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Comparison of Diabetes Education Content Experienced by Blind and Nonblind People With Diabetes

Nazanin Heydarian,¹ Qusay Hussein,² Zully Guerra,² Bhumi Patel,³ Allyson S. Hughes,³ Julia E. Blanchette,^{4,5} and Yessenia Castro²

This survey sought to examine disparities in diabetes self-management education and support (DSMES) to illuminate gaps underlying morbidity and mortality disparities experienced by blind people with diabetes and develop a pathway for improved health care delivery and health outcomes. Blind participants were more likely to report getting DSMES on strategies to promote treatment adherence and noncompliance with medical regimen; yet, blind and nonblind participants did not differ on primary care provider visits or amount of time spent in diabetes education. These findings suggest that DSMES content may differ for blind versus nonblind participants.

Diabetes is a significant public health concern, affecting 37.3 million people, or 11.3% of noninstitutionalized adults in the United States (1). Worldwide, the prevalence of diabetes in adults aged 20–79 years was estimated at 10.5% (2). Self-care and management behaviors lead to optimal health outcomes for people with diabetes (3). The Association of Diabetes Care and Education Specialists outlines seven behaviors for diabetes self-care and management: taking medication, reducing risks, monitoring, being active, problem-solving, healthy coping, and healthy eating (4). Diabetes self-management education and support (DSMES) focuses on diabetes care, information about diabetes, and support of patients' self-management routines (3,5).

Diabetes is the leading cause of vision loss in the United States (6). Furthermore, blind and low-vision people are more likely to experience diabetes complications, including depression (7), cardiovascular disease (CVD), kidney disease, neuropathy, and lower-extremity

KEY POINTS

- » Blind people more often reported receiving diabetes self-management education and support (DSMES) on strategies to promote treatment adherence and noncompliance with the medical regimen than nonblind people.
- » No differences between blind and nonblind participants were found in self-reported time spent in diabetes education since diabetes diagnosis or in number of primary care provider visits during the past year.
- » Understanding disparities in DSMES can illuminate morbidity and mortality disparities experienced by blind people and help to develop a pathway for improved health care delivery and health outcomes.

amputation (8), than their nonblind counterparts (1). Exploratory research shows that people with diabetes who are blind or have low vision report difficulty checking blood glucose levels (e.g., difficulty using test strips) and lacking skills and tools to prepare and access nutritious foods and take medication as frequently as prescribed (9).

For blind and low-vision people with diabetes, one of the most significant barriers to effective diabetes self-management is the lack of DSMES designed for this population (10,11). As a result, blind and low-vision people face difficulties reading medication labels and are at higher risk for experiencing a medication error

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than their sighted peers (11). A nationally representative survey study of blind and low-vision people with diabetes showed that they have lower diabetes self-management self-efficacy than nonblind people with diabetes, yet receipt of DSMES was associated with higher diabetes self-management self-efficacy (12). There remains a need to characterize DSMES received by blind people and compare it to that of nonblind people with diabetes to improve diabetes care and outcomes experienced by blind people with diabetes.

Objective

This study aimed to 1) identify the frequency of diabetes self-management topics about which blind people report being educated and 2) examine whether there are differences in frequency of reported diabetes self-management education topics between blind people and nonblind people with diabetes. Addressing the aims will contribute to the characterization of disparities experienced by blind people with diabetes.

Research Design and Methods

A survey study known as the Studying Wellness Experiences and Expectations to Health Educate, Alleviate, and be a Resource for Treatment of Diabetes and Cardiovascular Disease (SWEETHEART) project was conducted nationwide from September 2019 through December 2020 via Qualtrics. This project served as the data source for the present article. This study was approved by the University of Texas institutional review board.

Participants

Inclusion criteria were: 1) age 18–65 years; 2) history of CVD, including, arrhythmia, stroke, heart attack, elevated blood pressure (defined as systolic blood pressure ≥ 120 mmHg or diastolic blood pressure ≥ 80 mmHg), coronary heart disease, or congenital heart defects, or type 1 diabetes or type 2 diabetes, or prediabetes (defined as an A1C of 5.7–6.4%); and 3) ability to read in English. For the current study, we focused on those participants with a diagnosis of diabetes. People >65 years of age were excluded because we were interested in examining the experiences of those whose onset of blindness occurred earlier in life. Blind people were oversampled to obtain an equivalent sample of blind and nonblind people. Blindness was defined as 20/200 vision in the furthest seeing eye with correction or a visual field of $\leq 20^\circ$.

Participants were recruited from the listservs of organizations of the blind and social media pages and by word of mouth. Participants were also recruited from the diabetes online community and the CVD online community. One year into the study, we enlisted the services of a participant panel service company to complete data collection. Overall, 144 blind people and 262 nonblind people with diabetes completed the survey. Table 1 summarizes their demographic characteristics.

Measures

The SWEETHEART project used a comprehensive survey with the purpose of identifying disparities between blind and nonblind people with regard to diabetes and CVD self-management and risk behaviors, attitudes about these behaviors, and knowledge and education about self-management behaviors. DSMES topics were within the following domains: symptom monitoring and response, physical activity, diabetes etiology and progression, medication management, dietary recommendations, alcohol/tobacco/illicit drugs recommendations, treatment adherence, weight monitoring, and seeking social support. Table 2 includes the complete list of education topics. Participants were asked how many minutes of instruction they had received from a trained diabetes care and education specialist (DCES). Participants then identified topics that were covered in their diabetes education. All surveys were conducted on Qualtrics.

For the current study, we focused on the sample of participants with diabetes and their reported DSMES. Participants with both diabetes and CVD were randomly assigned to receive either those measures on diabetes self-management and outcomes or those on CVD self-management and outcomes. This article reports the results from those participants with diabetes who were assigned to complete the diabetes-related measures.

Procedures

Participants received an e-mail with information about the purpose of the study and the survey. Participants first read an informed consent document and proceeded to the survey if they wished to participate. Next, participants were prompted to provide demographic information. Participants then completed the survey, composed of the questions and measures discussed above. The order of measures and items within each measure were randomized so that order effects would be random error in the analyses. All participants completed demographic and health behavior

TABLE 1 Demographic Descriptive Statistics

Characteristic	Blind Group (n = 144)	Nonblind Group (n = 262)	Significance
Age, years	28.59 ± 12.046	33.28 ± 10.513	$t(396) = -4.04, P < 0.001$, Cohen's $d = 11.079$
Education, years	6.84 ± 1.494	6.67 ± 1.47	$t(396) = 1.153, P = 0.250$, Cohen's $d = 1.479$
Race/ethnicity			—
White	80	84	
Black	8	5	
Asian	6	5	
Native American/Alaskan	4	2	
Hispanic	7	5	
Sex			—
Male	53	64	
Female	47	34	
Diabetes type			$\chi^2(3) = 11.748, P = 0.008$
Type 1	33	20	
Type 2	63	77	
Diabetes-related vision loss	49	13	$\chi^2(1) = 60.230, P < 0.001$

Data are mean ± SD or % unless otherwise noted.

measures. Upon completion of the survey, participants were given a \$30 gift card as remuneration for their participation.

Data Analysis

Descriptive analyses of demographic variables were conducted using SPSS, v. 28, statistical software (13). Then, multiple imputation was conducted, and log-transformed odds ratios (ORs) and their 99% CIs were computed on the pooled imputed data using MPlus, v. 8.3, statistical software (14). Log-transformed ORs were converted into weighted proportions in Microsoft Excel for ease of interpretation and are reported in Table 2. We report P values as well as 99% CIs and interpreted statistically significant results regarding the CIs because this is more conservative than results with P values ≤ 0.001 . We conducted a large number of comparisons, which increased our chances of making a type 1 error (15).

Results

Log-transformed ORs and their 99% CIs were computed to compare 36 DSMES topics on which blind and nonblind people have received education (Table 2). Between-group and within-group relationships were examined.

Between-Group Differences

Blind people were more likely than nonblind people to report being counseled on strategies to promote treatment adherence (blind 36.4%, 99% CI 26.8–47.2%; nonblind 18.2%, 99% CI 12.8–25.1%) and noncompliance with the medical regimen (blind 23.8%, 99% CI 15.8–34.1%; nonblind 8.5%, 99% CI 5.0–14.1%).

To further examine the differences between DSMES experienced by blind people compared with nonblind people, a between-subjects t test was conducted to compare the subjective rating of minutes of diabetes education. Blind people did not report significantly more time spent in diabetes education since diabetes diagnosis than nonblind people (blind mean 44.93 ± 34.25 minutes vs. nonblind mean 42.44 ± 32.48 minutes; $t(314) = 0.653, P = 0.514$, Cohen's $d = 0.075$). Furthermore, blind people did not report a greater frequency of primary care provider visits during the last year than nonblind people (blind mean 4.52 ± 3.05 vs. nonblind 4.17 ± 2.28 ; $t(64) = 0.499, P = 0.619$, Cohen's $d = 0.128$).

Within-Group Differences

We examined differences within groups across the domains of DSMES that consisted of multiple items. These domains were symptom recognition, symptom response, exercise, diabetes etiology and progression,

TABLE 2 Comparison of DSMES Topics Between Blind and Nonblind Participants

Item	Blind Group	Nonblind Group	<i>t</i>	<i>P</i>
Consultation on diabetes management within a year of diagnosis	72.50 (61.8–81.1)	81.30 (73.3–87.3)	−0.498	0.053
Symptom recognition				
Recognizing symptoms of high/low blood glucose	76.90 (66.7–84.7)	79.50 (72.3–85.2)	−0.154	0.541
Recognizing escalating symptoms	35.70 (26.1–46.5)	19.70 (14.1–26.8)	0.816	<0.001
Symptom monitoring	44.20 (33.9–55.1)	37.80 (30.4–45.8)	0.268	0.205
Symptom response				
Responding to symptoms of high/low blood sugar	77.40 (67.0–85.3)	74.20 (66.0–81.0)	0.177	0.484
Consultation on diabetes symptom management within a year of diagnosis	68.20 (57.1–77.5)	78.30 (70.3–84.6)	−0.522	0.034
Symptom response plan	28.70 (20.0–39.3)	14.70 (9.9–21.3)	0.849	0.001
Exercise				
Exercise recommendations	80.60 (70.5–87.8)	84.40 (76.6–89.9)	−0.262	0.371
Specific activity/exercise recommendations	42.00 (31.8–52.8)	34.00 (26.9–41.9)	0.34	0.113
Staying physically active	49.70 (39.1–60.3)	46.30 (38.5–54.3)	0.133	0.524
Improving exercise	47.10 (36.6–57.8)	48.90 (41.0–56.9)	−0.074	0.724
Diabetes etiology and progression				
Definition of diabetes linking disease, symptoms, and treatment	68.30 (57.5–77.4)	51.20 (43.2–59.0)	0.72	0.001
Diabetes cause	53.00 (42.3–63.4)	43.70 (36.0–51.7)	0.373	0.074
Risks for progression	61.50 (50.7–71.4)	56.40 (48.3–64.1)	0.214	0.315
Medication management				
System for medication management	60.80 (50.0–70.7)	70.30 (62.5–77.0)	−0.42	0.055
Purpose and use of medication	54.70 (44.0–65.1)	38.20 (30.7–46.2)	0.673	0.001
Taking medication as prescribed	56.60 (45.8–66.9)	48.30 (40.4–56.2)	0.337	0.108
Use of nonsteroidal anti-inflammatory drugs	13.30 (7.5–22.4)	4.20 (2.0–8.9)	1.24	0.002
Noncompliance with medication regimen*	23.80 (15.8–34.1)	8.50 (5.0–14.1)	1.212	<0.001
Nutrition				
Diet/fluid intake recommendations	51.00 (40.4–61.6)	42.50 (34.8–50.5)	0.345	0.099
Low-sodium diet	21.90 (14.2–32.1)	19.20 (13.7–26.3)	0.163	0.527
Improving diet	53.10 (42.4–63.6)	56.40 (48.3–64.1)	−0.13	0.534
High-sodium/processed food binges	15.40 (9.1–24.8)	13.50 (8.9–20.0)	0.152	0.607
Sodium restrictions	12.60 (7.0–21.6)	9.70 (5.9–15.5)	0.299	0.363
Reducing sodium in diet	52.40 (41.5–63.1)	53.60 (45.0–62.0)	−0.048	0.826
Reducing processed foods	60.90 (50.1–70.8)	61.60 (53.5–69.0)	−0.027	0.9
Alcohol, tobacco, and illicit drugs				
Alcohol recommendations	25.90 (17.6–36.3)	19.70 (14.1–26.8)	0.353	0.152
Avoiding tobacco and illicit drugs	26.60 (18.2–37.1)	20.80 (15.1–28.1)	0.318	0.192
Avoiding smoking	22.40 (14.7–32.6)	21.20 (15.4–28.5)	0.067	0.79
Avoiding excessive alcohol	21.00 (13.5–31.1)	16.60 (11.5–23.4)	0.288	0.277
Avoiding illicit drugs	16.80 (10.2–26.4)	9.70 (5.9–15.5)	0.635	0.039
Treatment adherence				
Importance of treatment adherence	48.30 (37.7–58.9)	33.60 (26.5–41.5)	0.612	0.004
Treatment adherence strategies*	36.40 (26.8–47.2)	18.20 (12.8–25.1)	0.947	<0.001
Weight monitoring				
Daily weight monitoring	26.60 (18.2–37.1)	23.20 (17.1–30.6)	0.183	0.447
Monitoring weight	22.40 (14.7–32.6)	12.70 (8.3–19.1)	0.68	0.013
Seeking social support	21.00 (13.5–31.1)	12.00 (7.7–18.2)	0.669	0.017

Data are reported as weighted proportion (99% CI) unless otherwise noted. *Item was significantly different when examining CIs.

medication management, nutrition, alcohol/tobacco/illicit drugs, treatment adherence, and weight monitoring. Blind people were more likely to report receiving consultation on recognizing symptoms of high/low

blood glucose (76.9%, 99% CI 66.7–84.7%) than either symptom monitoring (44.2%, 99% CI 33.9–55.1%) or recognizing escalating symptoms (35.7%, 99% CI 26.1–46.5%). Nonblind people most frequently reported

recognizing symptoms of high/low blood glucose (79.5%, 99% CI 72.3–85.2%), then symptom monitoring (37.8%, 99% CI 30.4–45.8%) and least frequently reported recognizing escalating symptoms (19.7%, 99% CI 14.1–26.8%). Both blind and nonblind people endorsed receiving education on exercise recommendations (blind 80.6%, 99% CI 70.5–87.8%; nonblind 84.4%, 99% CI 76.6–89.9%) significantly more frequently than other exercise/physical activity–related items. We observed no within-group differences in disease etiology and progression topics.

Both blind and nonblind participants reported being counseled on the use of nonsteroidal anti-inflammatory drugs and noncompliance with the medical regimen the least frequently compared with other medication use and management topics. For nonblind participants, the items endorsed with significantly greater frequency included purpose and use of medication and taking medication as prescribed, and the most frequently endorsed item was system for medication management. Although there were no between-group differences observed within this domain, no such linear pattern was observed within the blind group (see Table 2 for all weighted proportions in this domain).

Within both groups, participants reported items regarding specific nutrition recommendations (low-sodium diet, high-sodium/processed food binges, and sodium restrictions) significantly less frequently than general nutrition-related topics (diet/fluid intake, improving diet, reducing sodium in diet, and reducing processed foods) (see Table 2 for weighted proportions).

Among nonblind participants, we found a greater likelihood to endorse the item for treatment adherence importance over the item for treatment adherence strategies. This within-group effect was not observed among blind participants. No within-group differences were observed for topics related to alcohol, tobacco, or illicit drug, weight monitoring, or seeking social support. These results begin to illuminate which aspects of the domains of DSMES are emphasized for blind and nonblind people with diabetes.

Discussion

This study sought to identify the frequency of DSMES topics that blind people with diabetes report being educated on and examine whether there are differences in the frequency of reported DSMES topics between blind and nonblind people with diabetes. The results indicated that blind people were more likely to report having DSMES on strategies to promote treatment adherence and

noncompliance with the medical regimen. These between-group findings may indicate that clinicians expected blind people to be less engaged with behavior and treatment recommendations. This may indicate underlying ableism (i.e., disability-based bias) toward blind people with diabetes. Furthermore, future research should examine strategies to promote treatment engagement for blind people if they systematically differ from strategies recommended to nonblind people and the extent to which the recommended strategies are feasible and effective for blind people. Importantly, existing research shows that culturally competent health care providers can affect minority patient outcomes (16,17); yet, there is limited research about clinical cultural competence with regard to blind people with diabetes.

The results of this study also suggest that there is no difference in time and amount of DSMES between blind and nonblind people with diabetes. These findings contribute to a mixed literature suggesting that there may or may not be differences in the amount of time that blind people spend in medical appointments compared with their nonblind counterparts. Although some health care providers seem to expect to spend more time with disabled patients in general (18,19), our research has not found differences in clinicians' expectations for the duration of interactions with blind versus nonblind patients in a randomized experiment (20). Because of their patient load, clinicians may not be spending extra time with blind people who have diabetes.

When exploring within-group differences, we found that, for both groups, recognizing symptoms of high or low blood glucose seemed to be the most salient topic of DSMES or perhaps the topic most prioritized by health care professionals. Additionally, we found that participants reported receiving education on exercise recommendations more frequently than on other exercise or physical activity–related topics. DCEs serving blind clients may benefit from familiarizing themselves with adaptive exercises so that they are able to discuss exercise recommendations with blind people with diabetes who may benefit from these adaptations.

Similarly, we found that both blind and nonblind participants reported receiving general education about nutrition and were less frequently counseled on specific nutrition strategies. This finding suggests a need to address topics surrounding physical activity and nutrition with greater specificity in DSMES for all people with diabetes. Blind people may also benefit from counseling on adaptive methods for purchasing and preparing nutritious foods.

We also found that nonblind participants were more likely to endorse receiving DSMES on treatment adherence importance over treatment adherence strategies but reported medication management strategies more frequently than medication management importance. We also found that, for both blind and nonblind participants, consultation on the use of nonsteroidal anti-inflammatory drugs was reported the least frequently among medication management topics. Long duration of use or taking too much of nonsteroidal anti-inflammatory drugs can bring on gastrointestinal health complications such as colitis. Perhaps this topic is not prioritized in routine DSMES in general.

Future research should examine the DSMES content and resources tailored for blind and low-vision people with diabetes. Diabetes and blindness special interest groups such as the American Council of the Blind's Diabetes in Action (21) and the National Federation of the Blind's Diabetes Action Network (22) provide information, meet-up opportunities, list serves, and other programs and resources to provide the most up-to-date information on accessibility workarounds for current diabetes technology. Other technologies that are making diabetes management more accessible include tools such as audio glucose meters that read glucose levels out loud, lancets that have a drum instead of having to individually place single lancets in a device; insulin pens that make an audible clicking sound as the pen is rotated to deliver units of insulin, and magnifiers that can be placed over a syringe to enlarge the lines that indicate the amount of insulin to deliver (23). Additionally, the Association of Diabetes Care and Education Specialists is creating opportunities for members to connect with peers for diabetes support (24). Future research can explore patient and care provider knowledge of these resources and adaptive strategies.

Overall, clinicians and blind people with diabetes need evidence-based resources and education about diabetes in blind people. Minimal resources and continuing education exist about treating blind people with diabetes, which may further exacerbate health disparities in this population. National and international diabetes organizations should create training resources to reduce the health disparities experienced by blind people with diabetes as well as resources to connect blind people to key information about and strategies for managing diabetes. Importantly, existing successful frameworks of education dissemination such as Project ECHO would likely be successful to train primary care providers on treating blind people with diabetes. Project ECHO provides

educational opportunities for clinicians, including live webinars and example patient case studies, to learn about the state-of-the-science clinical best practices (25).

Limitations and Future Directions

This study yielded novel findings to help in understanding critical gaps in DSMES experienced by blind people. Nevertheless, there are a few important limitations to consider. First, our results relied on self-reports from the patient perspective. We started this line of inquiry from the patient perspective because this perspective reflects the information retained from DSMES and thus serves as the available knowledge base for patients to move forward with day-to-day decision-making regarding their diabetes self-management. Future research is needed to determine whether content was actually covered as frequently as reported. Additionally, this study focused on adults 18–64 years of age. Future research should include older adults to explore DSMES content in this subpopulation of blind people.

The scope and depth of topics assessed were limited by the time and space constraints of the survey. Future research should further examine the content and quality of the DSMES blind people receive to determine its adequacy and disability sensitivity. Specifically, future research should delve into what strategies are taught, whether they systematically differ from strategies recommended to nonblind people, and the extent to which the recommended strategies are feasible and effective for blind people. Future research can also examine contextual variables associated with the quality and disability sensitivity of DSMES such as the location where DSMES was received. DSMES is typically provided in a clinical setting (e.g., at an endocrinology or primary care clinic). Furthermore, people who live close to vision rehabilitation centers may have easier access to disability-sensitive DSMES and DCEs with specialized training in nonvisual methods and strategies for managing diabetes. Additionally, future research can examine vision rehabilitation skills training that is related but not specific to diabetes management such as orientation and mobility, independent shopping and food preparation, and adaptive recreational physical activity. Finally, future research on DSMES for blind people may examine receipt of education about accessible durable medical equipment and workarounds to navigating initially inaccessible durable medical equipment.

Conclusion

The results of this study showed differences in the DSMES experience for blind and nonblind people with diabetes. These findings add to the literature on what blind people with diabetes experience in clinics in terms of health education. Given the interconnectedness of blindness and diabetes, the limited research examining the experiences of blind people with diabetes is a significant gap in public health knowledge. Importantly, understanding disparities in diabetes education can illuminate mechanisms underlying morbidity and mortality disparities experienced by blind people and help to develop a pathway for improved health care delivery and health outcomes.

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DUALITY OF INTEREST

No potential conflicts of interest relevant to this article were reported.

AUTHOR CONTRIBUTIONS

N.H. wrote and edited the manuscript, conceptualized the study, and collected the data. Q.H. wrote the first draft of the introduction. Z.G. wrote the first draft of the Methods section and contributed to the study conceptualization and data collection. B.P. contributed to the first draft of the introduction. A.S.H. contributed to interpretation of results and drafting of the Discussion section and edited the manuscript. J.E.B. contributed to interpretation of results and drafting of the Discussion section. Y.C. contributed to the conceptualization of the study and data collection. N.H. is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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