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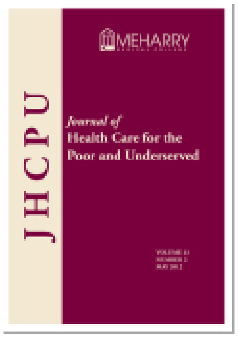

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Self-management among Patients Living with Diabetes in the United States Virgin Islands

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Abstract: The United States Virgin Islands (USVI) is facing a diabetes epidemic similar to the one on the U.S. mainland, yet little is known regarding the cultural context relevant to self-management in this U.S. territory. We conducted in-home interviews (n=53) supplemented by self-administered questionnaire and A1c testing with U.S. Virgin Islanders to characterize self-management knowledge, attitudes, and behaviors among patients living with diabetes. The mean glycosylated hemoglobin (A1c) was 7.63 (Range = 5–13); a composite score of traditional self-management behaviors was not associated with A1c. Several recurrent themes emerged from qualitative analysis including: 1) cultural nuances shaped perspectives on self-management, 2) culturally-specific challenges were barriers to effective self-management, 3) medical homes were rarely viewed as the primary source of education and support, and 4) fear largely motivated or stalled self-management practices. This study highlights the need for culturally-tailored measures and interventions to address the specific needs within this population.

Key words: Racial/ethnic disparities, territorial health, diabetes, self-management.

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Managing the emerging diabetes epidemic is a significant public health challenge in the United States Virgin Islands (USVI). The USVI, a territory of the U.S., is a culturally unique community: most residents are of African descent and represent a distinct ethnic group with lifestyle influences from both the U.S. mainland and other Caribbean islands. The prevalence of diabetes among African Caribbean people residing in the USVI is similar to that of African Americans on the U.S. mainland, at 10–12%, but is double that of estimates for African Caribbean residents on neighboring islands.[1–4]

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Understanding this disparity requires a multipronged exploration of several potential contributing factors. Insights into culturally-specific perspectives may inform intervention development, as in other settings.[5–7] In particular, capturing patient self-management skills and diabetes knowledge is important, as recommended by the American Diabetes Association's (ADA) national guidelines.[8] The impact of family and social support on self-management attitudes, behaviors, and glycemic control is another important factor that varies across patient culture and ethnicity.[9,10] Given existing racial/ethnic differences in glycemic control,[11] we sought to explore how culturally-influenced views on self-management might contribute to diabetes outcomes in the USVI.

Little is known about how the unique social and cultural context of the USVI influences self-management behaviors and attitudes. Factors such as ethnicity, knowledge about diabetes, and individual family and patient characteristics all affect these outcomes in other populations and can inform the selection and design of interventions to improve the ability of patients to manage their health successfully. Therefore, we used quantitative and qualitative methods to achieve the following research objectives: 1) identify patterns of self-management behaviors among patients with adult onset diabetes in the USVI; 2) examine the association between self-management behaviors, patient-level characteristics (i.e., level of education, diabetes knowledge, income, and social support), and the clinical outcome of glycosylated hemoglobin (A1c); and 3) characterize the impact of culture on self-management attitudes, knowledge, and behavior.

Methods

Design, data collection, and sample. We employed a mixed methods design to allow for a more comprehensive approach to addressing a multifaceted problem.[12] The use of mixed methods is most appropriate when a problem is complex, such as an individual's perspective on managing chronic illness, thereby requiring in-depth study from a variety of perspectives to understand it.[13] Quantitative data were collected using a self-administered survey questionnaire to acquire demographic information; a quiz to measure basic, general knowledge about diabetes (Diabetes Knowledge Scale: Form DKNC); and a measure of social support (Norbeck Social Support Questionnaire).[14–16] To assess recent glycemic control objectively, a glycosylated hemoglobin (A1c) was obtained for each participant at the time of the interview using a calibrated DCA 2000+ Analyzer.

Qualitative data were obtained through semi-structured, face-to-face interviews facilitated by a standard interview guide (Box 1) to capture participants' personal and cultural experiences that influence day-to-day diabetes management. All interviews were conducted by a single culturally-concordant researcher (co-author, MAN) in the participant's home at a time of his/her convenience. Open-ended questions elicited detailed descriptions and explanations concerning each participant's level of understanding of ideal diabetes self-management and his or her routine self-management activities. Further, interview questions asked respondents to specify facilitators and barriers affecting their daily self-management behaviors. Digital recordings of the interviews were professionally transcribed and reviewed by the interviewer for accuracy.

The purposive sample consisted of 53 adults across the three main islands. The sample

Box 1.

SEMI-STRUCTURED INTERVIEW GUIDE

1) Tell me what you do every day to take care of your diabetes.
2) What does your physician mean when he/she tells you to manage your diabetes?
3) What makes it easier to take care of your diabetes every day? What makes it more difficult?
4) Does anyone help you take care of your diabetes? How? Does anyone make it harder for you to take care of your diabetes? How?
5) Is there anything else you can share with me that might help me better understand what influences how you think about having diabetes?

size was determined by the achievement of thematic saturation; that is, no new ideas emerged from subsequent interviews.[17] All study participants met the following criteria: 1) at least 21 years of age; 2) diagnosed with adult-onset diabetes after January 2005; 3) resided in the USVI for at least 10 years and self-identified as a U.S. Virgin Islander; 4) able to identify a medical home; 5) absence of known systemic diabetic complications; and 6) not pregnant and no history of gestational diabetes. Participation was voluntary. Individuals were recruited from the patient panels of private physicians, government clinic appointment schedules, self-referral, and snowballing (one participant refers another community member meeting inclusion criteria).[17]

Variables. The primary outcome variable of interest was A1c, a blood test that approximates the degree of glycemic control over the prior three months. A1c levels are widely considered an accurate reflection of an individual's self-management behaviors once on a maximized medication regimen.[18] A1c measurements were collapsed into a three-level variable (controlled <7.0, poorly controlled 7–9, and very poorly controlled >9) for statistical analysis per Health care Effectiveness Data and Information Set (HEDIS) guidelines at the time of the study.[19]

The primary independent variable of interest was self-management behavior, determined by a composite score of four binary dimensions: 1) daily glucometer testing, 2) adherence to prescribed medication regimen, 3) moderate exercise, and 4) adherence to appropriate diet. Participants received one point for meeting the "yes" criterion for each dimension. Scores could range from zero to four, with four indicating excellent self-management and zero indicating poor self-management. These composite scores were derived from independent coding of two researchers analyzing the interview data of all study respondents (an approach similar to approaches taken in prior self-management research).[20] Previously developed measures of self-management behaviors had not been validated in a U.S. Virgin Islander population but pre-existing measures did inform our composite score development.[21] The kappa statistic achieved for independently-derived self-management composite score was 0.95 (C.I.: 0.85–1.00), indicating a high level of inter-rater reliability. Any discrepancies were resolved by negotiated consensus. These composite scores were correlated with measures of social support, knowledge, income, education, and the clinical outcome variable, A1C.

Several other demographic variables were included in the analysis; the associations between age, gender, level of education, source of medical care, island of residence, occupation, time since last medical visit, household income, and glycemic control (A1c) were examined.

Disease-specific knowledge was measured using Diabetes Knowledge Scale, Form C (DKNC), which was an equivalent form of one of three 15 question short quizzes.[14] Social support was measured using the Norbeck Social Support Questionnaire (NSSQ).[15,16] The NSSQ asks participants to list and rate their own social support network members on emotional and tangible support and according to particular network properties such as stability of relationships, and frequency of contact with the listed support persons. The questionnaire concludes with questions about recent losses of supportive relationships due to death or relocation. Despite not being previously validated in the population of interest, we included these questionnaires to provide supplemental information.

Data analysis. *Quantitative*. SPSS 14 for Windows was used to analyze the quantitative data.[22] Descriptive statistics were used to obtain measures of central tendency (mean, median, and mode) and dispersion (range, variance, and standard deviation) for continuous variables and frequency distributions for the categorical variables. Analysis of frequency (chi-squared test) was utilized to determine the relationship between the categorical variables. If the parametric assumptions were met, Pearson correlation coefficient was utilized to determine the relationship between variables measured on ratio or interval scales; otherwise, the Spearman correlation coefficient was used. We estimated and tested the statistical significance of associations between self-management composite scores, other measured variables, and the outcome of A1c. A1c was correlated with self-management composite scores, age, gender, employment, education, income, support loss, knowledge and medical home (private practice *vs.* government-operated clinic). Government-operated clinics are overseen by the local Department of Public Health and have intimate operational associations with the local hospital, sometimes being physically housed within the hospital. These sites differ from federally qualified health centers (FQHC) in this management structure; FQHCs have greater autonomy than the clinics in the Virgin Islands. Federally qualified health centers and the government-operated clinic similarly provide care for often vulnerable patient populations. T-test statistics tested the difference in variables between the normal and elevated A1c groups. When the parametric assumptions were not met, the Mann-Whitney test was used.

Qualitative. A two-member code team (MAN and MNS) created code definitions as concepts emerged inductively from the data. Each member of the coding team independently coded individual transcripts line-by-line, meeting regularly to resolve discrepancies and to review the code structure. We used the constant comparative method of qualitative analysis[23] to compare coded segments of text with expand existing themes and identify new themes. Codes were refined until we reached a final coding structure that was then applied to all of the transcripts. Atlas.ti 5.2 qualitative data management software facilitated data organization and retrieval.[24]

Data were collected over a four-month study period between January 2008 and April 2008. The study was reviewed and approved by the University of the Virgin Islands Institutional Review Board.

Results

Sample. The mean age of the sample was 57.6 years (SD ± 11.74), range 26 to 80 years. Participants were fairly evenly distributed between St. Thomas/St. John and St. Croix and most were women (Table 1). A slight majority of respondents (51%) was employed and the remaining participants were either retired or unemployed. Concerning the highest level of education achieved, 38% completed elementary schooling and 21% reported completing a college degree (associate, baccalaureate, or a master's degree). About 40% reported an annual individual income of less than $12,000 and only 8% indicated an annual income of at least $50,000.

Physician contact. All individuals identified one individual physician as their diabetes health care provider, with 83% stating that they had seen their physician for a diabetes-related visit within the last three months. Only 6% of participants did not have a physician encounter within the previous nine months. The majority of participants (55%) received care from private physicians; 45% identified government-operated clinics as their medical home. Study participants were asked to recall the content of their most recent physician visit by identifying topics that were discussed from a list of diabetes-relevant management issues. Responses revealed that while exercise, diet, diabetes medication regimen, fasting blood sugar, cholesterol levels, and foot care were discussed with at least half of the patients, only 19% of patients reported discussing A1c measurements with their physicians.

Correlates of A1c measurement. The mean A1c was 7.63 (SD ± 1.72, Range = 5–13). Almost 60% of participants had an $A1c \geq 7$, and 17% of the participants had very poor glycemic control ($A1c > 9$).

Gender. Gender was the only demographic characteristic that was significantly associated with the outcome variable, A1c. Male participants achieved significantly tighter glycemic control than women (Fisher's Exact Test, $p=0.0271$). Employment status, education, income, age, knowledge, and medical home type were not significantly associated with A1c.

Diabetes knowledge. Participant diabetes knowledge varied widely. Of the 15 test items on the DKNC, study participants' performance ranged from one correct (1/15) to fourteen correct (14/15). The majority of the participants (69%) answered fewer than half of the 15 questions correctly. Although the difference in A1c between those who failed and those who passed the diabetic knowledge tool did not reach a statistical significance ($p=.06$), the average A1c level of those who answered correctly on more than half the diabetic knowledge questions was 5.53 (*versus* 7.87 for those participants who scored lower).

Social support. Greater emotional and tangible support was correlated with lower A1c, although none of the associations reached statistical significance. Higher subscale scores (greater overall perceived support) ($r=-0.17$, $p=.2222$), longevity of relationships ($r=-0.17$, $p=.2273$), higher numbers of identified support people ($r=-0.15$, $p=.2772$)

Table 1.

SAMPLE CHARACTERISTICS (N=53)

Characteristic	N (%)[a]
Residence	
St. Thomas	23 (43)
St. Croix	26 (49)
St. John	4 (8)
Gender	
Male	8 (15)
Female	45 (85)
Education	
Elementary	20 (38)
High School Graduate	22 (42)
College Degree	11 (21)
Employment	
Employed	27 (51)
Unemployed	12 (23)
Retired	14 (26)
Annual Income ($)	
Less than 12,000	21 (40)
12,000–20,000	7 (13)
20,001–30,000	8 (15)
30,001–50,000	12 (23)
Over 50,000	5 (8)
Time since Diagnosis (years)	
Less than one	2 (4)
1–2	12 (23)
3–4	11 (21)
4–5	10 (19)
Over 5	18 (34)
Medical Home	
Private practice	29 (55)
Government-operated clinic	24 (45)
Diabetic Knowledge (15 Questions)	
$\leq$7correct answers (Fail)	37 (69)
$>$7correct answers (Pass)	16 (30)
Hemoglobin A1c	
Normal (A1C $<$ 7)	22 (42)
Poorly Controlled (7 $\leq$ A1C $\leq$ 9)	22 (42)
Very Poorly Controlled (A1C $>$ 9)	9 (17)

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[a] Percentages may not sum to 100 due to rounding

and increased frequency of contact (r=−0.12, p=.4095), were correlated with lower A1c values. In contrast, the correlation coefficients of the number of individuals in the support network who have died or relocated (r=−0.07, p=.6042), and the perceived depth of the loss (r=−0.01, p=.9179), both approximate zero.

Self-management behaviors. Analysis of the interview text demonstrated that most participants adhered to daily glucometer testing (60%) and a prescription medication regimen (77%) (Table 2). Only 40% of participants followed a diabetes-appropriate diet. Using the Mann-Whitney test, those participants who followed a diabetes-appropriate diet had significantly lower A1c measurements (p=.0398). Similarly, only 40% of participants participated in moderate weekly exercise, and no significant differences in glycemic control were noted between exercisers and non-exercisers (p=.3636).

A composite score was generated by obtaining the total score for adherence to all of the self-management behaviors: daily glucometer use, medication adherence, diet adherence, and regular moderate exercise. These variables were dichotomous, coded as No = 0 and Yes = 1. Therefore, the composite score for each subject ranged from 0 to 4 (Mean = 2.19, SD ± 1.09). Only 14% of participants met the "yes" criterion for each of the four self-management behaviors, and their mean A1c (7.10 ± 1.88) was significantly lower than the mean A1c (8.39 ± 2.20) for participants with a composite score of 1 (p-value < .05) (Table 2). In addition, higher composite scores were significantly

Table 2.

ADHERENCE TO INDIVIDUAL SELF-MANAGEMENT BEHAVIORS, COMPOSITE SELF-MANAGEMENT BEHAVIORS, AND MEAN A1C (N=53)

	Adherence		Non-Adherence	
Self-management behaviors	**N (%)**	**A1c (std dev)**	**N (%)**	**A1c (std dev)**
Glucometer testing (daily)	32 (60)	7.53 (± 1.56)	21 (40)	7.76 (± 1.97)
Prescription medication	41 (77)	7.66 (± 1.77)	12 (23)	7.53 (± 1.56)
Diabetic-appropriate diet*	21 (40)	7.11 (± 1.22)	32 (60)	7.98 (± 1.92)
Moderate-weekly exercise	21 (40)	7.60 (± 1.85)	32 (60)	7.65 (± 1.65)
Self-management composite score[a,b]				
1	14 (26)	8.39 (± 2.20)	n/a	n/a
2	18 (34)	7.32 (± 1.37)	n/a	n/a
3	14 (26)	7.66 (± 1.56)	n/a	n/a
4	7 (14)	7.10 (± 1.88)	n/a	n/a

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*p-value < .05

[a] Overall F= 1.18, *p*-value = 0.3336

[b] Scores could range from 0 (no appropriate self-management behavior) to 4 (all appropriate self-management behaviors). No participant received a composite score of 0.

correlated with greater diabetic knowledge (r=0.30, p=.0289), higher educational achievement (r=0.30, p=.0315), and higher individual income (r=0.43, p=.0013).

Qualitative findings. Four relevant, novel, and common themes characterize key participant perspectives that influence the adherence to self-management behaviors among patients with diabetes in the USVI. First, cultural nuances shaped perspectives on self-management. Second, culturally-specific challenges were barriers to effective self-management. Third, medical homes were rarely viewed as a primary source of diabetes education or support. Fourth, fear of disease complications largely motivated or stalled self-management practices.

Each theme had several associated sub-themes and illustrative quotes (Box 2). The influence of the unique cultural context of the USVI was evident across all of the transcripts. Participants valued the inclusion of local cuisine in their diet, but rarely knew whether these food choices were diabetes-appropriate or how to modify local food recipes. They also placed equal, if not greater, value on alternative therapies compared with therapies offered by their medical provider. In particular, many participants relied on herbal bush therapies recommended by family or friends and did not typically discuss these therapies with their providers. The importance of recommendations by family and friends was pervasive. Participants also self-adjusted their medication regimens, frequently in response to advice from peers. As for the use of alternative therapies, participants did not routinely inform their providers of changes they made to their diabetic medication regimen. The perceived role of health care providers also emerged as a novel theme. Participants did not view their medical homes as the primary sources of diabetes education and support; family and friends, instead, were centrally important. However, participants wanted opportunities to discuss alternative therapies in a non-judgmental environment with their providers and also wanted providers to offer additional educational resources such as nutritionists and group sessions. Participants also universally experienced other barriers to successful self-management such as stigma, inflexibility within the workplace, and the limited access and associated expense of foods imported from off island such as mainland produce. We also found that many participants were extremely afraid of diabetic complications and this possibility served as either a strong motivator for behavioral change or as a paralyzing influence that stalled them from adhering to the behaviors they could clearly articulate as necessary to manage their health.

Discussion

We sought to explore and characterize patterns of self-management behavior among patients living with diabetes in the USVI. Several patterns of self-management knowledge, behaviors, and attitudes emerged across our diverse sample. The mean A1c measurement was within accepted parameters despite the overall poor performance on knowledge testing, and the low percentage of adherence to all four of the assessed self-management behaviors. Male participants were likely to have significantly lower A1c measurements than their female counterparts. Interestingly, the only self-management behavior associated with significant lowering of the A1c was following a diabetes-appropriate diet. The qualitative data identified several challenges to adhering to an

Box 2.

KEY QUALITATIVE THEMES, SUB-THEMES, AND ILLUSTRATIVE QUOTATIONS

Themes	Sub-themes	Quotations
Cultural nuances shaped perspectives on self-management	Use of herbal, complementary, and alternative remedies (CAMP)	"(My neighbor) is a diabetic too. . . . Sometimes she buys bush and give me some. I don't know the name of it but it is supposed to help with sugar. So I use that." (Female, age 52)
	Importance of maintaining local diet	"I take liberty every day. Right now I have . . . 3 plantains, 5 or 6 tanya, sweet potatoes, and I plan to take pig tail and cornmeal dumplings and make a big pot of peas soup. . . . You know the attitude I take. I live 70 years eating the same thing. What, now it's going to kill me?" (Female, age 69)
Culturally-specific challenges were barriers to effective self-management	Stigma	"I think this needs to be more out in the open. Because you can have diabetes and control it and do everything that everybody else does. But it's so secretive . . . everyone will treat you like you're dying. There's a stigma attached, yes. To being diabetic or having to take medicine for it." (Female, age 54)
	Limited access to healthy food options/exercise	"Making the good food choices is hard. They're simply not available in stores. Well, sometimes. Now, they tell me blueberries is good. I can eat that. But when you find that, it's five dollars for a little bag so…" (Female, age 65)
Medical homes were rarely viewed as a primary source of diabetes education or support	Lack of educational resources	"I think there should be better resources for diabetics. Once you're diagnosed there should be a place that you can go to for regular classes and monitoring. I can't believe we don't have that in this day and age. There isn't even a dietician there (doctor's office)." (Female, age 54)
	Self-adjustment of medication dosing and regimen influenced by friends and family	"Well, the doctor told me to take the insulin two times but my mother tell me—I want to know if this is right. He tell me to take twenty five units in the morning and twenty five in the night. But she said it's too much, and just gives me fifteen at night. So that's what I do." (Female, age 43)

(Continued on p. 280)

Box 2. *(continued)*

Themes	Sub-themes	Quotations
Fear of disease complications largely motivated or stalled self-management practices	Denial/ Minimization	"I don't want to think about it (having diabetes). Like I say, I don't say I'm a diabetic. I only say my sugar is a little elevated. I don't even want to call the word." (Female, age 64)
	Resilience	"I see the struggle when people lose limbs. I play the flute and don't want to lose fingers so I changed everything . . . I stopped the alcohol. And I cut back on all the starchy, Caribbean foods. You have to make up your mind that you're going to back out of all those foods you grew up with. I grow my own vegetables now. And that is another way I can get exercise." (Male, age 52)

appropriate diet such as the desire to maintain the cultural diet, the prohibitive cost of non-locally grown foods, stigma from family and co-workers, and poor communication with their primary providers. The provider relationship was also relevant to other self-management behaviors. Few participants (19%) reported having discussed A1c with their primary health care physicians, and approximately half of our sample recalled discussing other specific aspects of diabetes at their most recent visits. Participants more readily accepted and trusted disease management guidance provided by family members and friends, especially others living with diabetes, than recommendations made by their physicians. Although the vast majority of participants (77%) filled and took their prescription medications, many patients were comfortable adjusting medication dosage and frequency without notifying their medical providers. Participants also easily incorporated complementary and alternative therapies into their treatment regimen without physician consultation. Still, many participants were highly motivated by the fear of complications and stated they would welcome communication with their physicians if the medical home offered culturally-relevant resources such as diabetes education and nutrition counseling.

Consistently with earlier work,[24–26] we did not find a statistically significant association between scores on diabetes knowledge questionnaires and glycemic control. However, we did find an association between higher knowledge scores and more comprehensive self-management behaviors. Therefore, it may be premature to dismiss the relevance and importance of diabetes education to self-management, especially in a population heavily influenced by the suggestions of peer group members. Our findings also highlight the important role of social support networks, which may explain the interesting finding that male participants achieved tighter glycemic control than female participants. As in other research,[9,27–29] greater social support was associated with better glycemic control and males scored higher on positive social support measures. We also identified important and potential targets for intervention as the specific cultural context influenced food preference for high carbohydrate and high caloric diets and limited communication with primary care providers. Associated barriers were cultural stigma, cost of healthy food alternatives, and distrust of medical providers, especially when compared with the level of trust placed in friends, family, and complementary and alternative therapies.

There are some limitations that should be considered as we interpret these findings. This study was designed as an exploratory analysis of self-management in an understudied population, and so the sample size was purposefully small and limited by resource availability. The sample was recruited from medical homes and all participants are, by design, in on-going relationships with primary care providers. Therefore, we were not able to capture the perspectives of people living with diabetes who do not have medical homes. Furthermore, participation was voluntary and recruitment may have selected for patients who are highly motivated or engaged in their medical care. If this was the case, we would most likely overestimate adherence to appropriate self-care behaviors. Given the low percentage of participants who demonstrated a passing level of diabetes knowledge, complete self-management behaviors, and insight into their diagnoses, the need for intervention across the territory is perhaps even more pressing than suggested here. Although these findings are not generalizable to other environments, careful attempt was made to include study participants from across the territory, with approximately equal participation from the two larger islands of St. Thomas and St. Croix. Even though the study did not attempt to recruit equal numbers of men and women in the study, the overwhelming over-representation of women prevented any closer examination of gender differences applicable to self-management.

An important strength is the application of a mixed methods research design, which allowed for triangulation of the findings through quantitative questionnaires, clinical outcome measurements, and semi-structured interviewing. Lastly, this study is among few that have been conducted in the USVI and provides important guidance to patients living with diabetes, their families, and health care and public health providers.

Our findings have several implications with direct and immediate relevance to the USVI. It is clear that health care providers should focus on creating an environment in which patients are invited to and feel comfortable sharing the modifications and alternative medications they may incorporate into their self-care plan. Frequent physician visits are not sufficient to achieve diabetic control and more attention can be paid to the content of patient interactions with their medical homes. Physicians can recognize the importance of peer group support and reinforcement and create opportunities for group interactions with diabetes educators within the office setting. Importantly, providers can routinely assess patient knowledge and understanding of diabetes and make culturally-relevant resources available. Recognizing the unique cultural influences affecting health outcomes in the U.S. territories is a critical step towards achieving health equity for all of the nation's citizens.

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