



Barriers to Technology Use and Endocrinology Care for Underserved Communities With Type 1 Diabetes

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OBJECTIVE

Disparities in type 1 diabetes related to use of technologies like continuous glucose monitors (CGMs) and utilization of diabetes care are pronounced based on socioeconomic status (SES), race, and ethnicity. However, systematic reports of perspectives from patients in vulnerable communities regarding barriers are limited.

RESEARCH DESIGN AND METHODS

To better understand barriers, focus groups were conducted in Florida and California with adults ≥ 18 years old with type 1 diabetes with selection criteria including hospitalization for diabetic ketoacidosis, $\text{HbA}_{1c} > 9\%$, and/or receiving care at a Federally Qualified Health Center. Sixteen focus groups were conducted in English or Spanish with 86 adults (mean age 42 ± 16.2 years). Transcript themes and pre-focus group demographic survey data were analyzed. In order of frequency, barriers to diabetes technology and endocrinology care included 1) provider level (negative provider encounters), 2) system level (financial coverage), and 3) individual level (preferences).

RESULTS

Over 50% of participants had not seen an endocrinologist in the past year or were only seen once including during hospital visits. In Florida, there was less technology use overall (38% used CGMs in FL and 63% in CA; 43% used pumps in FL and 69% in CA) and significant differences in pump use by SES ($P = 0.02$ in FL; $P = 0.08$ in CA) and race/ethnicity ($P = 0.01$ in FL; $P = 0.80$ in CA). In California, there were significant differences in CGM use by race/ethnicity ($P = 0.05$ in CA; $P = 0.56$ in FL) and education level ($P = 0.02$ in CA; $P = 0.90$ in FL).

CONCLUSIONS

These findings provide novel insights into the experiences of vulnerable communities and demonstrate the need for multilevel interventions aimed at offsetting disparities in diabetes.

Health outcomes in type 1 diabetes in the U.S. are profoundly shaped by socioeconomic status (SES), race, and ethnicity from childhood and throughout the life span. People living with type 1 diabetes from low SES households face elevated risks for suboptimal glycemic control, diabetic ketoacidosis (DKA), disease

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morbidity, and mortality (1–12). Race and ethnic minority status further compound disparate outcomes for non-Hispanic Black (NHB) and Hispanic communities with type 1 diabetes as risks for living in poverty and economic deprivation are two times higher than for White communities (13). In addition, disparate outcomes in type 1 diabetes independent of SES exist based on race and ethnic minority status for multiple comorbidities and diabetes-related death (14–18). These disparities, though long-standing, are being magnified by the devastating impact of coronavirus disease 2019 (COVID-19) for underserved communities with diabetes, and the urgency of addressing health disparities and structural racism in type 1 diabetes is dire (19–24).

Two areas related to disease management in which differences in SES, race, and ethnicity might have bearing on outcomes are utilization of diabetes-related technologies like continuous glucose monitors (CGMs) and insulin pumps as well as routine endocrinology preventative visits. There are marked benefits for using CGM and insulin pumps in type 1 diabetes including improved HbA_{1c} and quality of life; however, these technologies are underutilized in the U.S., and this is especially true for low SES communities and NHBs (18,25–28). Moreover, national claims data in the U.S. demonstrate a significant portion of people with type 1 diabetes do not receive any care from an endocrinologist (29), and other research indicates pervasive underutilization of subspecialists by low SES and NHB individuals living with chronic diseases like type 1 diabetes (30).

Understanding barriers to technology use and to routine endocrinology care for underserved communities with type 1 diabetes is critical in developing targeted interventions to address disparate outcomes. Research on type 1 diabetes tends to rely solely on recruitment efforts through major endocrinology centers (31) and subsequently underrepresents communities with type 1 diabetes most in need of strategic outreach. As part of a larger needs assessment for spearheading a Project Extension for Community Health Outcomes (ECHO) type 1 diabetes outreach program (32,33), focus groups were conducted with individuals living with

type 1 diabetes with intentional recruitment efforts aimed at including the perspectives of low SES and racially diverse adults with type 1 diabetes.

RESEARCH DESIGN AND METHODS

Focus groups were conducted from fall of 2018 to spring of 2019, prior to the COVID-19 pandemic, in Florida and California with sessions offered in English and Spanish. Recruitment for focus groups included intentional efforts to have representation from adults who may not see endocrinologists on a regular basis and are often underrepresented in existing research by targeting adults with type 1 diabetes ≥18 years who 1) were hospitalized for DKA in the previous year, 2) had HbA_{1c} >9% and “no showed” to two or more consecutive endocrinology visits, or 3) were seen for primary care needs at a Federally Qualified Health Center (FQHC).

Focus group sessions lasted 1 h, followed a standard protocol script with a semistructured format, and were audio recorded. A multidisciplinary team of diabetes professionals including endocrinologists, clinical health psychologists, epidemiologists, sociologists, community health workers, and public health professionals identified focus group domains and developed questions using existing research on disparities in health outcomes and gaps in knowledge therein (Table 1). Participants completed

pre-focus group surveys and, after sessions were finished, were provided \$65 cash as incentive for their time. Pre-focus group surveys developed in REDCap were completed on tablets and contained questions about overall participant demographics, technology use, routine endocrinology care use, social support systems, and other questions related to diabetes management. The focus groups were led by trained faculty members with expertise in qualitative research. Acting as the moderator, the faculty member was supported by graduate assistants who had roles that included keeping track of time spent on each prompt to ensure balance, note taking, and focus group debriefs that followed each session. To ensure saturation goals were achieved and for balance across states, we aimed to conduct a minimum of 6 and maximum of 8 focus groups in each state (for a total of 12–16) (34,35). Given the ethical responsibilities surrounding recruiting communities facing unique health risks, at the conclusion of focus groups, participants could opt to learn more about diabetes resources available to them in their local area and were given direct contact numbers for follow-up with the faculty leading the focus group.

In total, eight sessions were held in Florida (seven in English and one in Spanish) and eight sessions in California (all in English) averaging five attendees per group. In Florida, six focus

Table 1—Focus group domains, sample questions, and prompts

| Domain | Sample Questions |
|--|--|
| Routine endocrinology care | Where do you go for care for your type 1 diabetes? |
| Barriers to endocrinology care | What are some of the challenges you face in getting the care you need for type 1 diabetes? |
| Transition from pediatric to adult endocrinology | What would you say are some of the major differences between getting diabetes care as a child and getting that same care as an adult? |
| Diabetes technology | Where do you go for information about diabetes-related technologies like blood glucose meters and insulin pumps? |
| Barriers to diabetes technology | What are some of the challenges you face in getting the diabetes technology you need for type 1 diabetes? |
| Resources for T1D | If you could make a wish list for things that would be the most helpful in allowing you to do better with type 1 diabetes, what would be on that list? |
| Needs of communities with T1D | Is there any additional feedback you would like to provide about the needs of adults with type 1 diabetes in the state of [Florida/California]? |

T1D, type 1 diabetes.

groups were filled using call lists for recruitment of people with type 1 diabetes who had been hospitalized for DKA in the past year and/or who had HbA_{1c} values >9% and “no showed” to two or more consecutive endocrinology visits. The other two focus groups in Florida were filled through recruitment at a rural FQHC and a nonrural FQHC. In California, six focus groups were filled using recruitment at FQHCs in rural and nonrural areas, and two were filled with participants from a local conference for people with type 1 diabetes.

Basic demographic characteristics were summarized by site and stratified by key themes of interest: technology use and endocrinology care. Frequencies and percentages are presented for categorical data and means \pm SDs for continuous variables. Differences in technology use (pumps and CGMs) by race/ethnicity, SES, and level of education were evaluated using Fisher exact tests to accommodate small sample sizes. Cochran-Mantel-Haenszel nonzero correlation tests were used to assess for trends of increasing frequencies of endocrinology visits by increasing levels of SES and level of education; race/ethnicity testing was not conducted due to sparsity of data. All

data management and analysis were conducted using SAS 9.4 (SAS Institute, Cary, NC). Statistical significance was evaluated with a predetermined level of significance of $\alpha = 0.05$.

Focus group audio recordings were transcribed by Datagain, an external qualitative analysis vendor, and a thematic analysis was conducted using two coders using a method of constant comparison associated with grounded theory (36). In addition to the external thematic analysis conducted by Datagain, subsequent content analysis (36) was conducted by two coders of all quotes from participants related to barriers to technology use and routine endocrinology care. The Social Ecological Model (37) (Fig. 1) was used as a framework for the coding scheme. The Social Ecological Model allows for identification of barriers at multiple levels, including individual, interpersonal, community, and societal/policy level (37). The Social Ecological Model provides an ideal scaffolding in disparities research, allowing barriers to be examined at different levels, and, subsequently, facilitates the development of targeted interventions accordingly (38). We adapted the Social Ecological Model in

a coding schematic with categories that included: 1) individual-level barriers related to personal values, beliefs, and preferences; 2) provider-level barriers related to interactions with health care providers or clinic protocols; and 3) system/policy-level barriers related to insurance or financial coverage. The κ statistic, computed in SAS, was used to evaluate the interrater reliability for identification of the primary barrier themes related to access and use for each endocrinology and technology. Raters were evaluated on their agreement about the presence or absence of selected themes across the transcripts. κ coefficients were evaluated using guidance by Landis and Koch, in which the strength of the κ coefficients of agreement is 0.01–0.20, slight; 0.21–0.40, fair; 0.41–0.60, moderate; 0.61–0.80, substantial; and 0.81–1.00, almost perfect (39).

RESULTS

Findings From Pre-Focus Group Surveys

A total of $n = 86$ adults (51 in FL and 35 in CA) with type 1 diabetes participated in focus groups (see Table 2 for participant demographics). Almost half

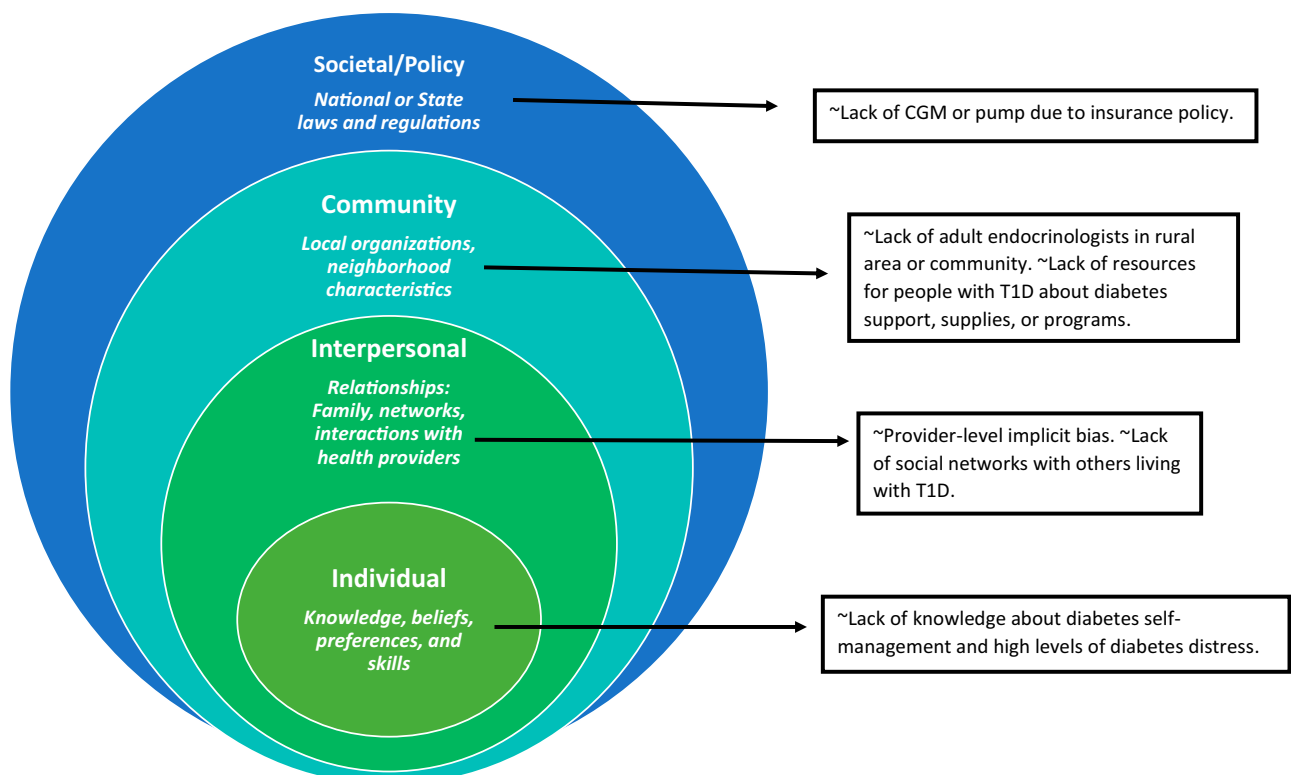


Figure 1—Social Ecological Model and multilayered barriers for underserved communities.

Table 2—Focus group demographics and technology use

| | Overall | Florida | | | | California | | | | |
|---|------------------------------|-----------|-----------|------------------------------|-----------|------------|------------------------------|-----------|-----------|---------------|
| | | FL | Yes | No | CA | Yes | No | CA | Yes | No |
| <i>N</i> participants | 86 | 51 | 22 (43.1) | 29 (56.9) | 35 | 24 (68.6) | 11 (31.4) | 35 | 22 (62.9) | 13 (37.1) |
| Current age, years | 42.0 ± 16.2 | | | 40.9 ± 16.7 | | | 43.5 ± 15.4 | | | |
| Age at T1D diagnosis, years | 20.5 ± 14.1 (<i>n</i> = 84) | | | 21.2 ± 14.5 (<i>n</i> = 51) | | | 19.5 ± 13.6 (<i>n</i> = 33) | | | |
| Technology use | Overall | FL | Yes | No | CA | Yes | No | CA | Yes | No |
| Race/ethnicity | | | | | | | | | | |
| NHW | 55 (64.0) | 32 (62.8) | 17 (77.3) | 15 (51.7) | 23 (65.7) | 16 (66.7) | 7 (63.6) | 18 (81.8) | 5 (38.5) | |
| Black/African American | 11 (12.8) | 10 (19.6) | — | 10 (34.5) | 1 (2.9) | 1 (4.2) | — | — | — | 1 (7.7) |
| Hispanic or Latino | 11 (12.8) | 7 (13.7) | 4 (18.2) | 3 (10.3) | 4 (11.4) | 3 (12.5) | 1 (9.1) | 2 (9.1) | 2 (15.4) | |
| Asian | 2 (2.3) | — | — | — | 2 (5.7) | 1 (4.2) | 1 (9.1) | 1 (4.6) | 1 (7.7) | |
| American Indian/Alaska Native | 1 (1.2) | — | — | — | 1 (2.9) | — | 1 (9.1) | — | — | 1 (7.7) |
| More than one race/ethnicity | 6 (7.0) | 2 (3.9) | 1 (4.6) | 1 (3.5) | 4 (11.4) | 3 (12.5) | 1 (9.1) | 1 (4.6) | 3 (23.1) | |
| Fisher exact <i>P</i> value | | | | 0.0068 | | | 0.7971 | | | 0.0490 |
| Estimated annual household income (SES) | | | | | | | | | | |
| <\$25,000 | 31 (36.1) | 19 (37.3) | 4 (18.2) | 15 (51.7) | 12 (34.3) | 10 (41.7) | 2 (18.2) | 7 (31.8) | 5 (38.5) | |
| \$25,000 to <\$35,000 | 10 (11.6) | 5 (9.8) | 2 (9.1) | 3 (10.3) | 5 (14.3) | 3 (12.5) | 2 (18.2) | 2 (9.1) | 3 (23.1) | |
| \$35,000 to <\$50,000 | 10 (11.6) | 7 (13.7) | 2 (9.1) | 5 (17.2) | 3 (8.6) | — | 3 (27.3) | 1 (4.6) | 2 (15.4) | |
| \$50,000 to <\$75,000 | 12 (14.0) | 10 (19.6) | 6 (27.3) | 4 (13.8) | 2 (5.7) | 1 (4.2) | 1 (9.1) | 1 (4.6) | 1 (7.7) | |
| \$75,000 to <\$200,000 | 12 (14.0) | 5 (9.8) | 3 (13.6) | 2 (6.9) | 7 (20.0) | 6 (25.0) | 1 (9.1) | 6 (27.3) | 1 (7.7) | |
| ≥\$200,000 | 4 (4.7) | — | — | — | 4 (11.4) | 2 (8.3) | 2 (18.2) | 3 (13.6) | 1 (7.7) | |
| Do not know or wish to provide | 7 (8.1) | 5 (9.8) | 5 (22.7) | — | 2 (5.7) | 2 (8.3) | — | 2 (9.1) | — | |
| Fisher exact <i>P</i> value | | | | 0.0183 | | | 0.6869 | | 0.5428 | |
| Highest level of education | | | | | | | | | | |
| Some high school, no diploma | 5 (5.8) | 4 (7.8) | 1 (4.6) | 3 (10.3) | 1 (2.9) | 1 (4.2) | — | 1 (4.6) | — | |
| High school diploma or GED | 20 (23.3) | 17 (33.3) | 5 (22.7) | 12 (41.4) | 3 (8.6) | 2 (8.3) | 1 (9.1) | 2 (9.1) | 1 (7.7) | |
| Some college, no degree | 20 (23.3) | 10 (19.6) | 4 (18.2) | 6 (20.7) | 10 (28.6) | 5 (20.8) | 5 (45.5) | 3 (13.6) | 7 (53.9) | |
| Associates degree | 8 (9.3) | 5 (9.8) | 3 (13.6) | 2 (6.9) | 3 (8.6) | 3 (12.5) | — | 1 (4.6) | 2 (15.4) | |
| Bachelor's degree | 14 (16.3) | 8 (15.7) | 5 (22.7) | 3 (10.3) | 6 (17.1) | 5 (20.8) | 1 (9.1) | 6 (27.3) | — | |
| Master's degree | 13 (15.1) | 5 (9.8) | 4 (18.2) | 1 (3.5) | 8 (22.9) | 6 (25.0) | 2 (18.2) | 7 (31.8) | 1 (7.7) | |
| Professional degree | — | — | — | — | — | — | — | — | — | |
| Doctoral degree | 4 (4.7) | 1 (2.0) | — | 1 (3.5) | 3 (8.6) | 2 (8.3) | 1 (9.1) | 2 (9.1) | 1 (7.7) | |
| Do not know or wish to provide | 2 (2.3) | 1 (2.0) | — | 1 (3.5) | 1 (2.9) | — | 1 (9.1) | — | 1 (7.7) | |
| Fisher exact <i>P</i> value | | | | 0.3508 | | | 0.8617 | | 0.5874 | 0.0211 |

For continuous variables, mean ± SD are presented and for categorical variables, column percentages are presented. Boldface *P* values indicate statistical significance. GED, General Educational Development; T1D, type 1 diabetes. †CGM use in Florida: *n* missing = 1; *n* = 50 for all CGM use demographic columns.

of the participants in both states had total annual household incomes of <\$35,000/year (47% in FL and 49% in CA), an overrepresentation of this demographic group, as only 38% of households fall in this income bracket in the U.S. (40). However, education levels were lower for participants in Florida (41% of FL participants had a high school degree or less; 11.5% of CA participants had a high school degree or less). In both states, >60% of participants were non-Hispanic White (NHW), and Florida had the greatest number of NHB and Hispanic participants.

Surveys completed prior to focus groups revealed low levels of technology use for Florida's participants: 38% used CGMs in Florida compared with 63% in California and 43% used pumps in Florida versus 69% in California (Table 3). There were also significant differences in pump use by SES ($P = 0.02$ in Florida; $P = 0.08$ in California) and race/ethnicity ($P = 0.01$ in Florida; $P = 0.80$ in California). In California, there were significant differences in CGM use by race/ethnicity ($P = 0.05$ in California; $P = 0.56$ in Florida) and education level ($P = 0.02$ in California; $P = 0.90$ in Florida). Thus, while rates of technology use were higher in California, there were statistically significant differences based on race and ethnic minority status and education.

In Florida, 16% reported never seeing an endocrinologist in the past year, and 22% had seen an endocrinologist only one time. In California, 51% had never seen an endocrinologist in the past year, and 23% only saw an endocrinologist once. Despite recruitment methods being heavily focused on those hospitalized with DKA in Florida, and this metric including seeing an endocrinologist during hospitalizations, the number of participants meeting recommendations to see an endocrinologist four times a year for routine preventive care was still very low (20% in Florida and 11% in California). In Florida, evidence suggests there was an association between SES and more visits with an endocrinologist as measured by total household income ($P = 0.04$). There was not a statistically significant or clear pattern in the distribution of frequency of visits and increasing education in California.

Findings From Focus Group Transcripts: Barriers to Technology Use and Endocrinology Care

The first step in thematic analysis was conducted by Datagain and identified two overall themes related to barriers for participants: 1) unclear qualifying criteria for receiving a CGM or pump and 2) endocrinologists are judgmental and lack understanding. To better differentiate these themes, a secondary content analysis (36) was subsequently conducted using all answers related to barriers for technology use and endocrinology use (a total of 28,496 words from focus group transcripts) using an adaptation of the Social Ecological Model and multilayered factors that impact health outcomes. Two coders identified if participants were referring to 1) individual-level barriers related to personal values, beliefs, and preferences, 2) provider-level barriers related to interactions with health care providers or clinic protocols, and 3) system/policy-level barriers related to insurance or financial coverage. In order of frequency, the barriers were identified as provider-level (16,209 words used in 125 separate accounts), system-level (10,460 words used in 84 separate accounts), and individual-level (1,827 words used in 16 separate accounts) with an interrater reliability score of 0.80 (95% CI 0.72, 0.89) for endocrine themes and 0.86 (95% CI 0.73, 0.99) for technology themes, indicating strong agreement in identification of major themes between coders.

The most pervasively identified barrier for technology use and endocrinology use was provider-level barriers (Table 4). For technology use, participants repeatedly listed system-level barriers related to financial coverage or insurance as preventing them from using or continuing to use technologies like CGM. Participants noted the "living hell" and "bureaucracy nightmare" of being unable to obtain coverage for desired technologies: a Florida participant shared: "When I was a child, I would be eligible for an insulin pump ... but I can't get this covered as an adult. I've had no such luck." In California, another participant noted: "I've come into an issue with insurance and I don't know how to get a pump. I've been trying to get a pump and a CGM for like 4 years." In other instances, individual-level barriers were described, like difficulty

wearing a CGM or pump in jobs in which participants sweated excessively or completed manual labor. "I am a waitress and mom, and the pump was just so much to carry that around" or "I sweat constantly as a construction worker, and it just doesn't work."

Yet, the most commonly identified barriers to technology use were at the provider level and related to information exchanged in face-to-face visits. This is referred to as interpersonal barriers in the Social Ecological Model (37). Participants in both states chronicled similar narratives of seeking technologies like CGM to improve their diabetes management but being overtly blocked or discouraged by endocrinologists who conveyed a range of discouraging feedback. The reasons given to participants as to why they could not pursue CGM or pump frequently cited "poor control" ($HbA_{1c} >9\%$) or an implication that a technology was too difficult for the participant to handle. Participants noted the irony of needing and wanting to improve glycemic control but being blocked from a technology based on elevated HbA_{1c} levels. Examples of quotes that demonstrate this are as follows:

"I have had my [endocrinologist] recommend that I get my A1C down below 7 before they will even attempt to let me use any kind of device [pump or CGM]. With my lifestyle and work and everything, the way it is, it's super hard to manage the diabetes as it is, which personally I think that would be a tool that would help me out a lot."—Florida Focus Group Participant

"I tried to get on the pump, and he [endocrinologist] told me I needed to lose weight and the only way I was going to get on a pump was to lose weight and to be in a lot of control."—California Focus Group Participant

Provider-level barriers evoked through interpersonal encounters were also the most commonly cited barriers for utilization of routine endocrinology visits. In recalling the transition from pediatric endocrinology to adult endocrinology, participants noted a stark contrast from warm and highly engaged pediatric endocrinologists to the world of adult

Table 3—Pre-focus group surveys: visits to endocrinologists

| | Florida | | | | | California | | | | | |
|---|----------------------|-----------|-----------|----------|---------------|----------------------|-----------|-----------|----------|----------|--------------|
| | 51 | | | | | 35 | | | | | |
| | Overall | One | Two | Three | Four or more | Overall | Never | One | Two | Three | Four or more |
| <i>N</i> participants responding* | 51 | | | | | 35 | | | | | |
| Age, years | 40.9 ± 16.7 (n = 51) | | | | | 43.5 ± 15.4 (n = 35) | | | | | |
| Age at T1D diagnosis, years | 21.2 ± 14.5 (n = 51) | | | | | 19.5 ± 13.6 (n = 33) | | | | | |
| How many times in the past year did you visit an endocrinologist? | Overall | One | Two | Three | Four or more | Overall | Never | One | Two | Three | Four or more |
| | 51 | 11 (21.6) | 13 (25.5) | 9 (17.7) | 10 (19.6) | 35 | 18 (51.4) | 8 (22.9) | 2 (5.7) | 3 (8.6) | 4 (11.4) |
| Race/ethnicity | | | | | | | | | | | |
| NHW | 32 (62.8) | 7 (21.9) | 7 (21.9) | 5 (15.6) | 7 (21.9) | 23 (65.7) | 14 (60.9) | 6 (26.1) | 1 (4.4) | 1 (4.4) | 1 (4.4) |
| Black/African American | 10 (19.6) | 1 (10.0) | 5 (50.0) | 2 (20.0) | 1 (10.0) | 1 (2.9) | — | 1 (100.0) | — | — | — |
| Hispanic or Latino | 7 (13.7) | 1 (14.3) | 2 (28.6) | 2 (28.6) | 2 (28.6) | 4 (11.4) | 2 (50.0) | — | — | — | 2 (50.0) |
| Asian | — | — | — | — | — | 2 (5.7) | — | 1 (50.0) | — | 1 (50.0) | — |
| American Indian/Alaska Native | — | — | — | — | — | 1 (2.9) | 1 (100.0) | — | — | — | — |
| More than one race/ethnicity | 2 (3.9) | 1 (50.0) | 1 (50.0) | — | — | 4 (11.4) | 1 (25.0) | — | 1 (25.0) | 1 (25.0) | 1 (25.0) |
| Estimated annual household income (SES) | | | | | | | | | | | |
| <\$25,000 | 19 (37.3) | 2 (10.5) | 6 (31.6) | 3 (15.8) | 2 (10.5) | 12 (34.3) | 7 (58.3) | 1 (8.3) | — | 1 (8.3) | 3 (25.0) |
| \$25,000 to <\$35,000 | 5 (9.8) | 1 (20.0) | — | 2 (40.0) | — | 5 (14.3) | 3 (60.0) | 1 (20.0) | 1 (20.0) | — | — |
| \$35,000 to <\$50,000 | 7 (13.7) | 1 (14.3) | 3 (42.9) | 1 (14.3) | 2 (28.6) | 3 (8.6) | 2 (66.7) | — | — | — | 1 (33.3) |
| \$50,000 to <\$75,000 | 10 (19.6) | — | 3 (30.0) | 2 (20.0) | 3 (30.0) | 2 (5.7) | 1 (50.0) | 1 (50.0) | — | — | — |
| \$75,000 to <\$200,000 | 5 (9.8) | — | 1 (20.0) | 1 (20.0) | 2 (40.0) | 7 (20.0) | 4 (57.1) | 2 (28.6) | — | 1 (14.3) | — |
| ≥\$200,000 | — | — | — | — | — | 4 (11.4) | 1 (25.0) | 2 (50.0) | — | 1 (25.0) | — |
| Do not know or wish to provide | 5 (9.8) | — | 3 (60.0) | 1 (20.0) | 1 (20.0) | 2 (5.7) | — | 1 (50.0) | 1 (50.0) | — | — |
| CMH nonzero correlation <i>P</i> value | | | | | 0.0399 | | | | | | 0.6135 |
| Highest level of education | | | | | | | | | | | |
| Some high school, no diploma | 4 (7.8) | 3 (75.0) | 1 (25.0) | — | — | 1 (2.9) | 1 (100.0) | — | — | — | — |
| High school diploma or GED | 17 (33.3) | 1 (5.9) | 4 (23.5) | 8 (47.1) | 3 (17.7) | 3 (8.6) | 2 (66.7) | — | — | 1 (33.3) | — |
| Some college, no degree | 10 (19.6) | 1 (10.0) | 4 (40.0) | 1 (10.0) | — | 10 (28.6) | 7 (70.0) | — | — | — | 3 (30.0) |
| Associates degree | 5 (9.8) | — | — | 2 (40.0) | 3 (60.0) | 3 (8.6) | 1 (33.3) | 1 (33.3) | — | 1 (33.3) | — |
| Bachelor's degree | 8 (15.7) | 1 (12.5) | 2 (25.0) | 1 (12.5) | 3 (37.5) | 6 (17.1) | — | 4 (66.7) | 1 (16.7) | — | 1 (16.7) |
| Master's degree | 5 (9.8) | — | 1 (20.0) | 2 (40.0) | 1 (20.0) | 8 (22.9) | 4 (50.0) | 3 (37.5) | 1 (12.5) | — | — |
| Doctoral degree | 1 (2.0) | 1 (100.0) | — | — | — | 3 (8.6) | 2 (66.7) | — | — | 1 (33.3) | — |
| Do not know or wish to provide | 1 (2.0) | 1 (100.0) | — | — | — | 1 (2.9) | 1 (100.0) | — | — | — | — |
| CMH nonzero correlation <i>P</i> value | | | | | 0.1268 | | | | | | 0.8764 |

Data are row percentages within racial/ethnic, SES, and education categories; statistics calculated excluding those who indicated "Do not know or wish to provide" for SES and education. Column percentage presented within "Overall" column to reflect overall distributions within demographic categories per site. CMH, Cochran-Mantel-Haenszel; GED, general educational development. *In Florida, 56 participants were surveyed, and 51 indicated the frequency of visits to an endocrinologist. In California, 36 people were surveyed, and 35 responded to indicate the frequency of visits to an endocrinologist.

Table 4—Quotes about provider-level technology and endocrinology barriers

| State | Quote (technology, interpersonal interactions) |
|-------|---|
| FL | Every time they [endocrinologist] say you got to give them 3 months of record if you want an insulin pump or something like that. I give them 3 months of record. They go, "You are doing so well with your injection and stuff. You don't need it." That is not listening to what I need to maintain where I am at. Right now, my A1C level is at 11.5. I take two different kinds of insulin. I take them every day, but my A1C ain't going [down]. They don't listen to you when you say, 'Give me a monitor that every 5 or 10 minutes shows you what your blood sugar is so if you need an extra unit of insulin you can take it instead of having your blood sugar go way up here,' and then you always take 5 or 6 units and it brings you down so quick you are out. You are almost in diabetic coma. I done been in a diabetic coma three times this year because they won't give me what I need to maintain. |
| FL | I have had my [endocrinologist] recommend that I get my A1C down below 7 before they will even attempt to let me use any kind of device [pump or CGM]. With my lifestyle and work and everything, the way it is, it's super hard to manage the diabetes as it is, which personally I think that would be a tool that would help me out a lot. A lot of times I'm in places where I don't have access to go buy a coke or carry stuff with me that isn't going to get ruined in heat or anything like that. Yeah, it's just basically been denied unless I can get my A1C down below 7. |
| FL | Here, and the endocrinologist, when I used to go to an endocrinologist, which has been 3 or 4 years since I've actually been to an endocrinologist, you know, it was the same thing back then. You bring your blood sugars in, they sit and lecture you. And I've heard all the new technology coming out, don't get me wrong, I was on insulin shots until probably last year, and that stuff, nobody else, I haven't even heard of being on insulin shots, everybody else went to the [pump]. They just weren't giving me the care I need to get advanced stuff [pumps]. Like I could have the [pump] and those kind of insulins. It's just not giving me the information I know I need, and complaining about it the whole time there, [telling me] you're going to die, your kids are going to not have a mama. I mean, literally, it's all crap, I don't need it. |
| FL | TV's the only place I find out about anything, you know? Then I ask my doctor, and they go, well I've never heard of that before. I'm like, well, it was on TV. Yeah, it's aggravating. I have nowhere to go to find out what I can, because I am an expert on me, I know what works and what don't work. But I don't know the new technology that's come out there. |
| FL | I would prefer insulin pump because I think that would help me control my diabetes, but since I've been deemed uncontrollable [by endocrinologist], chance is that I can't get one. |
| FL | But, also, I see it come to now ... being denied to have a pump because I am noncompliant. It is not that I try to ever be noncompliant. It is the fact that I have nine kids and I am busy and trying to regimen it with ... to new G6, the G5, which works, but again, what I have to do for a job ... being denied ... telling me I can't because I am not compliant. I only see you twice a year ... How many years do I have to be noncompliant or in the hospital before I can get to where it is going to help me? |
| CA | I tried to get on the pump and [endocrinologist] told me I needed to lose weight, and the only way I was going to get on a pump was to lose weight and to be in a lot of control. And so that put me in a lot of like downward spiral and not happy with the whole diabetes thing. To be in control. He told me the only way you can be on a pump—like, it was a requirement. The only way you can be on a pump is to be control and your blood glucose needs to be this and like 120. Like, I had to be at 120, that was it. That number is like engrained in my head because of what he said I have to be a 120, yeah, yeah. Yeah, so I—he probably know, but that was a big impact to me. And so, 5 years ago, I was like, I had a lot of lows, bad lows. Bad, bad lows, like driving bad and I think it's time to figure this out. |
| CA | A couple of years ago, this is 3 or 4 years ago, I got called in—my endocrinologist called me in and said, 'You're using way too many blood glucose strips.' And I totally understand because the people are selling these, that's a problem. But I said, 'because I was using about 12 to 14 a day, right?' I was just testing my ... that's before I had a CGM, and she apologized and she said, 'I'm so sorry, I just ... I was told I had to bring you in here and just tell you that you're using too many.' But after that when I, you know, a year or two later when I went and asked for a CGM, she said, well, this is her exact words. She said, 'Well, are you too lazy to test your blood sugars, is that—', she said those exact words. 'Are you too lazy to test your blood glucose?' |
| CA | So when I started seeing an endocrinologist, I was bouncing around to the five that were available in my network, and I didn't like any of them. I found out that one of them wanted me on a certain kind of pump. He wanted me on one of the pumps with the tubes, and I didn't want to be on that, so I kept doing shots. I realized I wanted to be on the Omnipod after doing some independent reading. I fought for 2 years to get on the Omnipod. Two years, not with the endocrinologist help was I able to get a prescription for the Omnipod, because I found the primary care physician who I was working with who wrote the appropriate letters and filled in the appropriate paperwork and checked the appropriate boxes and supported me. |
| CA | So, yeah, I went to—at that time I went to my endocrinologist, and there's only two at this [MCO], and I guess I found the wrong one. But she said, 'Well, we just don't let you do that.' You have to go through this whole ... you have to prove that you need one, and the, there was a bunch of different criteria. So you've got to wear this for a week and, and I met the criteria, because I got really low at night, and that was one of the criteria. So I went back to her and she said, 'Oh, sorry, we're just not going to approve it.' So then I got upset, I got really mad, because my nephew had one and I really wanted it, so I went to a different [MCO] and I got it within 5 minutes. They just prescribed it, so, it was really frustrating. I had to go to this whole Diabetes Center and get all set up with it and see a demonstration of all the different CGMs, and that took half a day. So, yeah, yeah. |

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endocrinology in which they described "being completely on [their] own." In both states, participants frequently described clinical encounters with adult

endocrinologists in which they experienced being demeaned, "belittled," and misunderstood as a person living with type 1 diabetes. A Florida participant

noted: "I feel like sometimes I don't even want to go to the doctor because I'm getting a lecture. I'm getting like in trouble. I feel like a little kid who's going

Table 4—Continued

| State | Quote (endocrinologist, interpersonal interactions) |
|-------|--|
| FL | My doctor here is ... well, when I was a child, my doctor was [pediatric endocrinologist] and she is the best that I know. Switching ... when I turned 18, they tried to ... like she is saying ... tried to keep me in for as long as they could. Once I had to get switched over to [adult endocrinology], it is different. The doctors will come and talk to you and then that is pretty much it. They will be like, 'You have got to take it serious. I will give you a new sliding scale. Here is how you do it. I will see you in 3 months' is basically how they treat you. When you are a kid, they explain things. Then, when you are at the doctor when you are a kid, they take you to the nutritionist, they give you different types of papers with listings of foods and snacks and low carbohydrates and things like that. When you switch over to adult, they don't educate you anymore. |
| FL | I am here 4 years ago from Michigan. I was seen at University of Michigan by a fellow ... I don't remember ... but, by a resident. I don't remember the overseeing doctor's name anymore. But, I was under much better care up there. They seemed to really have a want and a caring heart for their patients. Whereas, here, even though I have established a relationship with my endocrinologist, it is not the same. It is not as personal. It is harder to control my care the same way when it is not as personal because you don't have somebody that you want to be held accountable to. And then, it is even worse. |
| FL | I think for me the human aspect of this disease. When I am seeing an endocrinologist, I feel a lot of anxiety around ... I am hearing a lot of fear and negatives as opposed to what I might be doing right. I kind of prep myself to go in for what feels kind of like an attack when I am looking for help and support. That is not always the experience. It is just I feel like in my 28 years of living with this disease, there has been a spectrum of doctors and a range of communication patterns, like he was talking about where coming in, it is very vulnerable and recognizing that this is a human being and we are more than a disease and we are more than numbers and good and bad, using those judgement words can be really tough for me. |
| FL | I would say another thing is the inconsistency between endocrinologists. One doctor tells you one thing and then you are operating under that. Then, you need to go to another doctor like, 'No, no. You have to do this. You don't have to do that.' It just feels like, 'Does anybody know anything about this?' I feel like it is such a fluid disease and it is kind of frustrating. |
| FL | I think it did become sort of magnified because I was already accountable for so many things about my daily life that I would come in to see an endocrinologist seeking support and seeing help to manage this huge disease and I would hear, 'This is what you are doing wrong. You need to do this better.' There was never really a 'Wow! You are doing this and here is an opportunity.' |
| CA | I have been seen by some world-renowned endocrinologists in my lifetime and I'm now being seen by somebody who's not even a licensed physician. In my experience, the qualifier is not the license or the extensive medical background, it has to do with some basic assumptions about the patients that they deal with. Yes, there are problems in getting good care as a type 1 diabetic. The problem with that is getting a care provider who will provide the kind of information and support and assistance that you need who is both competent and who assumes that you, the patient, are competent. Almost every physician that I have ever met, whether they are endocrinologists or GPs, operate under the assumption that all diabetics are doomed to start with and that we are unreliable, we cannot be counted on to participate in our own care, nor can we be counted upon to exercise the management skills or the discipline necessary to handle our own medication of insulin, any oral meds, or an adequate diet. |
| CA | It's the same that the doctors always thought they knew more. They didn't know how ... I could tell them how I felt and they thought they knew more than I, but I would explain this is how I feel. But they knew—they acted like they knew more about the diabetes than I do, but basically, we knew more about our own body, about how our diabetes is, but they want to tell us otherwise. You know, do you understand what I'm saying? Basically, they kind of talk to you like ... belittling you that you don't know what you're doing with your diabetes or something ... kind of something like that. |
| CA | So I've dealt with a lot of [health care providers], and they tend to think that they know a lot more than they do about type 1 diabetes, and it's frustrating. That's true throughout every level. I mean, I've met endocrinologists who don't know anything about type 1 diabetes. There's no guarantees based on the degree that their knowledge base is the same as mine. But yeah, it is a constant, never-ending education, I guess. I only have energy for so much, so there are a lot of comments that I just let fly past, because I'm like, 'Okay, I'm not focused on that. You don't know what you're talking about, but I can't educate you in this moment. We need to be discussing something else that I actually care about at this moment.' |
| CA | Even at my diagnosis when I was still under my parents' insurance and I also have a private employer insurance at the time for myself, so I had double coverage, but the endocrinologist that came to see me in the hospital said some things that really stuck with me that were inaccurate and very unhelpful to someone who's in ICU and coming out of DKA, like, you'll lose your feet. You'll never wear high heels again; you'll lose your driver's license. That should basically—I didn't know that I was really diagnosed or—even if she thought I was 'noncompliant,' still inappropriate thing to say. And those things have stuck with me for sure and I was diagnosed at a hospital right next to a [well-known Children's Hospital] where they have a well-known endocrinology clinic and yet, while I was in the hospital, they told me that they didn't have any CDEs available. Everyone that they sent in to talk to me, talked to me about like, type 2 diabetes. Like, how I needed to lose weight and exercise even though I couldn't ... I had already lost so much weight. There was no weight left for me to lose. So, there's definitely a lack of understanding and then I started seeing a different endocrinologist when I got out of the hospital and that went okay, I guess. It still felt like I had to do a lot of my own learning. |
| CA | The charts of just the data downloaded from the pump is—I mean it's what I've seen, you know, my endocrinologist based a lot of her recommendations on, and it's such an incomplete source of information. And so, I think it's ... for that reason I tend to, you know, not adopt her recommendations because I know that it's missing out on a lot of other pieces of information that I know because I lived through. And she doesn't, like she might see on the chart like oh, your blood glucose is trending low 2 hours after lunch on this day, so you need to change the settings. I'm like, 'Well, no, it's trending low because I end up having to carry a lot of boxes up the stairs that day at work. And so it doesn't need—I don't need to overhaul my settings. But maybe instead I can—yeah, so I think having a doctor that's willing to like understand my behaviors and sort of fill in the gaps in the data, and then also that asks the questions about like what's going on in your life, what would you like to do, what's most important?' |

CDE, certified diabetes educator; ICU, intensive care unit; MCO, managed care organization.

to the principal.” California participants described similar experiences noting “endocrinologists are more like the judges...and the visits I’m on trial,” and “basically, they kind of talk to you like ...belittling you that you don’t know what you’re doing with your diabetes or something.”

Moreover, participants did not see the value in the visit with adult endocrinologists as a mechanism of improving their overall health, and, thus, many simply stopped going. Participants also noted frustrations over protocols at endocrinology offices that did not allow them to schedule appointments as needs arise or in ways that accommodate working-class communities. One California focus group participant noted:

“And usually the [endocrinology] appointments are like 10 AM, 11 AM, or 2 PM. So, I end up having to take half the day off work to go to the appointment, and then also find time for the blood work and everything. So that was one ... another, like, reason why I went the 2 years without seeing my endocrinologist was there was just too much going on, and it didn’t seem like a valuable enough resource to me to make it work within my schedule.”

—California Focus Group Participant

Additionally, distance was identified as a barrier to utilization of endocrinology care in the focus groups that took place in rural FQHC settings. Examples of distance and transportation barriers are as follows:

“I have neuropathy in both of my feet and occasionally, I feel it in my hands. On top of the distance, doing that drive or walking or standing for long periods of time is difficult. I also have a sleep issue that they can’t figure out what the issue is. So, long drives and being alone for long drives, because I don’t...all my friends and all my family work...it also...it can become hazardous at times.” —Florida Focus Group Participant

“I have to take three transports to come because, of course, I don’t have a car. Or count on the

goodwill of someone to bring me, but it’s quite far.” —Florida Focus Group Participant

The only notable difference between focus group transcripts in Florida and California was that participants in Florida described being “kicked out” of their adult endocrinology clinics for “no showing” to a scheduled visit. The guidelines for being removed from a clinic for failing to come to a routinely scheduled visits varied, but were only described by Florida participants. A Florida focus group participant described this as follows: “I was just recently dismissed from the endocrinology practice because I had missed three appointments. Two of which I was admitted in the hospital for, so [I’m seeing] nobody at this point.” This small difference between Florida and California aside, thematic analyses revealed similar types of experiences and barriers in both states. The urgency of improving diabetes management was abundantly clear for participants, many of whom were facing dire health complications, including lower limb amputation and recurrent hospitalization for DKA.

CONCLUSIONS

Findings from focus groups conducted in Florida and California with strategic recruitment efforts designed to include representation from underserved communities with type 1 diabetes demonstrate multilayered barriers related to technology use and routine endocrinology care. Barriers at the system level related to financial costs were described as prohibiting utilization of technology, but overall, the most commonly described barriers for technology and endocrinology use were related to provider-level factors and interpersonal communications during clinical encounters. It is important to note that, in some cases, providers may simply be conveying their own perceptions about rules related to coverage by which insurance and device companies have established thresholds related to HbA_{1c}. Regardless, these thresholds, and providers educating them in face-to-face interactions, result in systemically denying access to patients most in need of these tools.

Furthermore, the lack of empathy and understanding that patients experienced

from adult endocrinologists was identified as a significant obstacle. These findings support other studies that have documented the experience of stigma for communities living with type 1 diabetes (41,42) and, additionally, demonstrate the powerful role that providers can play in evoking type 1 diabetes–related stigma. For underserved communities, the intersectionality of type 1 diabetes as a disease with other status characteristics like SES, as well as structural racism, may compound the experience of stigma. While this study focused on barriers at the individual, provider, and systems levels, future directions should include consideration of the synthesis of barriers at various levels and its unique impact on underserved communities.

To our knowledge, this study provides one of the only accounts of perspectives from underserved communities with type 1 diabetes in the U.S. in two very different geographic locations—the deep South and the Western Pacific Coast. The states also differ in that Florida did not expand Medicaid, whereas California did. Thus, the similarities in focus group themes from both states point to the importance of multilayered interventions in various contexts in the U.S. However, the study has limitations, including the small cohort size and limited generalizability. Given the limited size of the cohorts in both states, caution should be used when examining the significance testing from the pre–focus group survey data. Additionally, the differences in technology use in both states might be related to larger policy-level differences related to insurance coverage (43). Finally, focus groups did not allow for a systemic analysis of potential differences in experiences related to racial and ethnic minority status. While there was one focus group conducted in Spanish, groups were not structured in such a way to assign participation based on race or ethnicity, and questions were not directly included about racial discrimination. Discussion about racial discrimination did come up at two focus groups in Florida for NHB and Hispanic participants; however, future research will benefit from overt efforts to strategically focus on structural racism.

The urgency of addressing disparate outcomes for underserved communities with diabetes is abundantly clear in data we see emerging regarding the COVID-19 pandemic and further highlights systemic and pervasive health inequalities within the U.S. (19–22). Multilayered interventions are needed to promote health equity in diabetes. System-level barriers related to access and financial cost are widely recognized as obstacles for underserved communities, as is the need for efforts aimed at improving disease management at the individual level. Based on these data, we posit that there is also a critical need for provider-level interventions focused on reducing implicit biases and improving the experiences of people with type 1 diabetes in clinical encounters. Endocrinologists are important gatekeepers for the patients they serve and should be included in targeted interventions for reducing health disparities in diabetes.

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