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Pilot Feasibility Study of A Digital Storytelling Intervention for Immigrant and Refugee Adults with Diabetes

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Abstract

Purpose—The purpose of this pilot feasibility project was to examine the potential effectiveness of a digital storytelling intervention designed through a community-based participatory research approach for immigrants and refugees with type 2 diabetes mellitus (T2DM).

Methods—The intervention was a 12-minute culturally and linguistically tailored video consisting of an introduction, 4 stories, and a concluding educational message. A structured interview was used to assess the intervention for acceptability, interest level, and usefulness among 25 participants with T2DM (15 Latino, 10 Somali) across 5 primary care clinical sites. After watching the video, participants rated their confidence and motivation about managing T2DM as a result of the intervention. Baseline hemoglobin A_{1c} (A1C) and follow-up values (up to 6 months) were abstracted from medical records.

Results—All participants reported that the intervention got their attention, was interesting, and was useful; 96% reported that they were more confident about managing their T2DM than before they watched the video; and 92% reported that the video motivated them to change a specific behavior related to T2DM self-management. The mean baseline A1C level for the intervention

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participants was 9.3% (78 mmol/mol). The change from baseline to first follow-up A1C level was -0.8% (-10 mmol/mol) ($P<.05$).

Conclusions—Implementation of a digital storytelling intervention for T2DM among immigrant populations in primary care settings is feasible and resulted in self-rated improvement in psychosocial constructs that are associated with healthy T2DM self-management behaviors, and there was some evidence of improvement in glycemic control. A large-scale efficacy trial of the intervention is warranted.

Keywords

digital storytelling; Hispanic; immigrant and refugee health; Latino; Somali; type 2 diabetes mellitus

Immigrants and refugees often arrive in the United States healthier than most Americans,¹ but with time their health becomes similar to that of the general population, including with regard to unhealthy cardiovascular risk factors and incidence of type 2 diabetes mellitus (T2DM).² Unfortunately, when T2DM does develop, immigrants often do not receive the recommended T2DM-related health care services or adhere to health care recommendations, which leads to suboptimal diabetes outcomes.^{3,4} Furthermore, physical activity levels, diet, and medication adherence are lower or less healthy among immigrants than the general US population.⁵ Critical factors contributing to this disparity among immigrants and refugees include social and environmental conditions,^{6,7} low health literacy,⁸ and a cultural framework that may not include chronic disease management.⁹

Narrative-based (storytelling) interventions incorporate culture-centric health messaging to promote behavior change among vulnerable and underserved populations.^{10,11} Storytelling interventions for behavior change use narratives that resonate with targeted populations either through direct quotes from representative members or through story compositions inspired by culturally embedded informants.¹²⁻¹⁴ The ways in which stories elicit behavioral health changes have been conceptualized as *identification* and *transportation*. When narrative is drawn from within populations, *identification* with the storytellers is an important step for engagement, empowerment, and reframing the social norms of the listener.¹⁵⁻¹⁹ *Transportation* of the listener into the story is likewise important to generate persuasive effects for behavior change.^{17,20-23} In support of this premise, a group-based storytelling intervention for foreign-born patients in the United Kingdom demonstrated feasibility and acceptability of this approach among immigrants and refugees with T2DM in face-to-face (workshop) settings.²⁴ Storytelling interventions may be especially useful among immigrants, for whom communication barriers may make existing health education methods less effective²⁵ and among groups with strong oral traditions,²⁶ including those from Somalia and Latin America.^{27,28}

Narrative-based video interventions, in which story components are incorporated into health communication media, provide the opportunity for wide dissemination and inclusion of consistent content (ie, reproducibility) to promote positive health behavior change. Previous research has demonstrated that narrative-based video interventions are more likely to elicit positive motivations for healthful behaviors than non-narrative video messaging for cervical

cancer screening,¹⁴ breast cancer screening,^{14,29} and smoking cessation³⁰ among African American and Hispanic populations. A literature search yielded 3 published studies evaluating the effects of narrative-based video interventions on health behaviors or other outcomes. Larkey and colleagues³¹ reported no significant difference between a storytelling video intervention and a personal risk tool intervention for colorectal cancer screening among low-income patients, although engagement with stories facilitated positive attitudes associated with behavior change. In the first randomized trial of a storytelling video intervention for chronic disease management, Houston and colleagues³² demonstrated efficacy comparable to adding a medication for treatment of uncontrolled hypertension among African American women viewers. Furthermore, Campbell and colleagues³³ established the promising role of storytelling videos in management of diabetes mellitus through a randomized trial among patients with T2DM in Australia, which demonstrated significant improvements in self-reported T2DM self-management (diet, exercise, and glucose monitoring) among viewers.

Digital storytelling interventions are narrative-based videos elicited through a community-based participatory research (CBPR) approach that highlights the authentic voices of participants overcoming obstacles to health-promoting behaviors.³⁴ They differ from other forms of narrative-based videos in that participants are central to the production of knowledge. Through a group-based digital storytelling workshop, storytellers build their own narrative, choose images and sounds that best represent their experiences, and are guided through hands-on computer editing.²⁴ Through a process of social construction, participants work together to develop meaningful health behavior messages. This is different from media, in which experiences are generalized for communities (eg, documentary stories). Instead, groups of participants contribute to the shared understanding of each individual's story and strategies for success. This process has been used to empower participants through personal reflection³⁵⁻³⁷ and as a tool for health advocacy,³⁸ but the resultant storytelling videos can also shape health behaviors of viewers through influences on attitudes and beliefs.³⁹ Formative studies have demonstrated cultural acceptability and emotional engagement in response to a digital storytelling intervention derived through CBPR processes for cancer education among Alaska Native people.^{26,40} We are aware of no published studies evaluating the effects of digital storytelling interventions on health outcomes of viewers.

In examining novel methods to help reduce health disparities, authors of a recent systematic review identified the need for more culturally tailored chronic disease management interventions that incorporate health technology,⁴¹ but to date there are no published reports of interventions using narrative (storytelling) media for diabetes mellitus among minority or immigrant populations. The research team has previously reported on the development of a digital storytelling intervention using a CBPR approach for T2DM self-management among immigrants and refugees with poorly controlled diabetes.^{42,43} The purpose of this pilot feasibility project was to examine the potential effectiveness of a digital storytelling intervention designed through a community-based participatory research approach for immigrants and refugees with T2DM.

Methods

Research Design

The study included 2 components. The first was a cross-sectional structured interview to assess the intervention for acceptability, interest level, and usefulness among 25 participants with T2DM (15 Latino, 10 Somali). After watching the video, participants rated their confidence in and motivation for managing T2DM as a result of the intervention. The second component was a cohort study of hemoglobin A_{1c} (A1C) values among intervention participants compared with propensity-matched controls, measured up to 6 months after baseline values. This approach was used to demonstrate the feasibility of implementing the intervention in primary care settings and to generate preliminary evidence for intervention acceptability and its effect on T2DM behavioral intentions and process outcomes.

Study Setting and Participants

For this study, the digital storytelling intervention (42) was pilot tested with Latino and Somali patients at 5 health care institutions: 1) a nonprofit, academic health care institution that provides primary care to approximately 140,000 patients in a Midwestern city; 2) a nonprofit multispecialty health care network that provides primary care to patients in a several-county region; 3) a federally qualified health center serving mostly Latino patients in a Midwestern city; 4) a public academic health care institution that provides primary care to approximately 90,000 patients in a large Midwestern metro region; and 5) a community health center that provides primary care for approximately 70,000 patients in a large Southwestern metro region. The study was conducted at these sites in preparation for a future larger clinical trial and to test implementation feasibility in heterogeneous primary care settings. The study took place between September 2015 and March 2016. Institutional review board approval was obtained for study procedures at all sites.

Eligibility criteria included self-identifying as Hispanic or Latino or Somali; age between 18 and 70 years; receiving primary care at one of the participating clinical sites; at least 1 office visit within the previous 12 months to the primary care site; diagnosis of T2DM in the medical record; and T2DM diagnosis for 6 months or longer. Eligible patients were identified through existing registries of primary care patients with T2DM at each health care institution. At most sites, these patients were contacted by telephone before a planned visit to their primary care office to explain the study and to assess preliminary interest in participating. Enrollment was then conducted among sequential eligible patients before, during, or after clinic visits at each site until the target number of 5 participants per site (25 total) was accrued. Participants who provided written informed consent were enrolled into the study.

Intervention Development and Delivery

The impetus for the intervention emerged from a long-standing community-academic partnership (CAP), the Rochester Healthy Community Partnership (RHCP). The mission of this CAP is to promote health and well-being among the local community through CBPR, education, and civic engagement to achieve health equity.⁴⁴ Since its inception in 2004, the CAP has become productive and experienced at deploying data-driven programming and

outcomes assessment among immigrant and refugee populations.^{45,46} The CAP community and academic partners identified T2DM as a priority area for intervention work. The ensuing partnership discussions drew from lessons learned through previous work together and personal experiences to inform a strategy whereby community partners may inform clinical practice. The digital storytelling framework was adapted by the partnership.

Details of participatory intervention development have been reported elsewhere.^{42,43,47} Narrative theory¹⁰ and social cognitive theory⁴⁸ formed the conceptual basis for intervention development. First, a survey was developed by community and academic partners to understand knowledge, attitudes, and behaviors regarding T2DM among the Latino and Somali populations in one of the communities.^{43,47} Second, focus groups were conducted to further inform intervention content and to identify gifted storytellers.⁴² Third, these storytellers were recruited by community partners, and their stories about diabetes self-management (physical activity, diet, medication adherence, glucose self-monitoring) were systematically captured, recorded, and edited to derive the final intervention products,⁴² available in Spanish and Somali in digital formats and DVD.

The digital intervention package for each group (Latino and Somali) includes a brief introduction by a CAP community partner, 4 individual stories with transitions, and a short closing educational message reinforcing the 4 diabetes self-management behavioral goals (healthy diet, physical activity, medication adherence, and glucose self-monitoring). The Spanish language digital intervention package is 12 minutes long; the Somali digital intervention is 13 minutes long. The intervention was delivered by a study member in a private room in the clinic during a regularly scheduled visit to each patient's primary care clinic.

Data Collection

After viewing the digital storytelling intervention, participants completed a face-to-face structured interview that was delivered by a language-congruent study member or by a study member assisted by a professional medical interpreter. In addition to demographic variables, items for the survey were adapted from a health communication assessment tool produced by the National Cancer Institute,⁴⁹ including acceptability of the storytelling video and the extent to which participants perceived the video as interesting, useful, and able to capture their attention. Furthermore, the survey asked participants to rate their confidence (self-efficacy) and motivation about managing their diabetes as a result of watching the storytelling video. Participants were also asked open-ended questions about the perceived main message(s) of the video and any new behavioral intentions after watching the video. Study members marked participants' responses to these 2 items according to a prepopulated list of potential answers; if responses did not match one of these themes, then "other" was recorded. Finally, participants were asked whether they would show the video to family members or friends with diabetes if the video was made available.

To supplement the survey data, electronic health record abstraction was performed by study personnel to collect the diabetes-related health status of each patient, including laboratory values, blood pressure, duration of T2DM diagnosis, diabetes complications, and medications.

A control cohort of patients was derived from diabetes registries at each site (n=25) matched to each intervention patient by site, race/ethnicity (Hispanic or Somali), and baseline A1C value ($\pm 0.5\%$). Follow-up A1C values were abstracted up to 6 months after baseline for all patients in the intervention and control groups. These tests were performed in accordance with usual clinical care at each site; their timing and collection were not influenced by study procedures.

Data Analysis

Survey and abstracted health record data were reported using descriptive statistics. A paired-samples *t* test was used to assess changes in A1C value among intervention participants from baseline to the first follow-up value. An independent-samples *t* test was used to compare the change in A1C value between intervention participants and controls. All analyses were performed using SAS version 9.3 (SAS Institute, Inc). $P < .05$ was considered statistically significant.

Results

Twenty-five patients participated in the intervention evaluation, including 5 from each site (15 Latino, 10 Somali). The demographics and diabetes-related health status of the study participants are shown in Table 1.

The intervention evaluation demonstrated high acceptability (Table 2); 100% of participants reported that the intervention got their attention, was interesting, and was useful. In an open-ended question, participants reported a range of “main messages” coinciding with each of the behavioral domains (physical activity, healthy diet, medication adherence, glucose self-monitoring), that extended to behavioral intentions across each of these domains.

Furthermore, 96% of participants reported that they were more confident about managing their diabetes than before they watched the video (self-efficacy); 92% of participants reported that the video motivated them to change a specific behavior related to diabetes self-management; and 100% of participants reported that they would show it to family members or friends with diabetes if it was made available.

The mean baseline A1C value for the intervention participants was 9.3% (78 mmol/mol). The change from baseline to first follow-up A1C value was -0.8% (-10 mmol/mol) ($P=.02$). This improvement was most pronounced for the 15 Latino participants (-1.2% [-14 mmol/mol] change from baseline; $P=.04$), particularly among the 13 Latino participants with baseline A1C values of 7% (53 mmol/mol) or greater (-1.5% [-17 mmol/mol] change from baseline; $P=.03$). The change among Somali participants was not statistically significant (-0.4% [-4 mmol/mol] change from baseline; $P=.36$).

There were no differences in age, gender, or baseline A1C value between pilot participants (n=25) and matched controls (n=25) (Table 3). The change from baseline to first follow-up A1C measurement was -0.8% (-10 mmol/mol) for the intervention group and -0.4% (-4 mmol/mol) for the controls ($P=.31$). For Latino participants, the change was -1.2% (-14 mmol/mol) for the intervention group and -0.4% (-4 mmol/mol) for controls ($P=.28$). For Latino patients with baseline A1C values of 7% (53 mmol/mol) or greater, the change was

–1.5% (–17 mmol/mol) for the intervention group and –0.5% (5 mmol/mol) for controls ($P=.16$). For Somali patients, there were no differences between the intervention group and controls.

Discussion

This study demonstrated that implementation of a digital storytelling intervention for T2DM among immigrant and refugee populations in a primary care clinical setting is feasible and practical. Furthermore, the intervention was perceived as highly acceptable, interesting, and useful to both Latino and Somali patients with T2DM. To our knowledge, this is the first published evaluation of a digital storytelling intervention among these patient populations. The participatory development and implementation of this intervention is an example of community informing practice. If found to be effective, this intervention represents a potentially scalable, low-cost, high-reach intervention targeting vulnerable populations.

This study demonstrated the feasibility of implementing a digital storytelling intervention across heterogeneous primary care practice settings. One lesson learned from the enrollment process was that the intervention should be delivered with a scheduled diabetes visit, rather than an acute appointment or other visit that is unrelated to T2DM. Furthermore, implementation should be tailored to the individual context of each clinical practice.

The vast majority of participants reported improvements in self-efficacy and motivation for T2DM self-management as a result of watching the video. Previous research has shown that enhanced self-efficacy results in improved self-management for patients and populations with T2DM.⁵⁰ Likewise, self-efficacy is associated with diabetes self-management behaviors among Latino populations.^{51,52} Furthermore, improvements in autonomous motivation have been shown to be associated with enhanced glycemic control among patients with T2DM.⁵³ Therefore, it is an important finding that participants improved both their confidence and motivation for diabetes self-management.

A key difference between digital storytelling interventions and other narrative-based videos is that storytellers are not constrained by prewritten scripts or edited interviews. Although this approach fosters authenticity, the resultant story content is at risk for omitting key constructs for effective disease management. To examine how closely the video content followed standard medical care for T2DM, in an unprompted question, viewers in this study reported that the main messages of the video included all of the key behavioral constructs for T2DM self-management (physical activity, dietary quality, medication adherence, self-monitoring of blood glucose). Furthermore, participants reported that they intended to change specific behaviors according to these domains as a result of watching the video. This saturation of messaging in a digital storytelling format was most likely facilitated by the fact that 4 stories were included for each group.

In terms of health status changes, the A1C value decreased significantly from baseline to first follow-up among study participants who viewed the digital storytelling intervention. This improvement was most pronounced among Latino patients with a baseline A1C value of 7% (53 mmol/mol) or higher. The effect size was attenuated by the addition of a control

group. Nevertheless, the estimated effect size gleaned from this small, nonrandomized pilot study suggests the possibility of a clinically relevant improvement in T2DM outcomes as a result of intervention exposure.

There is some indication that although the storytelling intervention was well received by both Latino and Somali patients, the intervention may have produced greater improvements in A1C value in the Hispanic participants than the Somali participants. This finding may result from the small sample size, lack of randomization, or lack of standardized follow-up of A1C, or perhaps the storytelling intervention produced longer-lasting health behavior changes in the Latino participants. The ways in which different immigrant populations benefit from storytelling interventions warrant further exploration.

This study has several limitations. First, this was a matched case-control design, so participants were not randomly assigned to treatment conditions and, therefore, study participants may have differed from the control participants on unmeasured psychological or health behavior factors and characteristics. Additionally, although the control group was matched to the intervention group according to key variables, the evaluation of glycemic control outcomes was limited by a nonrandomized design, lack of standard time of measurement, and insufficient power to detect clinically meaningful differences in A1C. Furthermore, the follow-up A1C values were obtained at intervals dictated by the clinical practices rather than study procedures. Moreover, a pre-post design was not used to assess changes in psychosocial constructs. Instead, participants' self-rated improvements were recorded after watching the video. Finally, study participants were drawn from Latino and Somali groups only, with implications for generalizability to other populations.

Conclusions

This nonrandomized pilot study demonstrated that implementation of a digital storytelling intervention for T2DM among immigrant and refugee populations in primary care settings is feasible and acceptable and resulted in improvements in psychosocial constructs that are associated with healthy T2DM self-management behaviors. Furthermore, the observed changes in glycemic control suggest the possibility of a clinically relevant improvement in T2DM outcomes, which indicates that a large-scale efficacy trial of the intervention is warranted. Processes and products of this study are relevant to other communities aiming to improve chronic disease management through CBPR and digital storytelling.

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Abbreviations

A1C	hemoglobin A _{1c}
CAP	community-academic partnership
CBPR	community-based participatory research
T2DM	type 2 diabetes mellitus

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Table 1**Demographics and Health Status**

Characteristic	Value^a (N=25)
Age, y	52.8 (13)
Women	13 (52)
Race/ethnicity	
Latino	15 (60)
Somali	10 (40)
Born outside the United States	23 (92)
Limited English proficiency (speak English less than very well)	23 (92)
Health insurance	
Private	2 (8)
Medicaid	12 (48)
Medicare	2 (8)
None	6 (24)
Other	3 (12)
Employment status	
Employed ≥ 35 h/wk	5 (20)
Employed <35 h/wk	3 (12)
Unemployed	17 (68)
Education level	
8 grades or less	13 (52)
Some high school	3 (12)
High school graduate or GED	7 (28)
College or graduate degree	2 (8)
Duration of T2DM diagnosis, y	8.8 (6.1)
A1C value	
%	9.4 (2.3)
mmol/mol	79 (19.3)
LDL cholesterol, mg/dL	103.7 (34.9)
Systolic blood pressure, mm Hg	134.7 (24.4)
Daily aspirin use	12 (48)
Tobacco use	4 (20)
T2DM complications	
Nephropathy	3 (12)
Retinopathy	4 (16)
Neuropathy	4 (16)
T2DM medications	
Metformin	22 (88)
Sulfonylureas	9 (36)
Other pills	5 (20)

Characteristic	Value ^a (N=25)
Insulin	6 (24)

Abbreviations: GED, General Educational Development; LDL, low-density lipoprotein; T2DM, type 2 diabetes mellitus.

^aValues are mean (SD) or No. (%).

Table 2

Stories for Change Intervention Evaluation

Domain	Value ^a (N=25)
What is your general reaction to the video?	
Very acceptable	24 (96)
Somewhat acceptable	1 (4)
Not acceptable	0
Does the video get your attention?	
Yes, very much	24 (96)
Somewhat	1 (4)
No	0
Is the video interesting?	
Yes, very much	25 (100)
Somewhat	0
No	0
Is the video useful?	
Yes, very much	25 (100)
Somewhat	0
No	0
After watching the video, rate your confidence about managing your diabetes.	
Much more confident	20 (83)
Somewhat more confident	4 (17)
No more confident	0
Don't know	1 (4)
If the video was available, would you show it to family members or friends who have diabetes?	
Yes	25 (100)
No	0
What is the main message of the video?	
People with diabetes should eat a healthy diet	16 (64)
People with diabetes should follow advice from their doctor	12 (48)
People with diabetes should take medications as directed	9 (36)
People with diabetes should be physically active	6 (24)
People with diabetes should monitor their disease	5 (20)
Other	10 (40)
Does watching the video make you want to do anything different to manage your diabetes?	
Yes	23 (92)
No	2 (8)
What do you intend to do differently as a result of watching the video?	(n=23)
Eat a healthier diet	18 (78)
Take medications as directed	11 (48)
Be more physically active	11 (48)

Domain	Value ^a (N=25)
Improve blood glucose self-monitoring	3 (13)
Ask others for support	2 (9)
Other	8 (35)
Change in A1C from baseline to follow-up	
Latino participants (n=15)	-1.2% (-14 mmol/mol) (<i>P</i> =.04)
Somali participants (n=10)	-0.3% (-4 mmol/mol) (<i>P</i> =.36)
Overall (N=25)	-0.8% (-10 mmol/mol) (<i>P</i> =.02)

^aValues are No. (%) unless otherwise stated.

Table 3

Glycemic Control Outcomes

Variable	Intervention Group ^a				Control Group ^a				P Value
	Latino (n=15)	Somali (n=10)	Total (N=25)	Latino (n=15)	Somali (n=10)	Total (N=25)	Latino (n=15)	Somali (n=10)	
Age, y	52.1 (12.8)	53.7 (13.8)	52.8 (13)	55.1 (8.5)	62.8 (15.5)	58.2 (12.1)	.44	.31	.23
Women	8 (53)	5 (50)	13 (52)	7 (47)	5 (50)	12 (48)	.72	> .99	.78
No health insurance	6 (40)	0	6 (24)	7 (47)	0	7 (28)	.71	> .99	.75
Baseline A1C value							.88	.88	.82
%	9.8 (2.7)	8.5 (1.4)	9.3 (2.3)	9.7 (2.2)	8.7 (1.4)	9.3 (1.9)			
mmol/mol	84 (23.4)	69 (11.4)	78 (19.3)	83 (18.8)	72 (11.6)	78 (15.9)			
Follow-up A1C value							.30	> .99	.38
%	8.6 (2.1)	8.2 (1.6)	8.4 (1.9)	9.4 (2.2)	8.3 (1.4)	8.9 (1.9)			
mmol/mol	70 (17.1)	66 (12.9)	68 (15.4)	79 (18.5)	67 (11.3)	74 (15.8)			
Change from baseline to follow-up A1C value							.28	.91	.31
%	-1.2 (2.0)	-0.4 (1.2)	-0.8 (1.7)	-0.4 (2.1)	-0.3 (1.1)	-0.4 (1.7)			
mmol/mol	-14 (23.3)	-3 (9)	-10 (21.3)	-4 (21)	-5 (18.3)	-4 (17)			

^aValues are mean (SD) or No. (%).