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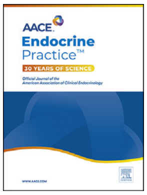

Original Article

The Experience of Discrimination Impacts Technology Readiness and Psychosocial States of Minoritized Families Living With Type 1 Diabetes: Findings From the BEAD-T1D Pilot Study

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ABSTRACT

Objectives: This study aims to understand the association of perceived discrimination with diabetes technology utilization and psychosocial states in minoritized families with public insurance and pediatric type 1 diabetes.

Methods: The *Building the Evidence to Address Disparities in Type 1 Diabetes* Pilot *(BEAD-Pilot)* study engaged parents/guardians of children aged<12 years with type 1 diabetes and public insurance. Parents/guardians were invited to participate in surveys, focus groups, and/or advisory groups. Surveys included validated measures assessing perceived discrimination, psychosocial factors, and diabetes technology acceptance. Data were analyzed via descriptive statistics, group comparisons, and regressions. Through semi-structured interviews, we explored barriers to diabetes technology use and data were coded inductively by a 5-member bilingual group.

Results: Discrimination correlated with lower diabetes technology acceptance ($r = -0.38$, $P = .05$). Higher perceived discrimination was significantly associated with increased depression ($\beta = 0.45$, $P < .001$) and decreased global health ($\beta = -0.27$, $P = .011$). Qualitative data revealed that parents experienced discrimination based on race, ethnicity, and insurance status, often leading to mistrust and reluctance to engage in care.

Conclusions: Perceived discrimination appears to be an underexplored but meaningful barrier to diabetes technology utilization. Addressing discrimination in health care and community settings, in addition to access, is essential for closing disparities in diabetes technology utilization.

Introduction

A focus on equity in diabetes care delivery through a pathway to more advanced diabetes devices and technologies can improve both diabetes management and outcomes for youth living with type 1 diabetes (T1D).[1-9] Despite efforts to increase access, disparities in diabetes technology utilization remain persistent, raising concerns that increased access alone is not sufficient to close the gap.[9,10] These utilization gaps are influenced by a variety of systemic and upstream drivers of health disparities and social determinants of health such as socioeconomic status, education, geographic location, and access to health care services.[1] In particular, the experience of discrimination has garnered increasing attention as a critical factor influencing both health decisions and health outcomes.[1,11-13]

Abbreviations: BEAD, building the evidence to address disparities; DTA, diabetes technology acceptance; EDS, everyday discrimination scale; LDS, lifetime discrimination scale; PEDQ-CV, Brief Perceived Ethnic Discrimination Questionnaire-Community Version; T1D, type 1 diabetes.

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Discrimination—whether experienced within health care settings or in broader societal contexts—has detrimental effects on individuals' health behaviors, decision-making, and access to care, leading to poorer health outcomes across various chronic conditions, including diabetes.[14-20] For example, racial and ethnic minorities often report higher levels of perceived discrimination within healthcare systems, which can erode trust, lower health literacy, and result in less frequent utilization of recommended treatments and technologies.[14] In addition, broader societal discrimination outside of health care settings can exacerbate stress, further complicating the management of chronic conditions like diabetes.[21-23]

Despite this substantial body of evidence linking perceived discrimination to negative health outcomes,[14-20] the role of discrimination in diabetes technology utilization has not been sufficiently explored. A majority of the focus has been on access to care, but we must also consider how the lived experiences of youth with diabetes and their families, especially those from marginalized groups, impact their willingness and ability to adopt and use advanced diabetes technologies.[6,8,10,24] To address this gap in understanding, the Building the Evidence to Address Disparities Pilot (BEAD-Pilot) study was initiated. The BEAD-Pilot study aims to explore the upstream drivers of health disparities, with a particular focus on how discrimination—both within and outside of the health care system—shapes decisions of people with diabetes regarding diabetes technology utilization. By better understanding these dynamics, the study seeks to inform targeted interventions that improve access to diabetes technology and address the barriers to its full utilization among populations disproportionately affected by diabetes disparities. In this manuscript, we report on direct experiences of those with diabetes and their families captured in the BEAD-Pilot study.

Participants

Parents/guardians (hereafter referred to as “parents”) of youth aged <12 years with T1D and public insurance coverage who were seen at a single-center quaternary children’s hospital, were recruited to participate in a survey, focus group, and/or parental advisory board to better understand barriers and promoters of diabetes technology utilization. Public insurance was chosen as an eligibility criterion as it is a proxy for lower socioeconomic status in the United States. Additionally, we aimed to recruit a cohort whose race and ethnicity is representative of individuals with public insurance in the United States. All eligible participants were approached and invited to participate in the study, using evidence-based, culturally congruent recruitment as the standard of care.

Materials and Methods

Study Overview

The BEAD-Pilot study aims to engage publicly insured families to: (1) construct an evidence base on factors that affect diabetes technology utilization in youth with public insurance and (2) formulate a pilot intervention to increase diabetes technology uptake.

Parents had the option of participating in a survey, focus group, and/or parental advisory board to better understand barriers and promoters of diabetes technology utilization. The survey portion consisted of 9 validated measures,[25-33] delivered in English or Spanish, measuring perceived discrimination, childhood trauma, technology readiness, and psychosocial well-being. All surveys were first professionally translated from English to Spanish and then back translated from Spanish to English by a bilingual study staff member to verify accuracy and quality of the translation. Semi-structured interviews/focus groups and advisory boards were conducted in Spanish or English to participants who consented to the study and completed the surveys. The semi-structured interviews/focus groups probed similar domains as the survey measures focused on diabetes care and technology. The advisory boards utilized semi-structured interviews and focused on identifying stakeholder needs in an intervention to increase diabetes technology uptake in minoritized families. This study was approved by the local Institutional Review Board, protocol number 65313. All participants provided informed consent or assent prior to participation, and all procedures followed were in accordance with the ethical standards of the Institutional Review Board.

Highlights

- Disparities in diabetes technology utilization are a significant burden
- Few interventions have resulted in sustained increase in technology use
- Upstream drivers of disparities include systemic bias that limits access
- Perceived discrimination is negatively associated with technology and mental health

Clinical Relevance

In this study, we identify that discrimination is associated with lower technology acceptance and poorer psychosocial states. Addressing discrimination in health care and community settings, in addition to access, is essential for closing disparities in diabetes technology utilization.

Survey Measures

Participant sociodemographics were self-reported by the parent/guardian. Annual income was reported as a categorical variable (Less than $25,000, $25,000-$49,999, $50,000-$74,999, $75,000-$99,999, $100,000-$124,999) and was additionally benchmarked to the regional median household income of the county the family lived.[34] Race and ethnicity were treated as social constructs in this study and were self-reported using National Institute of Health guidelines.[35] All surveys measures were administered via the secure REDCap platform and have published validity. Parent and youth demographics were completed by the parent who consented. Parents ($n = 28$) received $50 for survey completion. Following the completion of a sociodemographic survey, parents completed the following surveys (presented in the order seen by parents).

Brief Perceived Ethnic Discrimination Questionnaire-Community Version (PEDQ-CV)

The PEDQ-CV[25] is a 17-item self-report measure designed to assess perceived ethnic discrimination in a community setting. It focuses on experiences of discrimination based on race or ethnicity in everyday life, including within community interactions, health care, education, or employment. Respondents rate how often they have experienced each of the discriminatory events on a Likert scale, ranging from "1: Never" to "5: Very often."

Everyday Discrimination Scale (EDS)

The 10-item EDS[26] was our primary survey outcome and evaluates the experience of perceived discrimination experienced by an individual in their daily life, with a focus on subtle and commonplace instances of bias. Respondents are asked to rate the frequency of experiences like being treated with less courtesy or respect, receiving poorer service, or being threatened or harassed. The scale uses a five-point Likert scale, ranging from "Never" to "Almost every day." Higher scores reflect more frequent experiences of discrimination.

Lifetime Discrimination Scale (LDS)

The 6-item LDS[27] assesses experiences of discrimination across a person's life, specifically targeting experiences of unfair treatment due to factors like race, ethnicity, gender, or age. Respondents answer "Yes" or "No" to questions regarding whether they've encountered discrimination in various life contexts, such as in employment, education, or health care. A higher score reflects a greater lifetime exposure to discriminatory experiences.

Adverse Childhood Experiences (ACEs)

The 10-item adverse childhood experience questionnaire examines childhood adversity, focusing on experiences like abuse, neglect, and household dysfunction before the age of 18. Participants respond with "Yes" or "No" to each item, which covers experiences like parental substance abuse, mental illness, or domestic violence. The total score (ranging from 0 to 10) reflects the cumulative number of adverse experiences, with higher scores indicating more severe childhood adversity.

Diabetes Technology Acceptance (DTA)

The diabetes technology acceptance scale measures youth attitudes toward diabetes-specific technology (eg, insulin pumps, continuous glucose monitors). Participants rate 5 items on a five-point Likert scale, from "Strongly Disagree" to "Strongly Agree." Example items include "Diabetes technology makes my life easier" and "I feel confident using diabetes technology." Higher scores indicate more positive attitudes toward diabetes technology.

General Technology Attitudes (GTA)

The general technology attitude scale measures youth attitudes towards general technology (eg, apps, websites, smart phones, and computers). Participants rate 5 items on a five-point Likert scale, from "Strongly Disagree" to "Strongly Agree." Example items include: "Technology makes my life easier" and "Technology has made managing my health easier." Higher scores indicate more positive attitudes toward technology.

Patient Health Questionnaire-9 (PHQ-9)

The Patient Health Questionnaire-9[30] is a 9-item self-report tool used to assess the severity of depressive symptoms over the past 2 weeks. Respondents rate each item on a scale from 0 ("Not at all") to 3 ("Nearly every day"). The scores are summed to produce a total score ranging from 0 to 27, where higher scores indicate more severe depressive symptoms. The scale is widely used for diagnosing and monitoring depression.

Diabetes Distress Scale—Parent (DDS-P)

The 20-item Diabetes Distress Scale—Parent[31,32] measures the distress parents experience related to their child's diabetes management. Items reflect concerns over managing the child's treatment, emotional burden, and feelings of inadequacy. Parents rate their distress on a scale from "1: Not a problem" to "6: A very serious problem." The mean score is calculated, with higher scores indicating greater levels of diabetes-related distress.

Perceived Global Health (PGH)

The perceived global health[33] is a 7-item scale that evaluates an individual's overall perception of their health, quality of life, and mental and physical well-being. Respondents answer on a five-point Likert scale from "1: Poor" to "5: Excellent." The total score ranges from 7 to 35, with higher scores indicating a more positive perception of global health and well-being.

Focus Group Script Development

The interview/focus groups script was theoretically grounded in the Social Ecological Model[36-39] with questions evaluating interpersonal (ie the experience of discrimination in and outside the medical system), community, institutional/clinic, and healthy policy interactions for families. Focus groups were carried out in the parent's preferred language (English or Spanish) by bilingual research staff. Interviews/focus groups lasted approximately 60 minutes and parents ($n = 21$) were compensated $100 for their time. All participants who completed a focus group also completed surveys.

Advisory Board Script Development

The advisory board was designed as a semi-structured interview with a script theoretically grounded in the Social Ecological Model.[36-39] These sessions aimed to identify participants' needs related to increasing diabetes technology uptake, with the goal of developing an intervention informed by stakeholder engagement. Participants ($n = 13$) each completed one advisory board session. Two advisory board sessions were carried out in the parent's preferred language (one in English and one in Spanish) by bilingual research staff. Advisory board sessions lasted approximately 60 minutes and parents were compensated $150 for their time. All participants who completed an advisory board session also completed surveys and a focus group.

Analysis

Quantitative Data

Participant demographics were analyzed via descriptive analysis including counts and percentages, means and standard deviation, and medians and interquartile range. The relationship between experience of discrimination (measured via EDS) and the other psychosocial measures was assessed via Pearsons's correlations. Next univariate regressions evaluated the relationship between the experience of discrimination with sociodemographic and the remaining survey measures. Finally, 2 multivariate models, one evaluating the sociodemographic variables and a second evaluating the psychosocial measures were carried out. The a priori statistical plan has been published[40] and was carried out via R Studio.

Qualitative Data

The qualitative data were analyzed through inductive thematic and content analysis and codes that met thematic saturation were included. We also employed narrative analysis to identify quotes and themes that represent the experiences of individuals who hold one or more marginalized identities. The qualitative data were coded by a 5-member bilingual team and all transcripts were coded in the language that the focus groups were conducted in (i.e. Spanish focus groups were coded in Spanish) to retain linguistic context and significance. Three rounds of inductive thematic coding included: (1) initial round: each member coding 2 transcripts, (2) second round: all transcripts coded on a consolidated number of codes, and (3) third round: finalized codes that reached thematic saturation (Supplemental Fig. 1). The advisory board analysis was executed by a three-person bilingual team via inductive analysis. Transcripts were analyzed and organized using NVivo software (QRS International).

Results

Participant Characteristics

Parent and child demographic factors and youth diabetes characteristics for each study arm are presented in Table 1. Consistent with our inclusion criteria, all families included in the BEAD-Pilot study had public insurance. Although socio-demographics varied slightly by study arm, a majority of parents who participated identified as female and were caregivers to male children. Parents' age ranged from 37.2 ± 6.8 to 40.1 ± 8.5 years and children's age ranged from 7.7 ± 2.5 to 8.25 ± 2.2 years. Nearly half of the participants were Spanish-speaking (54% survey, 48% focus groups, and 39% advisory board). Over 70% of our cohort had an annual income of <$50,000. A majority (>90%) of children have started CGM and approximately half (53.6%) of the cohort had initiated insulin pumps and CGM.

Discrimination Survey Measures

Perceived discrimination was correlated with a number of psychosocial survey measures (Table 2). Perceived discrimination was inversely associated with global health ($r = -0.48$, $P = .01$) and diabetes technology acceptance ($r = -0.38$, $P = .05$), and positively associated with depression ($r = 0.64$, $P < .001$), lifetime discrimination ($r = 0.68$, $P < .001$), community discrimination ($r = 0.74$, $P < .001$). Diabetes and general technology acceptance measures were additionally correlated with global health ($r = 0.47$, $P = .01$ for both) and depression ($r = -0.54$, $P < .01$ for both).

In the univariate regression, the perceived discrimination was strongly associated with psychosocial measures but not with demographic or clinical characteristics (Supplemental Table 1). The 2 additional discrimination (PEDQ-CV and LDS) measures were strongly associated with perceived discrimination (measured by EDS), suggesting internal consistency and reliability of the cohort and survey measures: A one-point increase in perceived discrimination was associated with a 0.35-point ($P < .001$) increase in community discrimination and a 1.72-point ($P < .001$) increase in lifetime discrimination. A one-point rise in perceived discrimination was associated with a 0.45-point ($P < .001$) increase in depression and a 0.27-point ($P = .011$) drop in global well-being. In the multivariate regression model evaluating sociodemographic characteristics (Table 3), parent age was significantly associated with perceived discrimination: for each year of parents' age, the perceived discrimination increased by 0.22 points ($P = .044$). In the multivariate regression model evaluating survey measures (Table 3), depression was statistically

Table 1
Participant Characteristics

	Survey (*n* = 28)	Focus groups (*n* = 21)	Advisory board (*n* = 13)
Parent/Guardian demographics			
Age			
Mean (SD)	37.2 (6.80)	40.1 (8.50)	39.2 (7.62)
Median [Min, Max]	36.5 [23.6, 51.4]	41.0 [23.0, 57.0]	40.4 [23.6, 48.2]
Missing	1 (3.6%)	0 (0%)	1 (7.7%)
Gender			
Female	24 (85.7%)	18 (85.7%)	11 (84.6%)
Male	4 (14.3%)	3 (14.3%)	2 (15.4%)
Ethnicity + Language			
Hispanic + Spanish	15 (53.6%)	10 (47.6%)	5 (38.5%)
Non-Hispanic + English	7 (25.0%)	7 (33.3%)	1 (7.7%)
Hispanic + English	6 (21.4%)	4 (19.0%)	7 (53.8%)
Annual Income			
Less than $25,000	9 (32.1%)	2 (9.5%)	4 (30.8%)
$25,000-$49,999	11 (39.3%)	10 (47.6%)	8 (61.5%)
$50,000-$74,999	4 (14.3%)	1 (4.8%)	0 (0%)
$75,000-$99,999	2 (7.1%)	3 (14.3%)	0 (0%)
$100,000-$124,999	2 (7.1%)	5 (23.8%)	1 (7.7%)
Child demographics			
Age			
Mean (SD)	8.25 (2.22)	7.67 (2.54)	7.96 (2.27)
Median [Min, Max]	8.38 [3.79, 11.2]	7.00 [3.00, 11.0]	7.93 [3.79, 11.0]
Ethnicity			
Hispanic	19 (67.9%)	14 (66.7%)	12 (92.3%)
non-Hispanic	9 (32.1%)	7 (33.3%)	1 (7.7%)
Gender			
Female	11 (39.3%)	6 (28.6%)	4 (30.8%)
Male	17 (60.7%)	15 (71.4%)	9 (69.2%)
Glucose Management			
Glucose meter	2 (7.1%)	1 (4.8%)	1 (7.7%)
CGM	26 (92.9%)	20 (95.2%)	12 (92.3%)
Insulin delivery			
Multiple daily injections	13 (46.4%)	10 (47.6%)	3 (23.1%)
Insulin pump	15 (53.6%)	11 (52.4%)	10 (76.9%)
Technology use			
No CGM/PUMP	2 (7.1%)	1 (4.8%)	1 (7.7%)
CGM, No Pump	11 (39.3%)	10 (47.6%)	2 (15.4%)
Pump and CGM	15 (53.6%)	10 (47.6%)	10 (76.9%)

Table 2
Pearsons' Correlations Between Perceived Discrimination, Measured via Everyday Discrimination Scale, and the Remaining Survey Measures

	Correlation	*P* value
Community discrimination	**0.74**	**<.001**
Lifetime discrimination	**0.68**	**<.001**
Adverse childhood events	0.23	.24
Diabetes technology acceptance[a]	**−0.38**	**.05**
General technology acceptance[a]	−0.37	.06
PHQ-9 Depression Score[a]	**0.64**	**<.001**
Diabetes Distress Scale[a]	0.32	.11
Global Well-Being Scale[a]	**−0.48**	**.01**

Bolded values denote significance at or below $P = .05$.
[a] $n = 27$.

associated with perceived discrimination: for each one-point increase in depression, the perceived discrimination increased by 0.36 points ($P = .031$).

Experiences of Discrimination

Parents described the experience of being marginalized by race, ethnicity, immigration, insurance, language, and culture (Supplemental Table 2). The themes expressed by parents describing barriers in the provision of diabetes care can be simplified and mapped on to the social ecologic model for ease of interpretation (Fig. 1).

Many parents endorsed experiencing discrimination, consistent with the data from the quantitative results of this pilot.

> "*You probably noticed that I have an accent, right? You experience a lot of stuff when you're foreign. Sometimes when I get nervous, my English can't get out 100 percent. I get so much anxiety.*" — 37yo father
>
> "*Sí me tocó una experiencia de esas, pero trato de que no me afecte. No es algo que me fije mucho, ni nada; trato de no prestarle mucha atención, pero si es algo que uno ve. Te pasa hasta con el mismo personal médico; no nada más es en otros lados, también ahí. Siempre que me pasa a mí una experiencia así, lo que trato es de, 'Yo ya no quiero venir con esta persona; quiero que me la cambien.' Entonces, la cambian; pero sí es algo que pasa y muy, muy seguido*
>
> *Yes, I have had one of those experiences, but I try not to let it affect me. It's not something I focus on much or anything; I try not to pay much attention to it, but it's something you see. It happens even with the medical staff; it's not just in other places, it's there too. Whenever I have an experience like that, I try to say, 'I don't want to come with this person anymore; I want them to switch people.' So, they change them; but it's something that happens and very, very often.*" — 41yo mother

Table 3
Two Multivariate Regression Models Sociodemographic Data (3a) and Survey Measures (3b)

3A	β-Estimate [95% CI]	*P* value
Parent/Guardian age	0.223 [0.007, 0.439]	.044
Parent ethnicity + language		
Hispanic + Spanish	- ref -	-
Non-Hispanic + English	−0.366 [−4.97, 4.23]	.870
Hispanic + English	2.62 [−0.692, 5.92]	.115
Annual income >50k (ref <50K)	1.18 [−3.00, 5.35]	.564
Insulin pump use	−1.09 [−3.88, 1.70]	.425

3B	β-Estimate [95% CI]	*P* value
Adverse childhood events	0.254 [−0.51, 1.02]	.497
Diabetes Technology Acceptance	−0.054 [−0.649, 0.540]	.851
PHQ-9 Depression Score	0.357 [0.035, 0.678]	.031
Diabetes Distress Scale	0.661 [−0.542, 1.86]	.266
Global Well-Being Scale	−0.049 [−0.307, 0.209]	.697

As unique feature of these qualitative data, some parents described experiences of being discriminated by race and ethnicity, insurance, English-fluency, and immigration status, but did not consistently label these experiences as "discrimination" and often used proxy words to describe their experiences.

> "*I don't know if I can call it discrimination, but I do feel when we had her other doctor, it wasn't us like I wanted her to treat [child] or myself. Every time we get, we're able to see her with—everything it's normal for her body. I was like, I don't think it's more normal for her body to be over 300 every single day. I feel like maybe people think that being a Latin or Hispanic, it's normal to have diabetes.*" — 34yo mother
>
> "*Just the typical judgment of anyone on Medi-Cal or Hispanic. I think it's just that, just the stereotype of stereotyping people because of maybe what they look like or the type of insurance that they have.*" — 35yo mother

Parents also described sociocultural experiences that determine their readiness to engage in diabetes care ranging from mistrust, personal embarrassment grounded in limited health literacy, and concern about generational poverty.

> "*If the cycle of poverty that hits Americans, or just hits in general, continues, [child]'s gonna be low income. What's gonna happen when she turns 26? There are people who die because they can't afford insulin, and that's a tragedy because it's not Tylenol. It's something that a patient needs every day of their life, and they can't get it. I'm scared for [child]'s future.*" — 48yo father
>
> "*There's an embarrassment about not understanding something. Then you add on a language understanding, and it just basically makes it—it's been my experience, though I'm bilingual, that when someone's talking and you don't necessarily understand what they're saying or the words that they're saying, to just nodding your head and saying, ""Yeah. Yeah."" ... They could've said that the sky was purple, and you're like, ""Yeah, yeah,"" 'cause you don't understand it, and you're embarrassed by it…That's something that I think that, from the parents' perspective, could be an impact on the quality of care.*" — 48yo father

Families also described the additive burden of intersectional marginalized identities in supporting their child. In one example, a mother underscores the intersectional burden of language difference and health literacy resulting in suboptimal care.

> "*Para mí, noto la diferencia, bueno, mi esposo habla inglés, y cuando él a veces, me ha acompañado a alguna cita, yo noto esa diferencia…Y a veces, los intérpretes, no digo que son malos, son muy profesionales…no me puede explicar exactamente como lo está diciendo el médico.*
>
> *For me, I notice the difference. Well, my husband speaks English, and when he has sometimes accompanied me to an appointment, I notice that difference… And sometimes, the interpreters, I'm not saying they're bad, they're very professional…he can't explain it to me exactly as the doctor is saying it.*" — 45yo mother

Finally, they reported the adverse impact that adjuvant staff to diabetes care delivery, such as school partners and interpreter services.

> "*Mi hijo me puede interpretar, pero no lo dejan porque es menor de edad. Él también entiende y me dice, 'Mamá, eso no dijo el doctor.'*

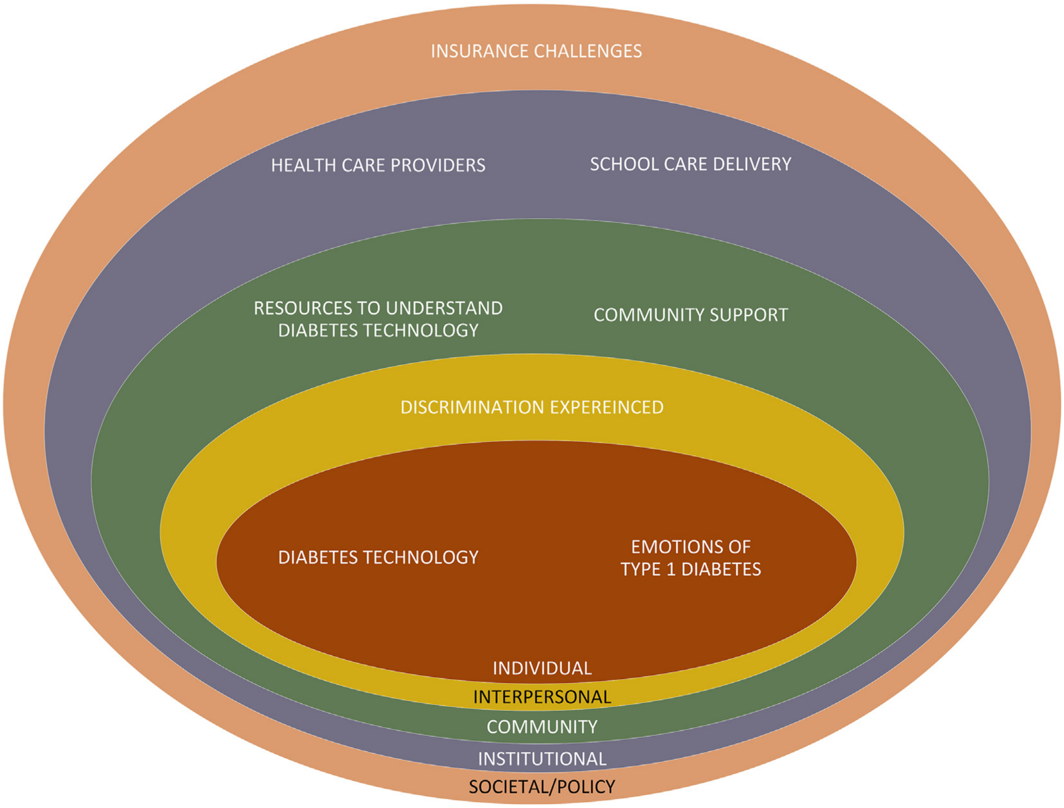

Fig. 1. The areas where the experience of discrimination occurred for parents/guardians theoretically grounded in social-ecological model. Legend: Each level of the social ecological model is depicted with a different color: red for individual, yellow for interpersonal, green for community, blue for institutional, and orange for societal/policy. The qualitative analysis codebook was finalized in 3 rounds of thematic and inductive analysis.

> *My son can interpret for me, but they don't let him because he's a minor. He also understands and tells me, 'Mom, the doctor didn't say that.*" — 51yo mother
>
> "*Un intérprete a veces está molesto; yo también, sí le he dicho que lo escucho molesto, se ve como que-o sea, hasta insultan. Ellos dicen, 'Fíjate bien la pregunta que te estoy haciendo.'*
>
> *An interpreter is sometimes upset; I am too, yes I have told him that I hear him upset, it seems like - I mean, they even insult me. They say, 'Look carefully at the question I'm asking you.'*" — 48yo mother
>
> "*Esto me preocupa mucho. Siento que no, ahorita está por empezar la escuela y todavía no han encontrado a nadie que este al cuidado de mi hijo y eso me hace sentir a mí muy triste…De por sí, casi no ha ido mi hijo a la escuela. Y siento que si fuera otra persona, porque hay muchos niños que sus padres hablan inglés y tienen ahí. Yo les digo, '¿Porque ella si va y por qué para mi hijo no tienen?'*
>
> *This worries me a lot. I feel like no, school is about to start right now and they still haven't found anyone to take care of my son and that makes me feel very sad... My son has hardly gone to school. And I feel like there was someone else, because there are many children whose parents speak English and have [school staff] there. I ask them, 'Why is she able to go and why don't they have any for my son?'*" — 48yo mother

Stakeholder-Recommended Solutions and Interventions

Needs for interventions to increase and support diabetes technology uptake varied by parent's preferred language (Fig. 2). English-speaking parents strongly preferred centering any intervention and decision-making on the child with the parents as secondary consideration. They preferred for the intervention to focus on early technology initiation and suggested a "try before you buy" approach with diabetes technologies to allow the child and the family to make an informed decision. In contrast, Spanish-speaking families preferred to have interventions and decision-making schema focused on the family unit. They also prioritized educating family members and the community on the types of diabetes and the role of diabetes technology as a priority, primarily to combat stigma and misinformation. Both groups preferred age-appropriate interventions that included peers with diabetes and requested solutions to school- and community-related challenges.

Discussion

This mixed-methods pilot study is among the first to evaluate the experience of discrimination on diabetes care and management in diverse families with T1D and public insurance. We build on prior analyses that have raised the importance of intersectional identities and the possible role of acculturation as influential in the perceptions on diabetes technology.[41] Intentional protocols allowed for excellent recruitment and retention throughout the study, limiting selection and attrition bias and increasing reliability of the results. This study begins to offer important insights into the complex interplay between perceived discrimination, psychosocial outcomes, and diabetes management from the perspective of parents and caregivers. The experience of discrimination was negatively associated with diabetes technology readiness, willingness to trust health care systems and professionals, and impacted the way

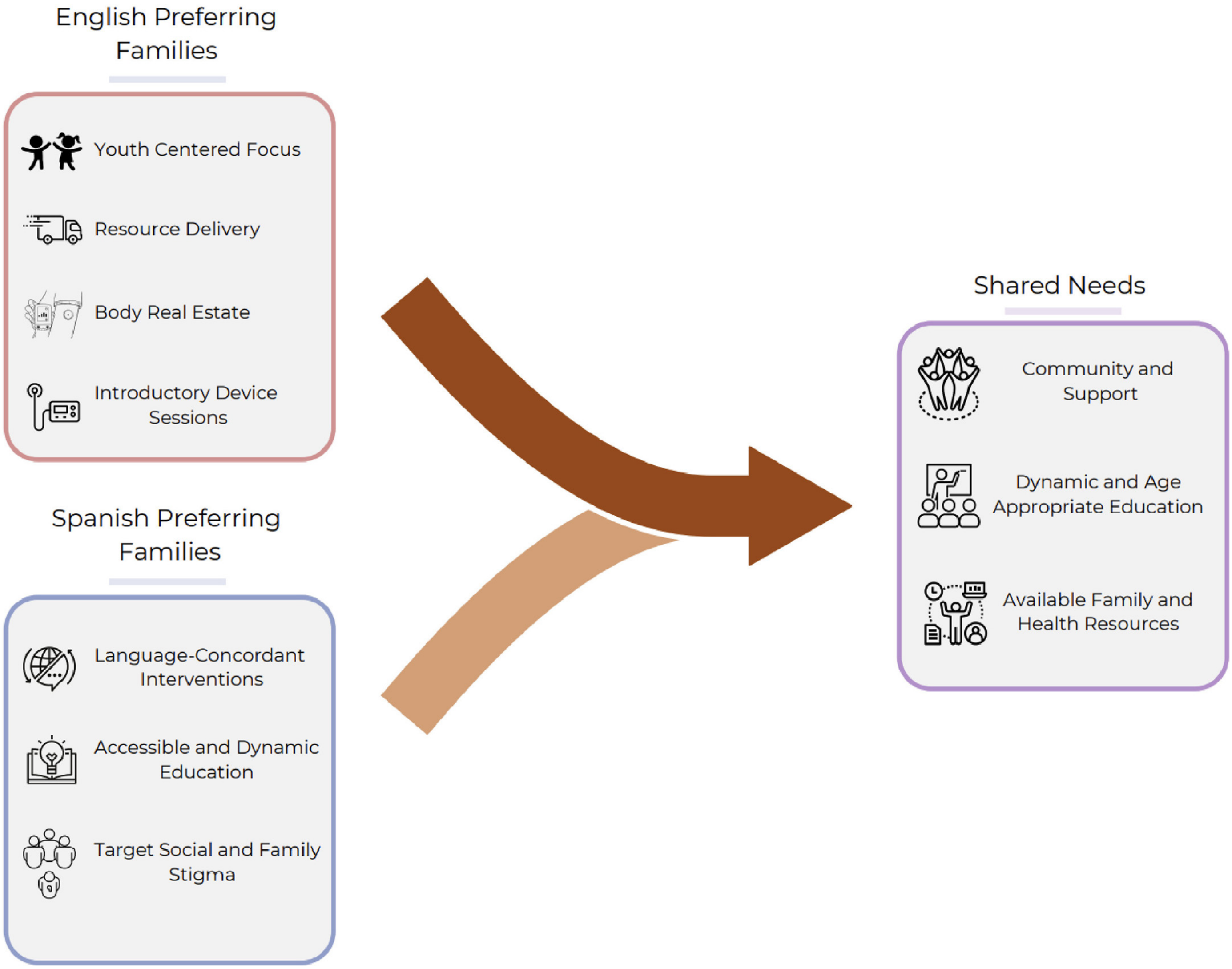

Fig. 2. Intervention need identified to increase and support diabetes technology uptake by parent's preferred language.

that families approach their child's health care. These data highlight how the experience of discrimination, both within and outside of the medical system, significantly influences diabetes health decisions. The findings from this study consistently highlight the significant role that perceived discrimination plays in shaping health choices, access to care, and the overall experience of managing diabetes as well as the broader familial and social dynamics involved.

Recent efforts focused on bridging disparities in diabetes care have centered around increasing diabetes technology uptake.[3,42-45] Many studies have demonstrated an improvement in outcomes for minoritized individuals, but not an elimination of the disparity.[4,9,10] These data offer the unaddressed impact of perceived discrimination as a potential explanation for the persistence of inequities in technology use despite improved access via changes in payer coverage and research studies aimed at increasing technology use. Although this study is among the first to clearly demonstrate the impact of perceived discrimination on psychosocial and clinical preferences, discrimination has been associated with poorer outcomes and hesitation in engagement with the health care system at large.[14-20] Despite the limitations in power in this pilot study, we were able to demonstrate strong internal consistency with the 3 measures of discrimination used in this study (everyday discrimination – the primary survey outcome in this study, community discrimination, and lifetime discrimination), thereby increasing the validity and reliability of these survey results. Additionally, we identify a strong relationship with perceived discrimination with adverse childhood events, diabetes technology acceptance, global well-being, and depression. While this study has not directly examined the impact of perceived discrimination on glycemia, studies have established both technology acceptance and the psychosocial measures are associated glycemic outcomes.[46-48]

In the qualitative data, parents and guardians had a unique perspective on the experience of discrimination – namely they did not consistently label it discrimination. While the quantitative data suggest the importance of considering perceived discrimination in T1D care and management, the qualitative data offer a roadmap for the approach. Some families preferred to use words other than discrimination to describe experiences including difference in treatment, ignorance, rudeness, or other euphemisms. Thus, researchers and clinicians can consider cultural sensitivity and vernacular when addressing experiences of discrimination to encourage open dialogue, allowing families to express their experiences in their own terms. This finding suggests that it is crucial to acknowledge and validate these experiences without imposing labels, all while remaining attuned to potential underlying issues of bias or unequal treatment that have been establish both in diabetes and the medical literature broadly.

Parents described experiencing discrimination on the basis of race, ethnicity, immigration status, language, and insurance. These multidimensional sources of discrimination often intersect, compounding the barriers to receiving equitable care. Families reported the additive burden of intersectional marginalized identities, indicating that multiple forms of discrimination—based on race, ethnicity, immigration status, and language—compound the challenges they face in supporting their child with diabetes. In a related publication from this pilot,[41] we demonstrated that the intersectional identify of ethnicity and language significantly impact technology readiness and psychosocial measures and hypothesize acculturation as a factors in this observation. Hispanic/Latino parents who spoke English endorsed higher rates of discrimination that those who spoke Spanish. These findings are mirrored in the qualitative data where many Hispanic/Latino parents who spoke English reported noting changes in treatment based on culture, accent, or insurance status. When Hispanic/Latino parents who spoke Spanish described these episodes, it was often accompanied by rationalization or exoneration of the behavior as either minimizing the impact on themselves or giving someone the benefit of the doubt. These findings are likely explained by the English-speaking families' increased acculturation and cultural assimilation that allows them correctly to recognize microaggressions, subtle transgressions, and cultural biases compared to their Spanish-speaking peers.[19,49]

Strength of our study includes the diversity of our cohort. Our cohort included predominantly low-income, predominantly Spanish-speaking families with public insurance, which has significant implications for healthcare access and diabetes management. Three quarters of our cohort identified as Hispanic and half were monolingula Spanish speakers. When evaluating the parent's annual income to county level data, the socioeconomic status of the cohort is apparent. The average median regional income was $131,185 [range $94,486 to $156,000][34] and over two third of cohort parents' annual income was less than $50,000. Finally, by nature of the inclusion criteria, all participants were publicly insured. We discuss separately the efforts and rigor that went into successfully recruiting and retaining this diverse population.[50] Due to local efforts for early CGM initiation in all youth newly diagnosed with T1D,[4,8,51] our cohort had high CGM utilization. Interestingly, and consistent with national trends,[9] this did not translate to ready adoption of insulin pumps and automated insulin delivery. The qualitative data suggest numerous barriers to diabetes technology update including the experience of discrimination, limitations of public payer coverage, and challenges of reporting technology failures to industry partners, offering a roadmap for evidence-based policy changes to support publicly insured families with T1D.

Families identified community-building as a key solution to increase diabetes technology uptake and sustained utilization. The differing priorities of the Spanish- and English-speaking families highlight the importance of tailoring diabetes technology interventions to the diverse needs of families based on language and cultural preferences. These differences suggest that effective interventions must be culturally sensitive and inclusive of both individual and familial perspectives. Clinicians and researchers could develop tailored programs that differentiate intervention strategies based on language preference, with English-speaking families benefiting from a focus on individual decision-making and early technology adoption, possibly through pilot programs or "try before you buy" trials. For Spanish-speaking families, the research community could prioritize family-centered approaches, integrating educational initiatives to combat stigma and misinformation, particularly within the broader community context. The majority of the existing literature on interventions to increase diabetes technology adoption has predominantly focused on English-speaking families. These data highlight the need for new theoretical frameworks and intervention strategies to effectively reach and engage non-English-speaking populations, particularly those who may have been historically underserved or overlooked in clinical research.

While this study provides unique insights, there are several limitations to consider. First, the exclusive focus on families with public insurance limits the generalizability of the findings and the results may not be directly generalizable to families with private insurance, who may have different experiences of access to health care services. However, there is a current gap in the literature on the unique barriers for families with public insurance. While we utilized the gold standard in translation of surveys, namely professional translation followed by back translation, the surveys were not formally validated in Spanish. Additionally, while the study focuses on parental perceptions, it does not explore the youth's perspective of discrimination or their psychosocial experiences, which could provide a more comprehensive view of the impact of discrimination on both parent and youth, both individually and as a dyad. This study does not directly explore the association of these experiences on glycemic outcomes, nor does it explore causal pathways between perceived discrimination, mental health outcomes, and diabetes management. Longitudinal studies could help clarify whether experiences of discrimination lead to worsened diabetes outcomes over time or whether interventions to reduce discrimination could improve health behaviors and technological acceptance.

This study is among the first to explore the complex relationship between perceived discrimination, psychosocial states, and diabetes management in marginalized families with T1D. The findings offer an evidence base on the impact of discrimination at multiple levels—from individual experiences to structural inequities—on diabetes care and management. By understanding and addressing the role of discrimination in diabetes care and management, health care providers can better support families in adopting and benefiting from critical diabetes technologies, ultimately improving long-term health outcomes.

Disclosure

The authors have no conflicts of interest to disclose.

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