CAREGIVERS' WORRIES ABOUT TYPE 1 DIABETES IN ADOLESCENT OFFSPRING: EXAMINING EXPERIENCES FROM HISPANIC PARENTS

PREOCUPACIONES DE PERSONAS CUIDADORAS SOBRE LA DIABETES TIPO 1 EN ADOLESCENTES: EXAMINANDO EXPERIENCIAS DE MADRES Y PADRES HISPANO-DESCENDIENTES

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ABSTRACT

Caregivers of youth with type 1 diabetes (T1D) are continuously worried about their child's health. Using a mixed-method strategy while conducting a secondary analysis of cross-sectional data, we examined the content of caregivers' worries about T1D in adolescents (aged 12-17) and the relationship between multiple worries (MW) and health- and family-related variables (HFRV). We screened 65 Hispanic caregivers (81.54% women; aged 32–58) for a youth depression-treatment study. Caregivers answered an open-ended question regarding their worries about their child's T1D. We identified the main themes of parental worries and coded responses using content-based categories. Using chi-square tests ($p \leq .05$) and Spearman correlation, we assessed associations between MW and HFRV. Categories of worries and their occurrence were: Comorbidity and Future Functionality (CFF; 41.51%), Psychological/Cognitive Aspects of Adolescents (10.38%), Issues About Self-Care (16.98%), Short Term Complications/Emergency Situations (19.81%), Repercussions on Families/Caregivers (9.43%), and Discrimination/Lack of Sensitivity (1.89%). MW (≥2) were associated with lower adherence to exercise, higher psychotropic medication use among adolescents, and lower family expressiveness and cohesion. Caregivers with concerns about CFF had children with higher rates of poor glycemic control and fewer hypoglycemia preventive behaviors. Our findings suggest that diabetes complications and adherence to self-care, are the main themes of caregivers' worries and that MW significantly relate to relevant HFRV.

KEYWORDS: adolescent, caregivers' worries, diabetes complications, family environment, self-care.

RESUMEN

Quienes cuidan jóvenes con diabetes tipo 1 (DT1) sienten preocupación continua por su salud. Utilizando una estrategia de métodos mixtos al realizar un análisis secundario de datos transversales, examinamos el contenido de las preocupaciones parentales sobre la DT1 en adolescentes (12-17 años) y la relación entre preocupaciones múltiples (PM) y variables familiares y sobre la salud (VFSS). Evaluamos 65 cuidadoras/es (81.54% mujeres; 32–58 años) durante un estudio para tratar la depresión juvenil. Respondieron una pregunta abierta sobre sus preocupaciones con la DT1 en jóvenes. Identificamos los temas principales y codificamos las respuestas con categorías basadas en contenido. Usando chi-cuadrado y correlación de Spearman, evaluamos la asociación entre PM y VFSS. Las categorías y su frecuencia fueron: Comorbilidad/Funcionalidad Futura (CFF; 41.51%), Aspectos Psicológicos/Cognitivos en Adolescentes (10.38%), Asuntos Sobre Autocuidado (16.98%), Complicaciones a Corto Plazo/Emergencias (19.81%), Repercusiones en la Familia/Cuidadoras(es) (9.43%) y Discriminación/Falta de Sensibilidad (1.89%). Las PM (≥2) se asociaron con menor adherencia al ejercicio, mayor uso de psicotrópicos y menor expresividad y cohesión familiar. Quienes tuvieron preocupaciones sobre CFF tenían hijos/as con tasas mayores de descontrol glucémico y menos prevención hipoglucémica. Nuestros hallazgos sugieren que las complicaciones diabéticas y el cumplimiento con el autocuidado son las principales preocupaciones parentales sobre la DT1 en adolescentes y que tener PM se vincula con VFSS relevantes.

PALABRAS CLAVE: adolescente, autocuidado, clima familiar, complicaciones de diabetes, preocupación parental.

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Type 1 diabetes (T1D) is a chronic illness that usually begins in infancy, adolescence, or young adulthood (American Diabetes Association Professional Practice Committee, 2024). Treatment is complex, demanding and associated with short- and long-term complications that frequently elicit parental worries about their offspring's health and future (Van Gampelaere, 2020). In Puerto Rico, 83%–89% of caregivers of T1D youth have expressed constant worry about their child's health (Cruz-Martínez et al., 2017; Rosselló et al., 2005). Kovacs et al. (1985) conducted initial studies that reported 55.66% of parents (64% of mothers and 41% of fathers), during direct interviews, expressed worries about their child with newly diagnosed T1D.

Although some understanding exists regarding these concerns, their specific content has not been thoroughly explored. Relevant findings include worries about shorter life expectancy, future medical complications, insulin reactions, adolescent's adherence to treatment, and even their self-management and care and transition to adulthood (Allen et al., 1983; Anderson & Tulloch-Reid, 2019; Buckloh et al., 2008; Dashiff, 1993; Ersig et al., 2016; Harrington et al., 2017; Long, 1997; Malerbi et al., 2012; Mellin et al., 2004; Saßmann et al., 2022; Sanjari et al., 2016; Vandagriff et al., 1992). Studies also report concerns about economic resources as well as access to services, treatments, and medical insurance (Dunne et al., 2019; Ersig et al., 2016; Joiner et al., 2020; Long, 1997; Pena et al., 2009; Vandagriff et al., 1992). Caretakers tend to assume the responsibility of ensuring that teenagers adhere to daily treatment and self-care behaviors (Ersig et al., 2016; Ness et al., 2020; Vandagriff et al., 1992). Other concerns relate to lack of sensitivity toward patients, access to primary health services, as well as a desire for more T1D education for caregivers (Lowes & Lyne, 2000; Vandagriff et al., 1992). Finally, worries about structural changes and repercussions of T1D on the family have also been reported (Faulkner, 1996; Markowitz et al., 2012; Moore et al., 2013).

Some studies highlight concerns about T1D management. Several involve parents' supervision of children in assuming responsibilities such as insulin reactions, diet adherence, and glucose management (Allen et al., 1983; Almeida et al., 2020; Dashiff et al., 2011; Markowitz et al., 2012, 2008; Patton et al., 2004; Quirk et al., 2014; Rosselló et al., 2005). Many parents feel that their children may not be assuming the responsibility and appropriate management of T1D expected for their age. This can create a fear of letting teens take responsibility for their T1D (Dashiff et al., 2011; Mellin et al., 2004). It is often difficult for parents to delegate these tasks to their children due to the close relationship developed, eliciting worries for their functionality in future environments such as college or work (Ness et al., 2020; Saßmann et al., 2022). Other carers also mention that they have concerns about cultural preferences that influence food choices, creating a challenge in occasions to select healthy choices (Joiner et al., 2020).

Other prominent concerns are fear of hypoglycemia (FOH) and diabetes complications (Amburgey et al., 2020; Driscoll et al., 2016; Ersig et al., 2016; Haustevedt et al., 2010; Monzon et al., 2021, 2024; Pate et al., 2016; Patton et al., 2011; Tumini et al., 2022; Van Gampelaere et al., 2019). Researchers have gathered elements such as constant prevention of nocturnal hypoglycemia, as well as how FOH could lead carers to avoid the latter by letting blood glucose run high causing episodes of hyperglycemia, that result in long-term effects on glucose levels (Freckleton, 2014; Monzon et al., 2022). Van Gampelaere et al. (2019) add that concerns about FOH can lead caregivers to adopt protective and avoidance behaviors. Some parental concerns about hypoglycemia relate to the possibility of complications (Harrington et al., 2017; Mellin et al., 2004; Saßmann et al., 2022), such as those arising from current T1D care (Malerbi et al., 2012). For instance, as argued by Monzon et al. (2021, 2022, 2023), parents may worry about the potential of nocturnal hypoglycemia to cause harm (e.g., seizures or death). Worries about other health complications and hospital readmissions are also common (Rosselló et al., 2005). Parents feel stressed by the "...difficulty of managing the constraints of diabetes and the fears related to diabetes in terms of risk" (Djiofack Kenstop et al., 2024, p.7). They express not always having the knowledge to manage all the restrictions and crises that might occur.

Some studies cite the lack of sensitivity of both medical and non-medical service providers, and how these attitudes can be hurtful and unhelpful (Howe et al., 2012; Lowes, 2000; Pena et al., 2009). Carers seek a strong relationship with healthcare providers and value effective communication and collaboration in T1D management (Buckloh et.al, 2008). On their behalf, Amillategui et al. (2007) argued that carers experience negative reactions from school personnel when informing them of T1D, creating a challenging and discriminatory environment. Parents suggest the presence of a school nurse to improve their child's T1D control and emphasize the need for educational sessions for personnel to provide basic understanding and management of T1D, and an effective emergency control (Amillategui et al., 2007). Djiofack Kenstsop et al. (2024) also mentions the importance of recognizing cultural barriers and policy implementation challenges that sometimes prevent patients and families from being active in participants care. These authors suggest that this collaborative work contributes to better self-care, diabetes control, and quality of life.

Other worries relate to the repercussions that T1D brings for caretakers and families. Caregivers tend to worry about family support in managing T1D (Allen et al., 1983). In some studies, parents mentioned that T1D has affected their family life, generating changes in scenarios, roles and family dynamics, such as work activities, to fulfill their child's needs (Faulkner, 1986; Harrington et al., 2017; Lindström et al., 2017; Moore et al., 2013). Conversely, T1D can bring the family closer together while negatively affecting the spousal relationship (Dashiff, 1993). The emotional sequelae that this can generate in caregivers can include feelings such as separation anxiety towards their child and concerns about what might happen if they are not there (Dashiff et al., 2008; Morrison et al., 2012). Furthermore, a sense of burnout due to T1D complications is often felt by the caregiver (Buckloh et al., 2008). Similarly, feelings of stress, guilt, anger, fear, frustration, denial, mourning, overwhelm, and even depression can be accumulated (Dashiff, 1993; Dashiff et al., 2011; Djiofack Kenstsop et al., 2024; Lindström et al., 2017; Lowes, 2000; Maas-van Schaaijk et al., 2013; Malerbi et al., 2012; Patton et al., 2011). These concerns involve thoughts about their offspring's death and a potential suicide attempt by youths (Rosselló et al., 2005). Another scenario in which to consider the emotional sequelae of T1D in the family is the COVID-19 pandemic. Zeiler et al. (2022) mention that during this pandemic the awareness of being part of a potential risk group caused concern, particularly among parents, leading to a strict following of preventive measures, while the pandemic either supported or hindered the shift from parental control to self-management of diabetes. Finally, caregivers also mentioned economic concerns such as difficulties accessing medical insurance, healthcare providers, and equipment needed for T1D care (Dunne et al., 2019; Joiner et al., 2020; Pena et al., 2009).

Overall, the literature reviewed presents caregivers' worries ranging from T1D management issues to social and financial support and even concerns for the emotional aftermath of managing T1D. Exploring the content of Hispanic caregivers' worries about T1D and examining the relationship between their worries, youths' self-care behaviors, and family climate may provide important data to inform the development of interventions to help parents in managing their worries and improving family relationships and adolescents' health. In this study we examined the specific content of caregivers' worries about T1D and the relationship that those worries had with health-related and family-environment variables among Hispanic parents. We expected reports of multiple worries to relate to worse outcomes in both domains. We also expected that most common worries would relate to self-care issues and to T1D complications.

METHOD

Design and Participants

This study is a secondary analysis of cross-sectional data collected during a youth depression clinical trial, aimed at testing the initial efficacy of a cognitive-behavioral treatment delivered in group format to T1D adolescents (Cumba-Avilés, 2017). Analyses are based on a cross-sectional bending of qualitative and quantitative data as in mixed methods research. Specifically, after identifying the more common themes in parental responses to an open-ended question, we examined the relationship of thematic content with quantitative indicators.

Participants were 65 caregivers screened for the treatment study. Previously, caregivers completed a request for participation (RFP) form and 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 Rican. About 64.62% (42) of adolescents (aged 12–17; 55.38% girls) attended public schools. The same proportion lived in urban zones, and 43.08% (28) resided in the San Juan Metro Area. Their mean age was 15.05 years (*SD* = 1.68). Primary caregivers were mostly women (81.54%; aged 32 –58). Their mean age was 43.34 (*SD* = 6.42). Their highest education level completed was as follows: 4.62% (3) did not finish high school, 12.31% (8) had a high school diploma, 30.77% (20) had an associate degree or completed a technical course, 41.54% (27) had a bachelor's degree, 7.69% (5) had a master's degree, and 3.08% (2) has a doctorate. Around 55.38% (36) were in full-time and 9.23% (6) were in part-time jobs. Most families (75.38%) were from lower-middle or low socio-economic status. Their mean household size was 3.94 (*SD* = 0.93) members (range: 2 to 7). The mean HbA1c value, a test of the average blood glucose levels in the past 3 months, was 9.03 (*SD* = 2.10; range from 5.76 to 17.70). We asked caregivers for a copy of their child's last test results to obtain these screening data. Only 14 youths were in insulin pump treatment. Their mean score in the Children's Depression Inventory was 18.28, suggesting that most had moderate or severe depressive symptoms. Their mean T1D duration was 6 years.

Measures

Kovacs-Diabetes Management Information Sheet (K-DMIS)

Using an adapted version of the K-DMIS, we obtained (from parents) information on youths' adherence to meal plans and exercise recommendations, hypoglycemia preventive behaviors, T1D age of onset, and access to an insulin pump (Kovacs et al., 1985). The instrument had several open-ended questions for caregivers, including the one that is this article's focus: "What worries you the most about your adolescent's T1D?"

Parental Clinical Interview Form (PCIF)

Cumba-Avilés and Feliciano-López (2005) developed the PCIF as part of the evaluation protocol of clinical trials for treating depression in adolescents. It includes the physical and mental health history of parents and youths, as well as their history of treatment, among other information.

Family Environment Scale-Family Relationship Index (FES-FRI)

This scale is a 27-item self-report of the quality of family relationships (Moos & Moos, 1994). We scored its items in an ordinal format that ranged from 1 to 4. The internal consistency (Cronbach's alpha; α) of its Total scores among caregivers of T1D children is .88 (Matos Melo et al., 2015). We used its Expressiveness (α = .51) and Cohesion (α = .83) subscales.

Procedures

Institutional review boards from the University of Puerto Rico, Río Piedras Campus (approval no. 1112-005) and the University of Puerto Rico, Medical Sciences Campus (approval no. A9530112) approved the study. We shared information on the main study via T1D clinics, local media, and printed materials. We recruited youth through summer camps, educational and recreational activities, and referrals from endocrinologists, school personnel, and other participants. Caregivers completed RFP forms by phone. We invited youth and one parent each to an in-person screening if they met initial eligibility criteria. Prior to data collection, participants signed informed consent/assent forms. Trained graduate students conducted assessments in Spanish. During screening, caregivers completed sociodemographic data, the K-DMIS, and the PCIF, and provided other clinical data about youth depression and T1D. Youth completed measures of depression-related symptoms (not reported here) and a clinical interview to assess inclusion or exclusion criteria. We scheduled a second assessment within two weeks for families who met the preliminary criteria for the clinical trial. The 51 caregivers who attended the second visit completed the FES-FRI.

Data Analyses

Qualitative Analyses

Using thematic content analysis, we evaluated caregivers' responses to the open-ended question and classified them into six general categories (see Table 1). We divided categories 1 and 3 into two subtopics; categories 4 and 5 included three, and category 2 had four subtopics. We present subtopics' names and definitions in Table 2. The second author and the project coordinator accorded final definitions for each general category and subtopic and developed coding rules after two revisions. We achieved a master key of codes through the codifications of these coders. Disagreements were resolved by consensus. Research assistants entered the master key and codes provided by the coders into a database to estimate overall raw agreement (%) and agreement not due to chance. Any response could include more than one element, which may require codes into different general categories, or into different subtopics of the same category.

Quantitative Analyses

We used SPSS 28.0 for statistical analyses. Using descriptive statistics, we estimated the response rates per category, calculated within codable units (106) and within caregivers (65). We used Cohen's Kappa (κ) to assess the reliability between coders and between each coder and key codes. We estimated bias-corrected and accelerated (BCa) 95% confidence intervals for κ coefficient using a bootstrap procedure based on 1000 samples. We defined groups of caregivers based on the number of general categories assigned to their responses (Unicode responses vs. Multicode responses) and on assignments of codes within the most frequently coded category. This allowed us to examine if caregivers' worries (based on general categories) were related to health- or family-related outcomes. Using Chi-squares (2-sided) and Fisher Exact Test (1-sided), we compared these groups in categorical variables, while using a Student's *t*-test (2-sided), we did the same with continuous ones ($p \leq .05$). Last, using 1-tailed Spearman correlation (r_s), we explored the association of multicode responses with family outcomes and adherence to meal plans. To examine the effect sizes of group differences, we used Cohen's *d* and estimated its 95% confidence interval. For categorical data analysis, we applied a transformation of the Chi-square value into *d* scores using the statistical tool designed by DeFife (2009).

RESULTS

Reliability of Coders

When considering general categories, the agreement between the two coders was excellent [Raw agreement (RA) = 96.23% (102 / 106); κ = .95 (.90 – .99)]. RA between Coder A and key codes was 99.06% (105 / 106), which resulted in κ = .99 (.95 – 1.00). We observed similar results for agreement between Coder B and key codes [RA = 97.17% (103 / 106); κ = .96 (.91 – 1.00)]. When considering subtopics, the agreement between the two coders was also excellent [RA = 94.34% (100 / 106)); κ = .93 (.87 – .98)]. RA between Coder A and key codes was 98.11% (104 / 106), which resulted in κ = .98 (.94 – 1.00). We observed similar results for agreement between Coder B and key codes [RA = 97.17% (103 / 106); κ = .95 (.90 – .99)].

TABLE 1.
Definition and Frequency of Occurrence of Categories Used for Content Analysis of Caregivers' Responses.

Thematic Categories	Definition	Sample of Codable Units[a]	Sample of Caregivers[b]
Comorbidity and Future Functionality	Concerns about complications or physical illness that youth may suffer due to the degree of impairment that these may cause, or due to having doubts related to whether they will be able to function independently in the next developmental stages.	41.51% (44)	66.15% (43)
Psychological/Cognitive Aspects of Adolescents	Concerns about negative thoughts or emotional reactions, or future consequences on the youth with T1D, as well as attitudes that may suggest indifference, denial or lack of education regarding their condition and ability to manage their emotions.	10.38% (11)	15.38% (10)
Issues About Self-Care	Concerns about poor diabetes self-management behaviors that minors exhibit or caregivers fear will show up in the future, as well as those related to their adolescent's weight/appetite.	16.98% (18)	27.69% (18)
Short Term Complications/ Emergency Situations	Concerns suggesting anticipatory stress/anxiety for situations such as low, extreme, or fluctuating blood glucose levels and difficulties these may generate (e.g., seizures or shock) and the possibility of their adolescent having to deal with these issues alone. This category also covers concerns about their offspring spending one or more nights in a medical care facility due to T1D.	19.81% (21)	30.77% (20)
Repercussions on Families/Caregivers	Concerns linked to economic aspects of T1D, general, or very broad concerns that cover almost everything, and those related to the consequences T1D can have on the lives of members of their household and on the interpersonal relationships between them.	9.43% (10)	13.85% (9)
Discrimination/Lack of Sensitivity	Concerns about the rejection, stigma, or lack of tact the adolescent could suffer and/or feel from others for having T1D.	1.89% (2)	3.08% (2)

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%. [a] *N* = 106; [b] *N* = 65.

Frequency per Global Categories

Categories of worries and their occurrence are presented in Table 1. The more frequent categories considering all codable units and the sample of caregivers were *Comorbidity/Future Functionality* and *Short-Term Complications/Emergency Situations*. These were followed by *Issues About Self-Care*. In Table 2, we present definitions per subtopic within general themes (if applicable) and examples for each subtheme (and global category #6) selected from parents' responses. Next, we present relevant data about the occurrence of codes within each subtopic.

TABLE 2.
Definitions of Subtopics within General Categories and Examples of Caregivers' Responses per Subtopic.

Subtopic	Definition	Examples of Caregivers' Responses
Global Category #1: Comorbidity and Future Functionality		
Long- and Median-Term Physical Complications	This subtopic addresses concerns about the negative effects or medical conditions youth could suffer due to T1D or poor self-care. It includes reduced quality of life or longevity, organ damage, additional need for treatment, and functional alteration of body parts.	"...that her organs will not suffer serious consequences (e.g., heart, pancreas, and kidney, etc.)" [*Man of 40; father of a 15-year-old girl]* "Its consequences because the damages…are irreversible. For example, that she ends up blind or needing dialysis. That scares me." *[Woman of 49; mother of a 14-year-old girl]*
Skills for Adult Life	This section includes worries about the functionality, or skills needed to manage daily activities that the adolescent may not have after becoming independent from caregivers.	"That she does not know how to handle herself, because I have always been with her" *[Woman of 37; mother of a 13-year-old girl]* "How it's going to be in the University; how she will handle it for the rest of her life, and on her own adult life" *[Woman aged 53; mother of a 14-year-old-girl]*
Global Category 2: Psychological/Cognitive Aspects of Adolescents		
Lack of Acceptance/Denial	This section refers to concerns due to the adolescent's lack of recognition of T1D, or because the child behaves as if this diagnosis has never occurred.	"...he doesn't accept his condition" *[Woman of 35; mother of a 12-year-old boy]* "I am concerned that she has not accepted her condition" *[Woman aged 50; mother of a 15-year-old girl]*
Indifference/Lack of Seriousness	This subcategory covers worries about the youth's lack of formality, interest, responsibility, or commitment to sustain a healthy lifestyle in accordance with the demands of having T1D. It includes situations in which the child pretends not to give importance to the condition.	"His indifference: he does not visualize that he can go through that. His relative died blind; part of his body was amputated." *[Woman aged 48; mother of a 16-year-old boy]* "His lack of seriousness with his life. Sometimes he doesn't care that he doesn't take action to lead a healthy life." *[Woman aged 55; great-grandmother of a 15-year-old boy]*
Lack of Knowledge or Understanding	This section addresses concerns about adolescents' lack of adequate information, comprehension, or discernment regarding the management of T1D.	"Her lack of understanding of the consequences of not taking care of herself" *[Man aged 45; father of a 15-year-old girl]*
Management of Emotions	This subcategory refers to worries about how youths deal with feelings, moods, and affective consequences attributed to T1D (e.g., sadness, anger, or fear) and living with the condition.	"The reaction to her condition, because I'm noticing her as fearful." *[Woman aged 41; mother of a 16-year-old girl]* "...the way he feels and that he locks himself up because he has diabetes." *[Woman aged 39; mother of a 12-year-old boy]*
Global Category 3: Issues About Self-Care		
Poor Self-Care	This subcategory refers to concerns about the poor T1D management that the child may have (e.g., eating management and sugar check).	"That he does not take the necessary steps to be able to live with that condition." *[Man aged 58; stepfather of a 16-year-old boy]* "She doesn't take care of herself as she should." *[Woman aged 50; mother of a 15-year-old girl]*
Appetite or Weight	This section addresses worries about how possible changes in the adolescents' body mass or desire to eat could affect their care/management of T1D.	"That her appetite might increase" *[Woman of 49; mother of a 15-year-old girl]* "Her weight because if she follows her diet, she could use less insulin." *[Woman aged 44; mother of a 17-year-old girl]*
Global Category 4: Short-Term Complications/Emergency Situations		
Fear of Hypoglycemia	This section refers to anticipatory anxiety about low blood sugar levels (e.g., fainting spells, mild to moderate sugar level	"Seizures, constant low blood sugar.*" [Woman aged 35; mother of a 17-year-old girl]*

Subtopic	Definition	Examples of Caregivers' Responses
	reductions, seizures due to extremely low sugar levels) or the possibility that the minor will be alone when they occur.	"That he dies of hypoglycemia" *[Woman aged 40; mother of a 13-year-old boy]* "I worry about low blood sugar; that I won't be close to her or that she can't react." *[Woman aged 37; mother of a 13-year-old girl]*
Hyperglycemia/Lack of Glycemic Control	This subcategory includes concerns or complaints about the possible chronic presence of extreme or fluctuating sugar levels or episodes of high blood sugar levels and their consequences (e.g., seizures attributed to hyperglycemia, ketoacidosis), even if not chronic.	"Lack of control in sugar. Most of the time it is high. Now with the pump there are times when it is very low." *[Woman aged 35; mother of a 14-years-old girl]* "That he finishes the 'honeymoon' and that, no matter how much he takes care of himself, the T1D gets out of control." *[Woman aged 50; mother of a 17-years-old boy]*
Hospitalization	This section addresses concerns related to past or future occasions in which the child spent or could spend a night or more in a specialized/intensive medical care facility due to T1D.	"The hospitalizations." *[Woman aged 35; mother of a 12-years-old boy]* "...that she has to be hospitalized" *[Woman aged 44; mother of a 16-years-old girl]*
Global Category 5: Repercussions on Families/Caregivers		
Financial Concerns	This subcategory considers worries about managing expenses or economic issues that affect the needs of a youth with T1D (e.g., health insurance coverage, money, and lack of supplies).	"…that I'm left without medical insurance." *[Woman of 38; mother of a 16-year-old boy]* "That I have to buy many things for the treatment and that I may not be able to supply." *[Woman aged 37; mother of a 13-years-old boy]*
Vital Impact on the Family/Caregiver	This portion refers to worries about how T1D has affected family life or environment in a particular way (e.g., relationships or the time spent with each other). It includes caregivers' insecurities about being close or not to their children, except if related to fear of hypoglycemia.	"I have 3 children and I feel that I have dedicated more time to him than to the others. I neglect the little one. I would like to give him more time. I have lost things for being after (mentions son's name)" *[Woman aged 36; mother of a 13-year-old boy]* "…to have her by my side... always with me." *[Man aged 45; father of a 15-year-old girl]*.
Generalized Caregiver's Concern	This section refers to parental responses that suggest diffuse, abstract, or global concerns about diabetes care without emphasizing a particular area.	"Everything. It is a difficult process." *[Man of 42; father of a 12-year-old boy]* "Many things" *[Woman aged 34; mother of a 15-year-old-boy]* "I'm worried about everything..." *[Man aged 45; father of a 15-year-old girl]*
Global Category 6: Discrimination/Lack of Sensitivity		
Not applicable	See Table 1 for the definition	"The way in which the implications of the condition's effects are communicated – inhumanly and tactlessly" *[Women, aged 42; mother of a 12-years-old boy]* "The discrimination and the way they make her feel." *[Women aged 37; mother of a 13-year-old girl]*

Note. T1D = Type 1 diabetes.

Frequency of Subtopics Within Global Categories

We divided the first five global categories into relevant subthemes. We labeled subtopics under global theme #1 ("Comorbidity/Future Functionality") as *Long- and Median-Term Physical Complications* and *Skills for Adult Life*. We coded the 34.91% (37) and 6.60% (7) of all codable units, respectively, within these subthemes. We labeled subtopics under global theme #2 ("Psychological/Cognitive Aspects of Adolescents") as *Lack of Acceptance/Denial, Indifference/Lack of Seriousness, Lack of Knowledge or Understanding,* and *Management of Emotions*. We coded around 1.89% (2), 1.89% (2), 0.94% (1), and 6.60% (7) of codable units, respectively, within these subthemes. Next, we labeled subtopics within global category #3 (“Issues About Self-Care”) as *Poor Self-Care* and *Appetite or Weight*. We coded the 14.11% (15) and 2.83% (3) of codable units, respectively, within these subthemes. We labeled subtopics within global theme #4 (“Short-Term Complications/Emergency Situations”) as *Fear of Hypoglycemia, Hyperglycemia/Lack of Glycemic Control,* and *Hospitalization*. We coded about 10.38% (11), 7.55% (8), and 1.89% (2) of codable units, respectively, within these subtopics. Then, we labeled subthemes under global category #5 (“Repercussions on Families/Caregivers”) as *Financial Concerns, Vital Impact on the Family/Caregiver,* and *Generalized Caregiver’s Concern*. We coded 2.83% (3), 2.83% (3), and 3.77% (4) of all codable units, respectively, within them. Finally, we coded only two responses (1.89%) under global category #6 (“Discrimination/Lack of Sensitivity”). One focused on the lack of sensitivity of some health professionals and the other on experiences of discrimination.

Relationship of Caregivers’ Worries with Health- and Family-Related Variables

Caregivers’ reports coded with ≥ 2 different global categories were associated with higher rates of psychotropic medication use and lower rates of adherence to an exercise routine in youth within the past 3 months (Figure 1). Reports containing ≥ 2 different codes were associated with lower cohesion rates [r_s = -.26 (-.49 – -.04); p = .034] and expressiveness scores [r_s = -.32 (-.52 – -.10); p = .012] among families enrolled in treatment (N = 51). In addition, reports containing ≥ 2 different codes of general categories were associated with more problems in adherence to meal plans [r_s = .22 (.04 – .42); p = .038; N = 65). Parents with at least one response coded in global category #1 had offspring with significantly higher rates of uncontrolled glycemic levels (HbA1c ≥ 9.0) in the past 3 months (N = 51) than their counterparts (Figure 1). Finally, the offspring of the former caregivers exhibited hypoglycemia preventive behaviors less frequently (M = 1.81, SD = 2.32; n = 43) than the remaining youth (M = 3.00, SD = 2.14; n = 22), whose caregivers had no response coded in that category [t (63) = -2.00, p = .05, d = -0.524 (-1.04 – -.01)].

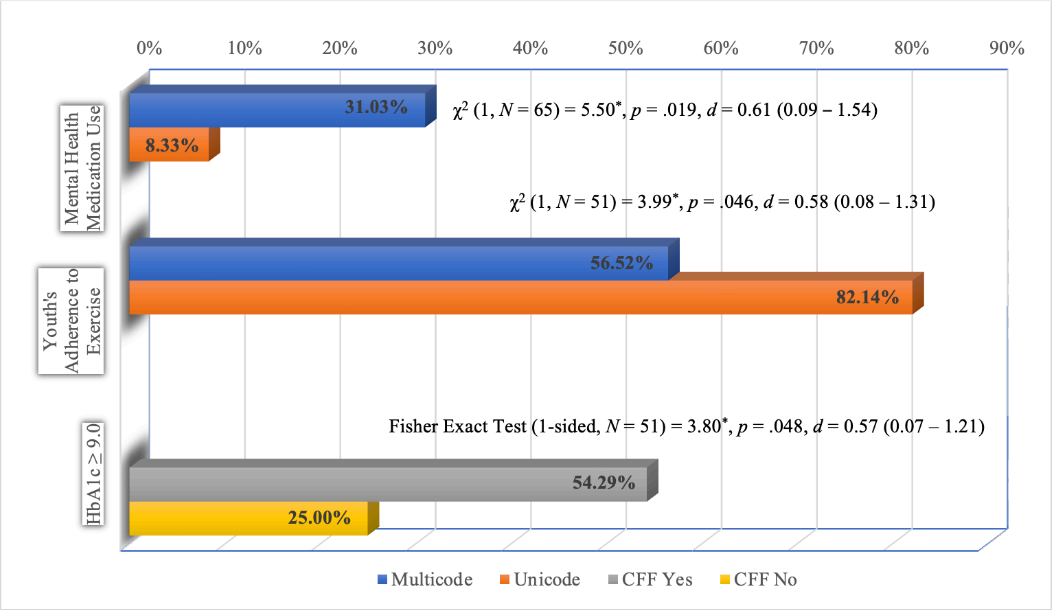

FIGURE 1.
Association of Health-Related Criteria with Multicode Responses and Responses Coded Within Global Category #1.
Note. CFF = Comorbidity and Future Functionality (Global Category #1); HbA1c = Glycosylated hemoglobin

DISCUSSION

This study represents the first attempt to explore the specific content of parental concerns regarding T1D and their association with health- and family-related factors in Puerto Rico. Results of this secondary analysis suggest that that Hispanic caregivers of T1D adolescents from Puerto Rico express concerns that may significantly impact both the adolescent's daily life and the family unit. These concerns, particularly if excessive and accompanied by intrusive behavior, appear to be related to adolescent's treatment adherence and may have a negative impact on family dynamics (Bozbulut et al., 2023; Weinger et al., 2001). The literature reviewed highlights various caregivers' worries, including management and care of T1D, future medical complications, insulin reactions, treatment adherence, self-care, life expectancy, and medical treatments, among others. (Allen et al., 1983; Anderson & Tulloch-Reid, 2019; Buckloh et al., 2008; Dashiff, 1993; Dunne et al., 2019; Ersig et al., 2016; Harrington et al., 2017; Long, 1997; Malerbi et al., 2012; Mellin et al., 2004; Pena et al., 2009; Saßmann et al., 2022; Sanjari et.al., 2016; Vandagriff et al., 1992). Our findings largely align with and support previous parental concerns reported in research literature. As expected, long- and short-term diabetes complications, as well as adherence to self-care recommendations, emerge as primary concerns among Hispanic caregivers regarding T1D. This finding, obtained with caregivers of depressed T1D adolescents (clinical sample), concurs with previous reports from Rosselló et al. (2005) in their general sample of caregivers of T1D youth.

Comorbidity/Future Functionality and *Short-Term Complications/Emergency Situations* were the most prevalent global categories in our sample. Caregivers indicated that a significant portion of their concerns revolved around potential physical complications or illnesses that their child might experience. either due to the level of impairment these might cause or doubts about whether their child will function independently in later developmental stages, especially due to the consequences of poorly managing T1D. As part of these long- and median-term physical complications (the most frequently coded subtopic in this study), caregivers expressed concerns about potential negative effects and/or bodily harm or medical conditions that they may suffer or develop in the future. The latter are linked to having T1D or not taking care of themselves properly. Examples of these concerns include fear of organ damage, need for treatment for other chronic conditions, risk of hospitalization, and concern about the future in the event of functional or degenerative alterations of a body part. On the other hand, *Fear of Hypoglycemia* (FOH) was the second most prevalent subtopic within all codable units. This aligns with the literature's emphasis on concerns about health complications, FOH, poor glycemic control, and its consequences (Amburgey et al., 2020; Driscoll et al., 2016; Erisg et al., 2016; Harrington et al., 2017; Haustevedt et al., 2010; Mellin et al., 2004; Monzon et al., 2021, 2024; Pate et al., 2016; Patton et al., 2011; Rosselló et al., 2005; Saßmann et al., 2022; Silina et al., 2023; Troncone et al., 2024; Tumini et al., 2022; Van Gampelaere et al., 2019; Vavila et al., 2019).

These worries added uncertainty about adolescent functionality and development of future skills for proper and responsible care (Vander Haegen et al., 2021). Caregivers mentioned concerns or doubts about their child's deficient T1D management. These included meal plans, glucose monitoring, and even how possible changes in adolescents' appetite or body mass could affect their care and management. The previous results align with the literature, as parents mentioned how these concerns entail constant care and supervision to encourage child assuming responsibility in matters such as glucose management, insulin reactions, metabolic control, and dietary management (Allen et al., 1983; Almeida et al., 2020; Markowitz et al., 2012; Matyka, 2008; Patton et al., 2004; Quirk et al., 2014; Rosselló et al., 2005).

Caregivers reported worries about a lack of acceptance, denial, indifference, and even a lack of knowledge and understanding of T1D in their adolescent that uncover emotional and even psychological concerns for youth and the family. Caretakers mentioned concerns about managing feelings and the emotional consequences of living with T1D. They also reported how living with T1D can have implications for the family environment and life. Changes such as dynamics in relationships, time dedicated to family and other members, and even challenges for managing expenses and needs of the youth with T1D were presented. Parents mentioned this can lead to emotional consequences due to the complications and care required, which aligns with literature that documents those caregivers may experience feelings of stress, guilt, fear, grief, intolerance of uncertainty, and even depressive symptoms (Dashiff, 1993; Lindström et al., 2017; Lowes & Lyne, 2000; Maas-van Schaaijk et al., 2013; Malerbi et al., 2012; Patton et al., 2011; Vander Haegen et al., 2021). Similarly, financial concerns, obtaining the necessary equipment for T1D care, access to medical insurance, and healthcare providers coincided with concerns presented in the reviewed literature (Dunne et al., 2019; Long, 1997; Pena et al., 2009).

On the other hand, responses with two or mode codes of general categories were associated with both health- and family-related variables. Specifically, providing responses that were multi-coded was associated with higher rates of psychotropic medication use, greater difficulties in adhering to meal plans, and lower rates of adherence to exercise. These findings confirm our expectations, as more parental concerns are common when caring for minors with more severe mental health comorbidity and less T1D-related adherence. The association of multi-coded responses with lower cohesion and expressiveness is consistent with studies that have found this type of environment among families of T1D youth, particularly if depressive symptoms are present (Cruz-Martínez et al., 2017; Weinger et al., 2001). Moreover, the finding that linked worries about comorbidity and future functionality with higher rates of poor glycemic control and lower involvement of children in hypoglycemia prevention confirms that these types of worries are sustained by the actual inappropriate self-care behavior of youths.

Our study has certain limitations. Firstly, the generalizability of findings to a broader population may be limited due to the modest size of our sample. Additionally, the reliance on data obtained from a single question within the K-DMIS restricts the depth and broadness of the insights gathered. Furthermore, we observed an underrepresentation of male caretakers' views and experiences due to the higher prevalence of female caregivers, accounting for 81.54% of the sample, potentially introducing bias into our findings. These limitations emphasize the need for cautious interpretation and suggest approaches for future research to address these constraints comprehensively. Considering this and our study's outcomes, we establish several recommendations for future research efforts. Firstly, conducting a more extensive and targeted investigation on the topic is advisable to deepen understanding. This also involves increasing the number of participants to support statistical robustness and widen the applicability of findings. To provide insights into potential sex differences in parental worries, we recommend trying for a balanced representation of male and female caregivers. Alternatively, designing a study focused only on male parents could offer valuable perspectives. Lastly, we recommend conducting planned studies to assess other potential correlates of parental worries (e.g., social support, caregivers' physical health, and T1D-specific family conflict). These suggestions aim to refine research methodology and enrich comprehension of parental concerns.

Our findings have implications for research, healthcare practice, and public policy. First, our data may serve as the basis for developing a scale to measure the diverse worries that Hispanic caregivers may experience with their adolescents living with T1D. Second, this study calls attention to the importance of navigating these concerns on illness management and its impact on family dynamics, while providing healthcare services to this population. Our results encourage healthcare providers to recognize concerns presented by caregivers and tailor interventions to address each worry properly. Support services for this population should address the diversity of needs presented by families affected by T1D, including access to mental resources and services, educational initiatives tailored to cultural and linguistic aspects of the population, and financial assistance programs. Finally, interventions should emphasize educational programs focusing on disease management, coping strategies, effective communications, and resilience building within the family unit to empower caregivers and family members to manage chronic illness effectively. Interventions like these may encourage caregivers and other relatives to increase confidence in managing chronic illness and challenges this may bring and contribute to developing positive health outcomes for adolescents.

In conclusion, Hispanic caregivers experience different types of worries throughout the care and management of their child T1D. These concerns can influence multiple aspects both at family and individual levels. A sensitive, thoughtful, and thorough assessment of parental worries early in the process of providing healthcare services is warrant. In this context, our findings suggest that parental interventions should include strategies to manage Hispanic caregivers' most common worries about T1D and the examination of the relationship between their worries, self-care behaviors in adolescents, and family climate to promote better adherence to T1D treatment, improved glycemic control, and an increased family and adolescent wellbeing.

Research Ethical Standards

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Approval from the Institutional Review Board for Human Research: The Institutional Review Board at the University of Puerto Rico, Río Piedras Campus (Approval no. 1112-005) and the Institutional Review Board of the University of Puerto Rico, Medical Sciences Campus (Approval no. A9530112) approved the protocol of the study.

Informed Consent: We obtained written informed consent/assent for participation from primary caregivers and adolescents as part of the procedures of the main research project. No additional consent or assent was needed for secondary data analysis.

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