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HISPANIC CAREGIVERS' CHALLENGES AND BARRIERS WHEN FACING TYPE 1 DIABETES IN THEIR ADOLESCENT OFFSPRING

Dificultades y barreras de personas cuidadoras hispanas ante la diabetes tipo 1 en su prole adolescente

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ABSTRACT

Objective. Caring for youth with type 1 diabetes (T1D) poses significant challenges that have not been explored in depth among Hispanics. We examined the content of caregivers' barriers when facing T1D in adolescents and the relationship between reporting multiple challenges (MC) and health-related outcomes. **Methods.** Sixty-five Hispanic caregivers (81.54% women) aged 32–58 completed intake assessments for a youth depression treatment study. They answered an open-ended question about their main difficulties with T1D in their offspring. We identified the main themes and coded them into content-based categories. Using Student *t*-tests, chi-square, and Spearman correlation, we assessed the association between having MC and health-related outcomes ($p \leq .05$). **Results.** Parental responses formed 89 codable units. Inter-rater agreement was excellent ($\kappa = .97$). Categories and their occurrence were: Social/Structural Barriers (22.47%), Cognitive Aspects in the Family (30.37%), Short-Term Complications/Emergencies (15.73%), Difficulties in Follow-up or Relative Responsibility (8.99%), Difficulties in Treatment Adherence (14.61%), Developmental Stage/Hormonal Aspects (4.49%), and No Difficulties (3.37%). The rates of caregivers with responses coded within these categories were 27.69%, 36.92%, 18.46%, 12.31%, 20.00%, 6.15%, and 4.62%, respectively. Adults whose responses suggested MC showed more T1D-related worries and had children who checked their glucose levels less often, had higher depression rates and showed fewer hypoglycemia preventive behaviors. **Conclusions.** The most frequent challenges to managing T1D in youth relate to family psychological aspects and socio-structural barriers. Reporting MC indicates higher depression rates and less adherence to self-care.

Keywords: *caregivers' difficulties, depression, diabetes self-management, family adaptation, socio-structural barriers*

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RESUMEN

Objetivo. Cuidar adolescentes con diabetes tipo 1 (DT1) plantea desafíos cruciales y aún inexplorados a profundidad en personas hispanas. Examinamos el contenido de las barreras enfrentadas por las personas cuidadoras ante la DT1 en su prole y la relación entre dificultades múltiples (DM) e indicadores de salud. **Métodos.** Sesenta y cinco personas entre 32–58 años (81.54% mujeres) completaron evaluaciones de elegibilidad para un estudio de tratamiento para la depresión juvenil. Contestaron una pregunta abierta sobre dificultades enfrentadas ante la DT1 en su prole. Identificamos los temas centrales, codificándolos en categorías basadas en su contenido. Usando pruebas *t* de Student, chi-cuadrado y correlaciones Spearman, evaluamos la asociación entre tener DM e indicadores de salud ($p \leq .05$). **Resultados.** Hallamos 89 unidades codificables. El acuerdo inter-codificadores(as) fue excelente ($\kappa = .97$). Las categorías y su ocurrencia fueron: Barreras Sociales/Estructurales (22.47%), Aspectos Cognitivos Familiares (30.37%), Complicaciones a Corto Plazo/Emergencias (15.73%), Dificultades en Seguimiento/Responsabilidad Relativa (8.99%), Adherencia al Tratamiento (14.61%), Etapa del Desarrollo/Aspectos Hormonales (4.49%) y Ninguna Dificultad (3.37%). La tasa de participantes con respuestas en estas categorías fue 27.69%, 36.92%, 18.46%, 12.31%, 20.00%, 6.15% y 4.62%, respectivamente. Aquellas(os) cuyas respuestas sugerían DM mostraron más preocupaciones sobre la DT1 y tenían hijos(as) con monitoreo glucémico menos frecuente, tasas mayores de trastornos depresivos y menos conductas preventivas de hipoglucemia. **Conclusiones.** Los aspectos psicológicos familiares y las barreras socio-estructurales son los desafíos más comunes. Reportar DM se asocia a tasas más altas de depresión y menos adherencia al autocuidado.

Palabras clave: *adaptación familiar, automanejo diabético, barreras socio-estructurales, depresión, dificultades de personas cuidadoras*

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INTRODUCTION

Type 1 diabetes (T1D) is a chronic disease with a complex treatment regimen that includes insulin use, glucose monitoring, a healthy meal plan, and physical activity (American Diabetes Association, 2024). Access to T1D technologies, insulin, and T1D-related supplies is difficult for families with economic disadvantages. Health care costs for T1D patients are higher than for type 2 diabetes or people without diabetes (Reynolds et al., 2023). Compared with adults, children with T1D from a US national sample of privately insured patients had higher out-of-pocket spending for insulin and diabetes-related supplies (Chua et al., 2020). The mean annual cost of T1D care for minors has increased recently (Crossen et al., 2020).

Caring for T1D adolescents is associated with significant challenges, many of which relate to difficulties in treatment adherence (Zysberg & Lang, 2015). For instance, due to non-compliance with T1D treatment, caregivers in Jamaica reported that keeping their children healthy was one of their greatest challenges (Anderson & Tulloch-Reid., 2019). Some difficulties faced by caregivers can be related to adolescents' feelings of incompetence in diabetes care, which reinforce their non-compliant behaviors (Castensøe-Seidenfaden et al., 2017). Other parents feel frustrated when their children deviate from established T1D management or decide to stop taking care of T1D altogether (Ersig et al., 2016). Additional difficulties in adherence relate to risk-taking behaviors, such as disordered eating and substance use (Azar et al., 2024; Lan et al., 2024). Youth's refusal to comply with adherence-related demands is a challenge more commonly faced by parents perceived as critical or negative (Grabill et al., 2010).

Several T1D-related difficulties reported by caregivers of adolescents include issues of parental supervision and the level of responsibility assumed by their children in diabetes care (Aalders et al., 2021; Azar et al., 2024). For example, when studying psychosocial variables in T1D care, Malerbi et al. (2012) found that 52% of parents had difficulties in setting limits with their children, which related to worse glycemic control. Conflicts around supervision of diabetes care have been reported as significant barriers by parents (Davis et al., 2019). Division of responsibility for T1D management between the adolescent and the caregiver can also be a barrier to successful care, as highlighted by Bozbulut et al. (2023) and Tong et al. (2022). This process often leads to potential conflict, which poses a relational challenge by itself (Anderson & Tulloch-Reid., 2019). In the words of Malerbi et al. (2012): "As children reach adolescence, the parental involvement in the treatment may conflict with the developmental task of increasing autonomy that adolescents have" (p.7).

Caregivers also face social and structural barriers to T1D management. According to Asaad et al. (2022), Saudi mothers identified lack of education about the condition and lack of availability of school nurses among the most difficult challenges when faced with T1D in their offspring. A lack of emotional support and empathy by healthcare providers can make the impact of the condition more challenging (Asaad et al., 2022; Kimbell et al., 2021). Davis et al. (2019) argued that systemic and structural factors can pose a barrier to care for T1D youth, as reflected in difficulties accessing health insurance, treatments, and support services from the schools. Other studies highlighted food insecurity, financial concerns, lack of social support, and lack of access to diabetes technologies as additional difficulties for caregivers (Anderson & Tulloch-Reid., 2019; Azar et al., 2024; Butler et al., 2020; Tong et al., 2022).

Additional research regarding this topic suggests that psycho-emotional aspects of family members may hinder adequate diabetes care (Tong et al., 2022). For example, in a longitudinal study conducted by Kovacs et al. (1990), researchers found that the degree to which mothers perceived T1D to be difficult to manage at any given point in time was associated with their overall levels of emotional distress. Mental health problems in adolescents also pose a significant challenge for parents when supporting their children in managing diabetes (Azar et al., 2024; Zysberg & Lang, 2015). According to Davis et al. (2019), many parents believe their children's fear of being "different" is a significant barrier to diabetes management. Similarly, Malerbi et al. (2012) found that 62.8% of parents in their sample felt overwhelmed by the demands of diabetes care. These authors

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affirmed that "after the diagnosis of T1D, the lifestyle of all family members changes, which interferes with their quality of life" (p. 1). Struggling with acceptance of T1D and adaptation to treatment, most parents in a study by Rosselló et al. (2005) reacted to the diagnosis with sadness, denial, and worry. These emotions may have an effect on caregivers' ability to support their offspring in managing T1D (Azar et al., 2024; Whittemore et al., 2012).

Short-term complications and related emergency situations (i.e., visits to an emergency department or hospitalizations) can also represent barriers faced by caregivers when managing T1D in youth. Living with the constant threat of worsening complications and repeated hospitalizations significantly adds to the burden of caregivers (Zysberg & Lang, 2015). The burdens of short-term complications and hospitalizations lead parents to seek and feel the need for in-depth educational interventions on managing to prevent such events (Choi & Shin., 2023).

For instance, short-term complications can include extreme glucose level fluctuations such as hypoglycemia. In several studies, fear of hypoglycemia (FOH) has been identified as a challenge by parents (Asaad et al., 2022; Castensøe-Seidenfaden et al., 2017; Zhang et al., 2022). Likewise, many caregivers consider the unpredictability of blood glucose fluctuations and the difficulty controlling them as significant challenges (Melo do Rego Sousa, 2023). FOH has been found more often in parents of T1D children than in their T1D children themselves. Lack of FOH can lead to ignoring glucose levels and increase the risk of future complications. When extreme, FOH has been identified as the root of other fears and stress in parents, while not having any clear significant impact on glycemic control levels (Andreopoulou et al., 2024).

Finally, understanding the developmental and hormonal changes in adolescence and how they can have an impact on diabetes care also poses a challenge for parents (Azar et al., 2024; Whittemore et al., 2018). Adolescence is intrinsically challenging and the hormonal and emotional turmoil in these years can make T1D management more complex (Codner et al., 2020). In fact, T1D control and complications can be adversely affected by the physiological changes of puberty, which are related to increased insulin resistance (Azar et al., 2024).

The challenges of caring for a T1D adolescent have not been explored in depth among Hispanic caregivers. The only study conducted in Puerto Rico (PR) that has examined this topic suggested that the major challenge faced by caregivers of T1D youth was related to adolescents' treatment adherence. This included acceptance of the condition, meal plans, and the inherent restrictions of T1D. This was followed by short-term complications such as episodes of hyper- and hypoglycemia and ketoacidosis (Rosselló et al., 2005). Butler et al. (2020) found that child and parent distress were important barriers to involvement in the T1D care of their children among African American and Latino parents. In a sample of 23 parents (20 females) of T1D adolescents of Latino origin (nine of them Puerto Ricans) living in the US, Joiner et al. (2020) reported some of their main difficulties in managing T1D in their offspring. They included the following: lack of knowledge and misunderstanding about T1D; emotional impact on the family (e.g., fear and worry); managing T1D shared responsibilities; feeling the school did little to help with T1D management; and dealing with T1D-related stigma and judgement.

A study by Tremblay et al. (2021) is consistent with this research regarding the need for treatment adherence and lack of understanding of T1D in community and/or family members. They also found that cultural patterns in nutrition pose a barrier and stressor for T1D parents, as non-contextualized nutritional guidance provides minimal help. According to Joiner et al. (2020), "efforts aimed at improving T1D self-management during adolescence with this population need to be tailored to meet the unique social and cultural contexts and delivered in a culturally and linguistically congruent manner" (p. 1). Examining the specific content of challenges and barriers faced by Hispanic caregivers from PR when managing T1D in their offspring could provide valuable insight that might inform psychosocial interventions for this population.

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The purpose of this study was to examine the specific content of parental challenges or barriers when facing T1D in their adolescent offspring and their connection with mental health variables and diabetes-related outcomes among Hispanics from PR. We expected that family-related issues, short-term complications, and difficulties in treatment adherence would be the most common themes among caregivers' responses. We also expected that responses that allude to two or more barrier categories would relate to worse health outcomes.

METHOD

Participants

This study is a secondary analysis of data provided by 65 caregivers who attended a screening assessment for an adolescent depression trial that examined the initial efficacy of a group-format cognitive-behavioral therapy delivered among T1D youth (Cumba-Avilés, 2017). Initially, their main caregivers completed a request for participation (RFP) form in which they reported on their child's depressive symptoms (i.e., at least three DSM symptoms in the previous two weeks or more, one of which must be depressed mood or anhedonia). Psychotic symptoms, history of bipolar disorder, last-year substance dependence/abuse, and imminent suicide risk were among exclusion criteria. A more detailed description of the main study is presented elsewhere (Cumba-Avilés & Sáez-Santiago, 2016).

Most caregivers (93.85%) and youth (96.92%) were Puerto Ricans; the rest were from other Hispanic groups. About 64.62% (42) of adolescents (aged 12–17) attended public schools. The same proportion lived in urban zones, and 43.08% (28) resided in the San Juan metropolitan area. The mean age for the 65 adolescents (55.38% female) was 15.05 years (*SD* = 1.68). Primary caregivers were mostly (81.54%) women. Their ages ranged from 32 to 58 years (*M* = 43.34, *SD* = 6.42). Almost half (47.69%) of caregivers had an education lower than a bachelor's degree. Around 55.38% (36) were employed full time and 9.23% (6) had part-time jobs. Most participants (75.38%) belonged to families of lower-middle or low perceived socio-economic status. Their mean household size was 3.94 (*SD* = 0.93) members, with a range of 2 to 7.

The mean hemoglobin A1c (HbA1c) value, a test of the average blood sugar levels in the past 3 months, was 9.03 (*SD* = 2.10; range from 5.76 to 17.70). To obtain this screening data, we asked caregivers for a copy of their child's latest laboratory test results. Only 14 youth were on insulin pump treatment. Their mean score on the Children's Depression Inventory was 18.28, suggesting that most had moderate or severe depressive symptoms. The average time since the child's T1D diagnosis was 6 years.

Measures

Diagnostic Interview Schedule for Children (DISC-IV)

This structured interview assesses DSM diagnostic criteria for mental disorders in youth. Its Spanish version has been successfully used in clinical samples with parents of Puerto Rican school-age children (Cumba-Avilés et al., 2002) and with depressed adolescents and their caregivers (Bernal et al., 2019). Caretakers in this study completed the Major Depression (MD) module at the screening session. Although designed for a DSM-IV diagnosis, we asked additional questions to ensure compatibility with DSM-5 criteria. Its inter-rater reliability (IRR) when used with caregivers of T1D youth ranged from .94 (past year) to 1.0 (current) for MD and from .86 (current) to .93 (past year) for Depressive Disorder Not Otherwise Specified (NOS).

Kovacs's Diabetic Management Information Sheet (K-DMIS)

Using an adapted version of this interview, we obtained T1D-related data from parents, such as youth adherence to glucose testing and hypoglycemia preventive behaviors, T1D age of onset, and access to an insulin pump (Kovacs et al., 1985). The K-DMIS includes open-ended questions for caregivers, one of which is the focus of this study: "What have been the biggest difficulties/barriers you have faced related to your child's diabetes?"

MINI International Neuropsychiatric Interview-Kid Version 6.0

This diagnostic interview assesses the criteria for the most common mental disorders in children (Sheehan et al., 2010). For this study, we used the

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MD module completed by parents and other information needed to make a differential diagnosis. Although designed for assessing DSM-IV criteria, we adapted its algorithm to ensure compatibility with DSM-5. The IRR of this module when used with caregivers of T1D adolescents was .88 for MD (current or lifetime) and 1.0 for Depressive Disorder NOS (La Luz-Barrios et al., 2023).

Procedures

Institutional review boards from the University of Puerto Rico, Río Piedras Campus (Approval # 1112-005) and Medical Sciences Campus (Approval #A9530112) approved the study. We shared information about the main study via T1D clinics, local media, and printed materials. We recruited youth and parents through summer camps, educational or recreational activities, and referrals from school personnel, endocrinologists, and other parents. Caregivers completed RFP forms via phone call. We invited adolescents and one parent each to an in-person screening if they meet initial eligibility criteria. After obtaining consent/assent, they completed measures at this visit and at a second visit scheduled within 2 weeks. Trained graduate students conducted assessments in Spanish. At the screening, caregivers completed a socio-demographic data form, the K-DMIS, and the Major Depression module of the DISC-IV and provided other clinical information regarding youth depression and T1D. Youth completed several measures of depression-related symptoms (not reported here) and a clinical interview, both aimed to assess inclusion or exclusion criteria. A second assessment was scheduled for the 58 families who continued to meet preliminary criteria for the treatment study at screening. The 51 caregivers who attended this second visit also completed the MD module of the MINI-Kid parent version.

Data Analyses

Using thematic content analysis, we evaluated responses to the open-ended question and classified them into 1 out of 7 general categories defined in Table 1. We divided categories 1 and 3 into three sub-topics, category 2 into four, and category 4 into two sub-topics. We present sub-topics' names and definitions in the Results section. Two clinical psychologists (the principal investigator and the project coordinator) accorded definitions for each general and specific category and developed coding rules. They obtained final definitions and coding rules after two revisions. We completed a master key of codes through codifications of these raters. Disagreements were resolved by consensus. We entered the master key of codes as well as codes provided by the two raters into a database to estimate overall raw agreement (%) and agreement level not due to chance. Caregivers' responses could include more than one element, which might need to be coded into different general categories or further subdivided into various sub-topics within the same general category.

We used SPSS 29.0 to conduct all statistical analyses. Using descriptive statistics, we estimated the proportion of responses per category. The latter was calculated within the total number of codable units (89) and number of caregivers (65). We used Cohen's kappa (κ) to assess the reliability between the coders and between each coder and the key codes. We estimated bias-corrected and accelerated (BCa) 95% confidence intervals (CI) for κ coefficients using a bootstrapping procedure based on 1,000 samples. We also defined groups of caregivers based on the number of general categories assigned to their responses: Uni-coded responses (Group 1) vs. Multi-coded responses (Group 2). This allowed us to examine if multi-coded responses (based on general categories) were related to health-related criteria of interest. With the chi-square and Student's *t*-test, we compared these groups in categorical and continuous variables, respectively ($p \leq .05$). Cohen's *d* was used to assess the effect size of mean differences in continuous variables when no differences were found between standard deviations, and Glass's delta (δ) was used when differences in standard deviations were present. For categorical variables, we transformed the chi-square value into a Cohen's *d* using the statistical tool by Lenhard and Lenhard (2022). Finally, Spearman's rho (1-tailed) was used to explore the association of multi-coded responses with hypoglycemia preventive behaviors.

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Table 1

Definition and Frequency of Occurrence of Categories Used for Content Analysis of Caregivers' Responses

Thematic categories	Definitions	Sample of codable units[a]	Sample of caregivers[b]
Social/structural barriers	Difficulties related to disadvantages in the possession of the resources needed to access services for people with T1D; being subject to stereotypes, discrimination, or social stigma for having T1D; and the reduced quality or availability of certain services, information, or accommodations to be provided by organizations or individuals inserted in the health care system.	22.47% (20)	27.69% (18)
Cognitive/affective aspects in the family	Psycho-emotional barriers in youths or caregivers due to T1D, problems in discerning the symptoms associated with the condition or its severity, and reduced flexibility in the ability to accept the illness and make life adjustments needed to adapt to this new reality.	30.37% (27)	36.92% (24)
Short-term complications/ emergency situation	Challenges related to the management of hypo- or hyperglycemia, glycemic uncontrol (including fluctuations between extreme values), and instances in which the adolescent must receive urgent/intensive medical services due to T1D or its physical health complications.	15.73% (14)	18.46% (12)
Difficulties in follow-up and relative responsibility	When regular monitoring/supervision of the youth's adherence to T1D treatment (whether or not such adherence is adequate) or trying to achieve an appropriate balance in self-care tasks between the adolescent and the caregiver constitutes a major difficulty, according to the caregiver's opinion.	8.99% (8)	12.31% (8)
Difficulties in treatment adherence	Problems complying with T1D management, either because youths forget or depart from the recommended treatment (e.g., meal plans, sugar checks, exercise, insulin use) or achieve reasonable care at the expense of much effort and/or personal or family burden.	14.61% (13)	20.00% (13)
Developmental stage/hormonal aspect	When adolescence itself or physiological changes in the youth's body (e.g., menstruation, hormonal fluctuations) are challenges in managing T1D or factors that increase the effect of other problems.	4.49% (4)	6.15% (4)
No difficulties	Responses that do not highlight problems about the child's diabetes.	3.37% (3)	4.62% (3)

Note. The third column portrays the percent of codable units coded in each thematic category. The fourth column shows the proportion of caregivers who provided at least one response coded in the interest category. As any caregiver could deliver codable responses to more than one category, percentages in the fourth column add up to more than 100%. T1D = type 1 diabetes; [a] $N = 89$; [b] $N = 65$.

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RESULTS

Reliability of Coders and Frequency per General Categories

Caregivers' responses yielded 89 codable units. When considering general categories, the inter-coder agreement was excellent [Raw agreement = 97.75% (87 / 89); κ = .97 (.93 – 1.00)]. We observed identical results for agreement between Rater B and key codes. Raw agreement between Rater A and key codes was 100.00% (κ = 1.00). When considering sub-topics, the inter-coder agreement was also excellent [Raw agreement = 96.63% (86 / 89); κ = .96 (.93 – .99)].

Once again, we obtained identical results for agreement between Rater B and key codes. Raw agreement between Rater A and key codes was also 100.00% (κ = 1.00).

Table 1 presents categories of challenges and their occurrence. "Cognitive/Affective Aspects in the Family" and "Social/Structural Barriers" were the more frequently coded, considering all codable units and the total sample. The categories "Short-Term Complications/Emergency Situations" and "Difficulties in Adherence to Treatment" were coded in about 15% of codable units and in between 18% and 20% of the participants, respectively. The remaining themes were coded in less than 10% of units and for less than 15% of parents. Specifically, 13 units were coded as "Difficulties in Treatment Adherence" and four as "Developmental Stage/Hormonal Aspects." Only three caregivers reported No Difficulties (3.37%).

Frequency of Subtopics Within Global Categories 1 to 4

We divided the first four global categories into subthemes. We labeled the subtopics under global theme 1 ("Social/Structural Barriers") as *Lack of Resources to Access Services, Social Unawareness, Discrimination or Stigma*, and *Quality/Availability of Services, Education, or Accommodations*. Of the units, 13.48% (12), 4.49% (4), and 4.49% (4), respectively, were coded within these subtopics. Subtopics from global theme 2 ("Cognitive/Affective Aspects in the Family") were labeled as *Youth's Emotional Aspects*, *Acceptance or Adaptation to T1D*, *Parental Emotional Aspects*, and *Lack of Knowledge/Understanding of T1D.* About 6.74% (6), 12.36% (11), 6.74% (6), and 4.49% (4) of codable units, respectively, were coded within these subtopics. Next, subtopics were labeled within global category 3 ("Short-Term Complications/Emergency Situations") as *Hospitalization or Emergency Hospital Visits, Glycemic Uncontrol/Hyperglycemia*, and *Hypoglycemia Management*. Of the codable units, 7.87% (7), 4.49 (4), and 3.37% (3), respectively, were coded in these subthemes.

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Table 2

Definitions of Subtopics Within General Categories and Examples of Caregivers' Responses per Subtopic

Subtopic	Definition	Examples of caregivers' responses
	Global category #1: Social/structural barriers	
Lack of resources to access services	This section addresses barriers to obtaining professional care, education, medical supplies or devices, food, or other T1D-related aids, as well as challenges in managing the expenses or needs of a person with the condition (e.g., finances, medical coverage, and money).	"Difficulty getting services (e.g., the pump). Many do not get them with the health plan." [Man aged 40; father of a 15-year-old girl] "The cost of having a child with T1D. The food, the supplies, and the fact that the father does not pay the pension on time (they use this money for strips, among other things)." [Woman aged 36; mother of a 13-year-old boy]
Social unawareness, discrimination or stigma	This subtopic includes challenges due to social ignorance about T1D; being labeled, rejected, or unequally treated for having T1D, and situations in which youths avoid activities or places, anticipating exclusion or lack of accommodations.	"Lack of acceptance. People limit him..." [Woman aged 49; mother of a 14-year-old girl] "Other people's lack of knowledge." [Man aged 49; father of a 14-year-old girl] "That he has to be deprived of certain things. He was not enrolled in the baseball academy he wanted." [Woman aged 45; mother of a 14-year-old boy]
Quality/availability of services, education or accommodations	This subtheme covers difficulties due to the scarcity or lack of adequate information, treatments, aids, or special arrangements for a person with T1D and negative evaluations about those available.	"Little education available." [Woman aged 39; mother of a 13-year-old boy] "Finding services according to the limitations of his comorbidity (ADHD and Asperger Syndrome)." [Woman aged 35; mother of a 12-year-old boy] "The school's food." [Woman aged 47; mother of a 15-year-old boy]
	Global category 2: Cognitive/affective aspects in the family	
Youth's emotional aspects	This section refers to adolescents' difficulties in managing feelings and moods when facing their lives with T1D, including its affective consequences (e.g., feeling that they do not fit in, fear of appearing different, etc.).	"That he doesn't like to show himself different. [Woman aged 50; mother of a 13-year-old boy]" "The discouragement that he gets, that he became slow." [Woman aged 49; mother of a 17-year-old boy] "She is very intense, and irritable." [Man aged 40; father of a 12-year-old girl]
Acceptance or adaptation to T1D	This subtopic addresses family members' difficulties in assimilating a T1D diagnosis and accommodating themselves to it. It includes their lifestyle adjustments and accommodations (e.g., to self-care routines).	"Difficulties adapting to injection schedules, meal periods; lifestyles they have. Time management." [Woman aged 38; mother of a 13-year-old girl] "The process of adaptation and management. Acceptance of diabetes." [Man aged 42; father of a 12-year-old boy]

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Table 2 (Continues)

Subtopic	Definition	Examples of caregivers' responses
Parental emotional aspects	This subtheme illustrates how T1D in children has impacted the affective or emotive aspects of their parents or caregivers (e.g., elucidating feelings of helplessness, discouragement, resignation, anxiety, fear, frustration, anger, hopelessness, etc.).	"Everything. That I would like to be there at all times and I can't." [Woman aged 35; mother of a 12-year-old girl] "The processes have been hard; I have gone through them alone; it has been difficult." [Man aged 45; father of a 15-year-old girl] "I was crying and scared." [Woman aged 54; mother of a 17-year-old boy]
Youth's lack of knowledge or understanding about T1D	This category refers to lack of adequate information, comprehension, or discernment between what constitutes symptoms of T1D and what does not. It also includes responses that imply that the adolescent does not have as clear an idea as expected about the condition's seriousness or severity.	"That he is not always aware that he has to take care of himself." [Woman aged 50; mother of a 13-year-old boy] "Make her understand the seriousness of her condition and the problems she may face if she doesn't follow treatment." [Woman of 42; mother of a 15-year-old girl] "Not knowing how to differentiate regular things from things related to diabetes." [Man aged 45; father of a 15-year-old girl]
Global category 3: Short-term complications/emergency situations		
Hospitalization or emergency hospital visits	This topic addresses difficulties due to adolescents' hospital admissions, their sudden need for services in medical institutions, or visits to urgent care rooms due to T1D.	"Hospitalizations in intensive care unit." [Woman aged 55; mother of a 16-year-old girl] "Two emergency room events, and the first of the diagnosis..." [Woman aged 53; mother of a 14-year-old girl]
Glycemic uncontrol/ hyperglycemia	This topic refers to difficulty in keeping appropriate blood glucose values or complaints about the chronic presence of extreme or fluctuating blood sugar levels.	"The biggest difficulty would be keeping the sugar stable." [Man aged 49; father of a 16-year-old girl] "When her blood sugar is high." [Woman aged 36; mother of a 13-year-old girl]
Hypoglycemia management	This section focuses on the challenges of managing low blood sugar levels (e.g., seizures or fainting due to severe episodes, mild to moderate low blood sugars, or shocks).	"The low blood sugar, the continuous fainting." [Woman aged 35; mother of a 17-year-old girl] "That she went into a state of coma [because of hypoglycemia]." [Woman aged 32; mother of a 12-year-old girl]
Global category 4: Difficulties on follow-up/relative responsibility		

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Consistency in follow-up/supervision	This subcategory considers problems that arise from parents having to frequently check and monitor their child's diabetes care. This monitoring may or not be related to youths' difficulties in treatment adherence.	"Having to pay attention to her/his alimentation and blood sugar levels." [Man aged 45; father of a 13-year-old son] "Even though you try to help him, he sees it as one hovering over him all the time." [Woman aged 50; mother of a 13-year-old son]

Table 2 (Continues)

Subtopic	Definition	Examples of caregivers' responses
Distribution of responsibilities in T1D management	This topic refers to difficulties that arise because adolescents do not assume their role in T1D treatment, because they are not developmentally ready to do so, or because they assume it, but at the cost of conflicts with their caregivers.	Getting him to be responsible for himself. [Woman age 42; mother of a 13-year-old boy] "Getting him to take control of his condition." [Woman aged 46; mother of a 17-year-old boy] "...that she still does not know how to take care of herself, administer insulin, eat snacks, etc." [Woman aged 39; mother of a 13-year-old girl]
Global category 5: Difficulties in treatment adherence		
Not applicable	See Table 1 for the definition	"The biggest difficulties have been with diets and exercises." [Woman aged 50; mother of a 15-year-old girl] "The girl does not want to monitor herself; (she) eats less, does not follow the diet, does not worry." [Woman aged 49; mother of a 17-year-old girl]
Global category 6: Developmental stage/hormonal aspects		
Not applicable	See Table 1 for the definition	"Adolescence, change of hormones, instability in the system." [Woman aged 55; great aunt of a 15-year-old boy] "How to work with her character." [Man aged 40; father of a 12-year-old girl]
Global category 7: No difficulties		
Not applicable	See Table 1 for the definition	"At the moment, none." [Woman aged 42; mother of a 13-year-old girl] "There hasn't been one since the diagnosis." [Man of 44; father of a 12-year-old girl]

Note. T1D = type 1 diabetes

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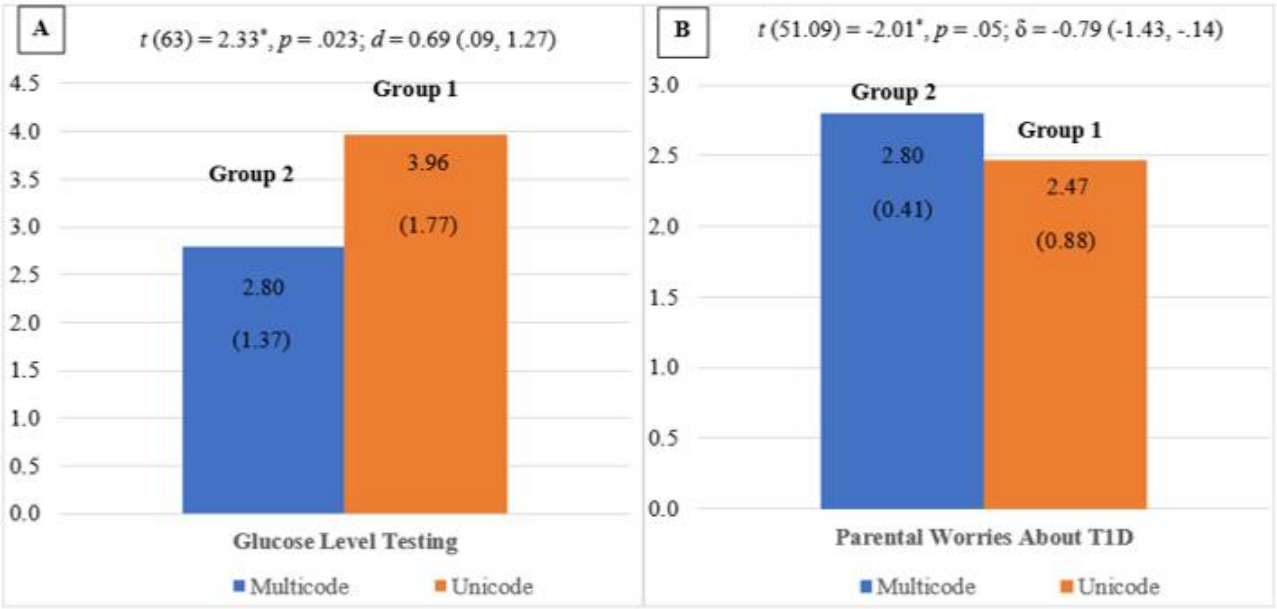
Finally, we labeled the subtopics under global theme 4 ("Difficulties in Follow-up/Relative Responsibility") as *Consistency in Follow-up/Supervision* and *Distribution of Responsibilities in Diabetes Management*. Of the codable units, 3.37% (3) and 5.62% (5), respectively, were coded in these subthemes. In Table 2, we present definitions per subtopic within general themes and examples for each subtheme (and for global categories 5, 6 and 7) selected from parents' responses.

Relationship Between Multi-Coding of General Categories and Diabetes-Related Variables

Caregivers whose responses received ≥2 different codes (Group 2) had children who presented significantly higher rates of current depressive disorders (66.67% vs. 36.00%) than those whose responses were unicoded [χ^2 (1, N = 65) = 4.43, p = .035, d = 0.54 (0.07, 1.08)]. The effect size of this difference was medium. Parents from Group 2 had offspring that checked their glucose levels significantly less frequently in the past 3 months than their counterparts did (see Panel A of Figure 1). The former also reported that they worried about their T1D offspring significantly more often in the past 3 months than caretakers from Group 1 (see Panel B of Figure 1). The effect size of these differences was medium (Cohen's d) in the first case and medium-to-large (Glass's δ) in the second. Using a one-sided Spearman correlation, multi-coded responses were associated with a lower frequency of hypoglycemia preventive measures in youths [r = - .23 (-.41, -.01), p =.033.

Figure 1

Group Comparison in Mean Scores of Parent-Reported Diabetes-Related Variables



Note. Panel A: Group comparison in frequency of glucose level testing. Panel B: Group comparison in the severity of parental worries about type 1 diabetes. T1D = type 1 diabetes; Group 1 = uni-coded responses (n = 50); Group 2 = multi-coded responses (n = 15).

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DISCUSSION

This study is the first to examine both the specific challenges faced by Hispanic caregivers of T1D adolescents in PR and their connection to mental health and T1D-related outcomes. Based on our literature review and findings of Rosselló et al. (2005), we expected that family-related issues, short-term complications, and difficulties with treatment adherence would be the more common themes among parental challenges. Parental responses yielded 89 codable units that were coded into 1 out of 7 categories. The challenges reported most often involved cognitive/affective aspects in the family and socio-structural barriers faced by caregivers while managing T1D care. These were followed by barriers regarding short-term complications and difficulties in adherence. For the most part, these findings were consistent with our hypothesis, as three of the four most often identified themes were in line with it.

Our findings on the relevance of social and structural barriers reported by caregivers align with previous literature on this topic. For example, Davis et al. (2019) noted that factors such as access to healthcare services, insurance, and school-based support significantly impact diabetes management among adolescents. In our study, the category of "Social/Structural Barriers" included obstacles like limited resources, stigma, and inadequate healthcare services, complicating caregivers' efforts to manage T1D. These findings are consistent with reports by Butler et al. (2020), who emphasized that food insecurity and limited access to necessary resources further exacerbate difficulties caregivers face in managing diabetes. Such systemic barriers are critical to understanding the broader context of T1D management and the additional strain they place on Hispanic families.

The inclusion of the psychosocial aspects of managing T1D within the family as a major barrier for 36.92% of the caregivers aligns with previous literature. For instance, Malerbi et al. (2012) found that psychosocial factors, including difficulties with setting limits on adolescents, were prominent among caregivers of youth with T1D. These challenges often reflect broader family dynamics, in which the emotional strain of managing a chronic condition like T1D can affect both parents and adolescents. Our findings also concur with studies that report that emotional problems may affect caregivers' ability to support their offspring in managing T1D (Azar et al. 2024; Whittemore et al., 2012). Likewise, the increased depression rates among the offspring of caregivers reporting ≥ 2 challenges are consistent with studies that relate increased barriers to T1D adherence to mental health problems in youth (Piñero-Meléndez et al., 2016).

Short-term complications and emergency situations were also significant themes in our study, with 18.46% of caregivers' responses alluding to difficulties in this area. Prior findings by Melo do Rego Sousa (2023) highlighted the challenges caregivers face in managing fluctuating, extreme blood glucose levels (hypoglycemia and hyperglycemia). Our findings also align with previous literature in regard to the consequences, frequent hospitalizations or emergency medical interventions because of these extreme fluctuations. The latter acts as an added burden to caregivers of T1D adolescents (Zysberg & Lang, 2015).

Barriers in treatment adherence were coded in 14.61% of the codable units (and noted by 20% of caregivers), while difficulties related to follow-up and relative responsibility were present in 8.99% of the responses (and noted by 12.31% of caregivers). Our results align with those of studies (e.g., Bozbulut et al., 2023) that discussed how caregiver-adolescent conflicts over the division of responsibility and treatment adherence can jeopardize diabetes management. This theme was also observed in our findings. Our results mirror other studies' results, suggesting difficulties in treatment adherence are a challenge for caregivers and are linked to negative emotions in their offspring. Therefore, barriers in adherence to treatment emerge as a variable with complex dynamics for caregivers of youth with T1D (Lan et al., 2024).

Lastly, only four adults responded that youth's developmental and hormonal aspects posed a challenge for T1D care, with three caregivers out of 65 reporting having experienced no difficulty in facing T1D in their adolescents (Table 1). Literature reviewed suggests that understanding the

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developmental and hormonal changes of adolescence that affect T1D care poses a challenge for parents (Whittemore et al., 2018). However, no study in our review found caregivers' reports indicating a lack of difficulties in T1D care. Still, an examination of particular cases showed that adults with no reported difficulties were biological parents in their early 40's with some college degrees and a high/upper-middle perceived socioeconomic status. They lived outside the San Juan metropolitan area. Their offspring were females that attended public schools and lived in two-caregiver homes, who never refused to exercise, did not resist insulin use, and checked their glucose levels 3-4 times a day. They had been hospitalized for T1D only once; had never used illicit drugs; had no history of disruptive behavior disorders, maltreatment, or abuse; had none or very few interpersonal problems; and their depression had an adolescent onset. Some of these characteristics may have served as protective factors.

We also hypothesized that providing responses that allude to two or more barrier categories would relate to worse health outcomes. Our findings show that caregivers whose responses received ≥2 codes reported more T1D-related worries. In addition, their adolescents were less likely to monitor their glucose levels regularly and engaged in less hypoglycemia preventive behavior in the last 3 months compared to their counterparts. Worries about T1D in their offspring have been reported as a prominent psychological factor among parents in previous studies conducted in PR (Rolón-Sanfeliz et al., 2025; Rosselló et al., 2005). Kovacs et al. (1990) found that the degree to which mothers perceived T1D to be difficult to manage was associated with their overall levels of emotional distress. In the context of multiple barriers to manage T1D in youth, it is a logical response from caregivers to worry, especially if they belong to a socioeconomically disadvantaged household, as most caregivers from our sample self-identified. As Hispanic families of T1D youth have limited access to quality healthcare services, diabetes education is not provided as often as needed. For example, Crespo-Ramos and Cumba-Avilés (2017) reported that only 41.18% of T1D adolescents in their study showed adequate levels of diabetes knowledge. In addition, only 45.10% of adolescents (and 49.02% of caregivers) correctly answered a question about how to manage hypoglycemia. This may contribute to lower youth adherence to medical recommendations for preventing and managing hypoglycemia and adequate glucose level monitoring.

Strengths and Limitations of the Study

This study has several strengths. It focuses on a population underrepresented in the literature, and it is groundbreaking for its examination of the specific content of parental challenges related to T1D in PR. This study provides valuable insights into the unique socio-cultural difficulties faced by Hispanic caregivers. These findings contribute to a better understanding of how cultural, social, and systemic factors intersect and interact to shape the caregiving experience in this context. Our study offers a foundation for future research and development of targeted psychosocial interventions that are culturally sensitive and tailored to the specific needs of this population.

However, our study's limitations should also be considered when interpreting its results. The main limitation is the relatively small sample size of 65 participants. Also, data were derived from a specific question in the K-DMIS, which may have limited the scope of information collected on parental difficulties. Future research could benefit from employing more comprehensive methods, such as in-depth interviews specifically designed to explore the particular contents of experiences of caregivers dealing with T1D. The gender inequity within the sample, with 81.54% of the caregivers being female, is also a possible limitation. Such unequal distribution restricts our understanding of male caregivers' experiences, which may differ significantly in relation to culturally specific gender roles. Future studies should aim for a more balanced representation of male and female caregivers to better understand potential gender-related differences in their experiences. Likewise, conducting studies focused exclusively on males could provide new insights into this area, as their perspectives are underrepresented in current research on T1D caregiving, particularly among Hispanic youth.

Conclusion

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The findings of our study could serve to guide the development of future psychosocial interventions aimed at caregivers of adolescents with T1D, particularly within the Hispanic community. Understanding the specific barriers faced by caregivers could also inform healthcare providers and public health officials in creating support systems that address these challenges directly, improving interactions between caregivers and healthcare services. Furthermore, this research may contribute to the design of strategies to mitigate the barriers faced by Hispanic caregivers, enhancing both T1D management and the mental health of caregivers and youth. This, in turn, could result in better health outcomes and improved quality of life.

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Approval of the Institutional Board for the Protection of Human Subjects in Research: The Institutional Review Boards of the University of Puerto Rico, Río Piedras Campus (Approval number 1112-005) and Medical Sciences Campus (Approval number A9530112) approved the protocol of the study.

Informed Consent: We obtained written informed consent/assent from youth and their parents.

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