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Diabetes Health Literacy Among Somali Patients With Diabetes Mellitus in a US Primary Care Setting

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Keywords

Somali; Diabetes Literacy; Immigrant; Refugee; Spoken Knowledge in Low Literacy in Diabetes (SKILLD)

The prevalence of diabetes mellitus among immigrants and refugees to the United States is initially lower than that of the general population, but with increasing duration of residence, prevalence rises dramatically (1,2). Persons from Somalia constitute one of the largest proportions of African-born US immigrants for the past 2 decades. The prevalence of type 2 diabetes mellitus among Somali immigrants is not known, but a study of 72 Somali psychiatric patients showed an increased prevalence of diabetes (24%) among this group compared with non-Somali controls (3).

Among Somali immigrants with diabetes, measures of disease control are suboptimal when compared with non-Somali patients, suggesting an increased risk of complications (4,5). Reasons for these findings have not been explored, but in the general population, correlates of diabetes management include socioeconomic position, adherence to clinic visits, ethnicity, and diabetes literacy (6-9). Diabetes literacy is defined as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate decisions about their diabetes, and it is an important mediator of disease control. Improved diabetes literacy has been associated with better adherence to clinic visits, medications, and diet, and generally better glycemic control and diabetes outcomes (10,11).

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Compliance with Ethical Standards

Disclosure of potential conflicts of interest

Authors J. Njeru, M. Hagi Salaad, H. Haji, S. Cha, and M. Wieland, declare that they have no conflict of interest

Research involving Human Participants and/or Animals

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent

Informed consent was obtained from all individual participants included in the study.

Diabetes literacy among Somali immigrants and refugees to the United States has not been previously described, but general literacy levels in Somalia are low (38%) (12). We hypothesized that Somali immigrants and refugees had relatively low diabetes literacy and that low diabetes literacy would negatively affect diabetes outcomes (13). Therefore, we used an existing assessment instrument to determine diabetes health literacy among Somali patients in a primary care setting. We also sought to determine the associations, if any, between diabetes literacy and disease outcomes.

Methods

Study Setting and Participants

This cross-sectional survey and chart abstraction was conducted in the primary care internal medicine and family medicine clinics of an academic outpatient practice that provides primary care for approximately 130,000 patients in Minnesota through several clinic sites. Study participants were self-identified Somali adult immigrants or refugees, actively empanelled to the practice, and with a physician-assigned diagnosis of type 2 diabetes mellitus.

Identification of adult Somali patients with diabetes was achieved through the linkage of 2 databases. First, an existing natural language processing algorithm with excellent sensitivity and specificity for identifying Somali patients at our institution (14) was used to identify adult Somali patients empanelled to the primary care practices. Second, this patient list was cross-referenced with an existing institutional primary care diabetes registry used in the clinical practice for patient and population management of diabetes.

The identified cohort of current Somali patients with diabetes was then cross-referenced with future appointments in the clinical scheduling system. Patients were consecutively recruited for survey participation during their regularly scheduled clinical encounters from July 2013 through January 2014. During the time between completion of the rooming process and initiation of the provider visit, potential participants were approached for possible participation in the study. In these clinics, the rooming process is done by a clinical assistant or nurse, and prepares the patient for the visit with the clinician, including checking their vital signs and updating medication records. Those who agreed to be enrolled completed the survey, with help from the assigned clinic interpreter where applicable. Participants provided written informed consent, which was translated into Somali and the study was approved by the Mayo Clinic Institutional Review Board.

Measures

The primary outcome of the study was diabetes literacy, as measured by the Spoken Knowledge in Low Literacy in Diabetes (SKILLD) scale. This SKILLD scale was developed for low-literacy groups and consists of 10 items that are presented orally (15). It correlates well with the oral Diabetes Knowledge Test and has been validated in populations with a wide range of health literacy levels (16). Scores are reported as the percent correct (possible scores range from 0%-100%), with 0% representing lowest literacy, and 100% as the highest

possible score. The mean (SD) SKILLD score obtained in the development of this scale among patients with low literacy was 49.5% (23.7%); the range was 0% to 100% (15).

The SKILLD scale shows evidence of good validity across several languages with little revision (17). Because it has not been used previously among Somali-speaking patients, the study team translated the survey instrument into the Somali language using the World Health Organization process of translation and adaptation of instruments: forward translation, panel discussion (cognitive briefing), and backward translation (18). This process incorporates meaning, intention, and cultural context into the translated instrument. The translated survey was piloted and refined with Somali women who were not study participants. The Somali translation was used for the study participants who needed Somali interpretation, whereas the English version was used for the patients who were proficient in English (Appendix).

Demographic information, including age, sex, need for interpreter, current annual household income, highest education level completed, and years of residence in the United States were obtained from patient interview and chart abstraction. Duration of diabetes diagnosis was obtained through chart abstraction. Diabetes process measures (hemoglobin A1C within 6 months, low-density lipoprotein [LDL] cholesterol within 12 months, urine microalbumin within 12 months) and diabetes outcome measures (hemoglobin A1C, LDL cholesterol, blood pressure) were obtained through chart abstraction at the time of survey administration, using the most recent data available.

Analysis

The diabetes literacy level is indicated by the SKILLD scale score; a score of less than 50% correct is considered low, whereas a score of at least 50% correct is considered high (15,16). The mean SKILLD score for the entire study population was calculated. Patient demographic and clinical characteristics, diabetes process measures, and outcome measures were described using means for continuous variables and frequency (percentage) for categorical variables.

Two-sample *t* tests were used to assess differences in diabetes health literacy between the groups on the basis of demographic variables, and a multivariate logistic model was used to identify associations between diabetes literacy and each of the independent demographic and clinical variables.

Patients with low vs high SKILLD scores were compared using 2-sample *t* tests for differences in demographic and clinical characteristics. *P* values of .05 or less were considered significant. All statistical analyses were performed using SAS software (version 9.3; SAS Institute Inc).

Results

A total of 52 patients were identified and approached for the study. Two were excluded for inability to give informed consent because of cognitive impairment. Fifty patients completed the survey. Baseline characteristics are outlined in Table 1.

The mean SKILLD score for the entire group was 42.2%. Only questions regarding signs of hypoglycemia, importance of foot care, and frequency of eye examinations (questions 2, 5, and 6) were answered correctly by at least 50% of study participants (Table 2). Fewer than 40% of participants identified symptoms of hyperglycemia correctly (question 1). Whereas most patients knew the symptoms of hypoglycemia and how to treat it, only 1 articulated the need to recheck blood glucose levels after treatment. More than half the patients correctly named reasons for examining the feet, but less than a fifth identified the correct frequency of foot examination. The 2 questions that required naming specific numbers (normal fasting glucose levels and normal or goal hemoglobin A1C levels) were answered correctly by less than 20% of participants.

Patients with a high SKILLD score ($\geq 50\%$) were younger than patients with a low SKILLD score ($<50\%$) (Table 3). We observed no difference in sex, marital status, annual household income, type of insurance, education level, body mass index, duration of diabetes diagnosis, and type of diabetes medication (oral hypoglycemic agents vs insulin) among those with high vs low SKILLD scores. The 3 patients who did not require an interpreter had high scores. The diabetes process and outcome measures were not significantly associated with the SKILLD score.

Discussion

In this study, we report that diabetes health literacy was relatively low among Somali patients with diabetes mellitus. We had hypothesized that diabetes outcomes would be associated with the SKILLD score, which had been demonstrated in nonimmigrant populations with low literacy (15). However, our data did not support this hypothesis.

Diabetes knowledge is acquired over time through various learning opportunities and experiences. Methods of acquiring this information include peer learning, direct patient education by health care providers, written material, and common media such as television and radio. Duration of the diabetes diagnosis corresponds with diabetes knowledge (16); when comparing our cohort with that of Rothman et al (15), the average duration of diabetes was 5.8 vs 8.4 years and the average SKILLD scores were 42% vs 49%, respectively.

The reasons underlying the low literacy level were not directly assessed in this study, but survey participants did report low educational attainment, low annual family income, and limited English proficiency, all of which have been linked to low health literacy in general (10,19,20). Our study participants had multiple potential disruptions of knowledge acquisition opportunities, including living through a civil war in their country, living in refugee camps in neighboring countries, and immigrating to a country with a very different sociolinguistic culture. Competing priorities for safety and survival possibly decreased the importance of health education and knowledge acquisition, particularly for chronic diseases (21). Caring for patients with this background requires recognition of these particular learning needs and adapting disease management strategies accordingly.

In the current cohort, diabetes outcomes were not associated with the SKILLD score. Given the well-established association between health outcomes and literacy levels in general

(10,11), this finding should not imply that health literacy interventions should be ignored in this population. Instead, this study implies that the intersection between health literacy and diabetes outcomes should be tailored to this population. Traditional means of patient education for diabetes may not improve diabetes knowledge and outcomes among Somali immigrants. Three study personnel (H.H., M.F.H.S., and J.W.N.) who administered the survey qualitatively noted that most participants answered questions based on their own experience or their awareness of the experience of someone they knew personally. Experiential knowledge, defined as “information and wisdom gained from lived experience” (22), may be more important than the traditional paradigm of patient education in the health care setting and written education material. Experiential knowledge may be obtained from information and meanings gleaned through participation in a shared activity with members of a group or community, and this may be an important facilitator in molding health-related behavior (23). Distributed health literacy through family and social networks is a potential resource for managing chronic health conditions in this population (24).

The Somali community has a strong cultural tradition in which important life teachings are passed down from generation to generation in the form of stories (25), and narrative ways of teaching may have an important role in improving health literacy and diabetes outcomes (26,27). Incorporating new technology into the concept of storytelling is one way to improve patient education in chronic disease management by preserving aspects of the age-old model of information transfer while reaching a wide audience. This method has been an effective intervention among patients with hypertension (28,29). Adapting health literacy instructional strategies and health education material to targeted populations is important to ensure that effective learning actually occurs (30). Addressing structural challenges embedded in the current system may help improve long-term diabetes management, as shown in the health literacy pathway model, in which practical health literacy skills are developed over time and with interactions with the health care system (31).

We observed a discrepancy between high adherence to diabetes process measures but relatively poor diabetes outcome measures (average hemoglobin A1C was 8%). This difference is telling in that while the decision and duty to request the tests falls upon the health care provider, completion of these tests is incumbent on the patient. Although the patients in this study had a relatively low diabetes literacy level, most completed the indicated tests on time, suggesting that patient engagement in a trusting relationship with his or her provider may have a more important role than theoretical knowledge of disease alone. Completion of tests requires patient action, and a high level of testing adherence was evident in this study. In contrast, long-term diabetes self-management requires substantially more patient involvement than periodic blood and urine tests. This process likely would be positively influenced by a trusting relationship between patients and their primary care practice. Further work is needed to identify ways of translating high levels of adherence to process measures into improved diabetes outcomes.

Our study has limitations. Although the number of participants was relatively small, the study was appropriately powered to address our research questions. We further suspect that a larger sample size would not have changed our conclusions. Generalizability of our results may be limited by the fact that all the patients were from one county and empanelled to

primary care practices at a single institution. Finally, although the process of creating the Somali translation of the SKILLD survey ensured adequate face and content validity, further psychometric tests of validity were not applied.

Conclusion

Our cohort of Somali patients with diabetes mellitus showed relatively low diabetes literacy and suboptimal measures of diabetes disease control. However, we observed no association between diabetes literacy and diabetes outcomes. Future work aimed at reducing diabetes-related health disparities among Somali immigrants and refugees in high-income countries should go beyond traditional means of patient education for low-literacy populations.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations

LDL	low-density lipoprotein
SKILLD	Spoken Knowledge in Low Literacy in Diabetes

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Table 1

Baseline Characteristics, Diabetes Measures, and SKILLD Score (N=50)

Characteristic	Value
Age, mean (SD), y	52.54 (16.01)
Female, No. (%)	31 (62)
Marital status, No. (%)	
Single	4 (8)
Married	29 (58)
Divorced or separated	7 (14)
Widowed	10 (20)
Needed interpreter, No. (%)	47 (94)
Annual household income (in US dollars), No. (%)	
>20,000	45 (90)
20,000-40,000	3 (6)
>40,000-60,000	2 (4)
Health insurance type, No. (%)	
Private only	1 (2)
Government only	30 (60)
Both private and government	19 (38)
Highest education level attained, No. (%)	
No formal schooling	22 (44)
Elementary education	18 (36)
High school graduate	9 (18)
College graduate	1 (2)
Body mass index, mean (SD), kg/m ²	30.31 (4.45)
Body mass index category, No. (%) ^a	
Normal	6 (12)
Overweight	19 (38)
Obese	25 (50)
Duration of diabetes, mean (SD), y	5.08 (0.38)
Family history of diabetes, No. (%)	22 (44)
Diabetes treatment, No. (%)	
Diet only	2 (4)
Oral medication only	33 (66)
Insulin only	5 (10)
Both oral medication and insulin	10 (20)
Diabetes-related complications, No. (%)	
None	26 (52)
Retinopathy	7 (14)
Neuropathy	17 (34)
Nephropathy	14 (28)
Used glucometer, No. (%)	41 (82)

Characteristic	Value
Diabetes process measures, No. (%)	
Hemoglobin A1C within the past 6 mo	46 (92)
Urine microalbumin within the past 12 mo	44 (88)
Low-density lipoprotein cholesterol within the past 12 mo	45 (90)
Diabetes outcome measures, mean (SD)	
Hemoglobin A1C, %	8.01 (1.64)
Systolic blood pressure, mm Hg	130.9 (15.4)
Diastolic blood pressure, mm Hg	70.2 (9.5)
Low-density lipoprotein cholesterol, mg/dL	99.2 (32.7)
SKILLD score, mean (SD), % correct	42.2 (15.0)

Abbreviation: SKILLD, Spoken Knowledge in Low Literacy in Diabetes.

^aNormal body mass index was defined as 18.5-24.9 kg/m²; overweight, 25-29.9 kg/m²; obese, ≥ 30 kg/m².

Table 2

Responses to Individual Items in the SKILLD Scale (N=50)

Question No. ^a	Knowledge Item	Answered Correctly, No. (%)
1	Signs of hyperglycemia	19 (38)
2	Signs of hypoglycemia	42 (84)
3	Treatment of hypoglycemia	1 (2)
4	Frequency of foot care	8 (16)
5	Importance of foot care	26 (52)
6	Frequency of eye examinations	29 (58)
7	Normal fasting glucose	6 (12)
8	Normal hemoglobin A1C	8 (16)
9	Frequency of exercise	12 (24)
10	Long-term complications of diabetes mellitus	20 (40)

Abbreviation: SKILLD, Spoken Knowledge in Low Literacy in Diabetes.

^aOriginal SKILLD questions and Somali translations are shown in the Appendix.

Table 3

Characteristics of Participants, Stratified by Low or High Diabetes Literacy

Variable	Low Diabetes Literacy (SKILLD Score <50%) (n=30)	High Diabetes Literacy (SKILLD Score ≥50%) (n=20)	P Value
Age, mean (SD), y	56.27 (13.09)	46.95 (18.57)	.04
Female sex, No. (%)	20 (67)	11 (55)	.41
Marital status, No. (%)			.40
Single	2 (7)	2 (10)	
Married	17 (57)	12 (60)	
Divorced or separated	6 (20)	1 (5)	
Widowed	5 (17)	5 (25)	
Needed interpreter, No. (%)	30 (100)	17 (85)	.03
Annual family income (in US dollars), No. (%)			.08
<20,000	29 (97)	16 (80)	
20,000-40,000	0 (0)	3 (15)	
>40,000-60,000	1 (3)	1 (5)	
Health insurance type, No. (%)			.64
Private only	1 (3)	0 (0)	
Government only	17 (57)	13 (65)	
Both private and government	12 (40)	7 (35)	
Highest education level attained, No. (%)			.79
No formal schooling	12 (40)	5 (25)	
Elementary education	10 (33)	8 (40)	
High school graduate	5 (17)	4 (20)	
College graduate	3 (10)	3 (15)	
Body mass index, mean (SD), kg/m ²	30.42 (4.84)	30.15 (3.90)	.84
Body mass index category, No. (%) ^a			.25
Normal	5 (17)	1 (5)	
Overweight	9 (30)	10 (50)	
Obese	16 (53)	9 (45)	
Duration of diabetes, mean (SD), y	5.59 (0.17)	4.32 (0.70)	.72

Variable	Low Diabetes Literacy (SKILLD Score <50%) (n=30)	High Diabetes Literacy (SKILLD Score ≥50%) (n=20)	P Value
Family history of diabetes, No. (%)	14 (47)	8 (40)	.64
Diabetes treatment, No. (%)			.72
Diet only	1 (3)	1 (5)	
Oral medications only	20 (67)	13 (65)	
Insulin only	4 (13)	1 (5)	
Both oral medications and insulin	5 (17)	5 (25)	
Diabetes-related complications, No. (%)			
None	12 (40)	14 (70)	.04
Retinopathy	5 (17)	2 (10)	.51
Neuropathy	12 (40)	5 (25)	.27
Nephropathy	10 (33)	4 (20)	.30
Used glucometer	24 (80)	17 (85)	.65
Diabetes process measures, No. (%)			
Hemoglobin A1C within the past 6 mo	28 (93)	18 (90)	.67
Urine microalbumin within the past 12 mo	26 (87)	18 (90)	.72
Low-density lipoprotein cholesterol within past 12 mo	27 (90)	18 (90)	>.99
Diabetes outcome measures, mean (SD)			
Hemoglobin A1C, %	7.86 (1.65)	8.22 (1.65)	.46
Systolic blood pressure, mm Hg	131.37 (13.63)	130.20 (18.09)	.80
Diastolic blood pressure, mm Hg	68.13 (9.22)	73.35 (9.26)	.06
Low-density lipoprotein cholesterol, mg/dL	99.17 (37.29)	99.35 (25.09)	.98

Abbreviation: SKILLD, Spoken Knowledge in Low Literacy in Diabetes.

^aNormal body mass index was defined as 18.5-24.9 kg/m²; overweight, 25-29.9 kg/m²; obese, ≥30 kg/m².