDIX 2:
Interview guidelines for teacher interviews

We will begin the interview as this disease always begins, with the onset.

What was the onset like? Was the child already in school or was it at the time of schooling that you knew you were going to have a child with T1D in your classroom (feelings, how do you prepare...)?

*** In the case that the onset occurred when you were already in school...
- During the hospital stay, did anyone from the school visit the child?
- In terms of social relationships, what things have changed?
- Keep playing as usual
- The child behaves the same way
- Your immediate environment is aware of the child's illness.

Regarding the school environment, let's start with that first interview/meeting with the family. How did it go?
- Did you receive diabetology training?

If so, who provided it to you?

If not, how were you trained?
- After that initial meeting, did you find the family willing to

collaborate with the school?
- Did you come out of this interview encouraged and strengthened?

How did the classmates take the child's diabetes?

How well integrated are you with your colleagues?

How do the rest of the teachers act?

What is the degree of integration with teachers?

With respect to school activities, can the child access any activity? (after listening to the answer, ask them, as an example, how they would organise a field trip).

- If the activity is within the school, do the teaching staff have the necessary diabetes education?
- If it is an activity within the school, but outside school hours, for example, the canteen or early bird service, who is the person responsible for the child's care?

On the academic level, how has having T1D affected the child?

Do you think there is enough support and resources?

- If the answer is no, who do you turn to when you need help?
- What resources do you think could improve the quality of life of these students?
- Do you feel supported by the teaching staff and the school's management team?
- And from the Provincial Board of Education?

What difficulties and limitations do you encounter?

In closing, I would like to know if you have confidence in yourself (how do you feel?).

Now, I would like you to recall an anecdote or episode you have experienced in the school environment.

And finally, let's talk about the uncertain future that makes us think so much...

How do you imagine all of this in ten years?

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