Journal of Clinical & Translational Endocrinology 31 (2023) 100313

Contents lists available at ScienceDirect

Journal of Clinical & Translational Endocrinology

journal homepage: www.elsevier.com/locate/jcte

A picture is worth a thousand words: A culturally-tailored video-based approach to diabetes education in Somali families of children with type 1 diabetes

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ARTICLE INFO

Keywords:
T1D
HbA1c
Somali
Culture
Diabetes education

ABSTRACT

Objectives: Type 1 diabetes (T1D) is highly prevalent in Somali immigrant children and hemoglobin A1c (HbA1c) levels are elevated in this population compared to non-Hispanic Whites. Current self-management diabetes education has not been tailored to this population. We aimed to improve delivery of T1D education to Somali immigrants by developing and testing a culturally-appropriate video-based curriculum.
Methods: This cross-sectional study involved Somali youth ≤ 19 years with T1D followed at two pediatric tertiary centers in Minnesota. Ten Somali-language T1D education videos were developed (~60 min for total program) based on core ADA curriculum and tailored to address cultural concerns and misconceptions. A diabetes knowledge questionnaire was administered to parents of all participants and to children aged ≥12 years. Pre- and post-educational session questionnaire mean scores were compared using a paired *t*-test to assess knowledge improvement immediately post-video education (primary endpoint) and retention at 3 months (secondary endpoint). HbA1c was measured pre- and 6 months post education (exploratory endpoint).
Results: Twenty-two Somali parents of 22 children participated (mean age 12.3 ± 4 years; 36 % female), 12 children ≥12 years. Diabetes knowledge scores significantly improved immediately post-video education compared to baseline ($p = 0.012$). This improvement persisted 3 months later ($p = 0.0008$). There was no significant change in mean HbA1c from baseline at 6 months post education (9.0 ± 1.5 % vs 9.3 ± 1.9; $p = 0.6$).
Conclusion: Culturally and linguistically tailoring diabetes education materials to African immigrants and delivering it audio-visually could improve effectiveness of diabetes education and increase knowledge and retention compared to simply translating standard diabetes education materials. The effect on HbA1c needs further study with a larger sample size.

Introduction

The University of Minnesota (UMN) and Children's Hospitals and Clinics of Minnesota (CHCM) follow increasing numbers of African immigrant children, the largest proportion coming from Somalia. At least 45,000 Somalis live in Minnesota, and their children have a high prevalence of type 1 diabetes (T1D) [1]. Approximately 1 in 300 Minnesota Somali children and adolescents have T1D. This is similar to diabetes prevalence in non-Hispanic Whites in the US (1 in 300 by age 18 years) and significantly higher than in African Americans (1 in 375 by age 18 years) [2], and is comparable to the prevalence of T1D among Finnish children (the highest in the world, 1 in 270 or 37 per 10,000) [3]. While acute and chronic illness and even well-child care can be challenging for all young patients, children born to recent immigrants

Abbreviations: ADA, American Diabetes Association; CDE, Certified Diabetes Educator; CHCM, Children's Hospitals and Clinics of Minnesota; HbA1c, Hemoglobin A1c; SD, Standard deviation; T1D, Type 1 diabetes; UMN, University of Minnesota; US, United States.

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https://doi.org/10.1016/j.jcte.2023.100313
Received 21 August 2022; Received in revised form 23 January 2023; Accepted 30 January 2023
Available online 4 February 2023

from resource-poor nations face special challenges, including language barriers, low parental education levels, cultural and religious influences, gender isolation, traditional diets, low socio-economic status, potential physical and psychological trauma, and the psychosocial stressors inherent in immigration. Medical adherence may be compromised if families don't understand or don't trust medical recommendations. Similar to data published from Finland and by others, Minnesota pediatric Somali patients with T1D have higher HbA1c levels (9.5 ± 1.6 %) compared to non-Hispanic White peers (8.8 ± 1.6 %) ($p = 0.01$) [3–5].

Successful management of T1D requires that patients and families understand and perform multiple complex tasks each day. There is a plethora of published studies, spanning different age groups, race/ethnicity, and type of diabetes, emphasizing the critical importance of diabetes self-management on successful glycemic control and positive health outcomes [6–11]. Thus, self-management education is recognized as the cornerstone of treatment, and T1D education materials and programs are well developed at every diabetes center in the US following standards set forth by the American Diabetes Association (ADA). Data supporting culturally-tailored diabetes education in individuals with type 2 diabetes is well represented in the literature [12–16]. However, this is not the case in T1D, where data on culturally-tailored education are scant and greatly needed [17,18].

Our usual diabetes self-management diabetes educational practices are not tailored to Somali immigrants. Therefore, a new approach may be needed to better overcome health disparities in this population [4]. Published data support that the use of video education for health literacy in the Somali population is accepted and effective [19–21]. Furthermore, research in other minority groups has shown the importance of culturally-specific diabetes self-management education to improve diabetes knowledge, adherence and glycemic control [22,23]. The objective of this study was to improve diabetes knowledge in Somali immigrant families of children with T1D who had previously received our standard education curriculum designed according to ADA T1D recommendations [24]. We developed and tested a new format for diabetes education in this population, using a video-based, culturally-appropriate, language-specific approach. *We hypothesized that diabetes knowledge would significantly improve in parents and patients aged 12 and older immediately following the tailored video education program, and that this knowledge would persist after 3 months.*

To achieve this goal, we worked with Somali healthcare professionals and community members. We developed an oral, Somali-language, video-based T1D education program tailored to Somali immigrant families, accounting for factors such as parental literacy and numeracy level, culture, and religion. We then tested the efficacy and acceptability of these materials on a different group of Somali patients followed at UMN and CHCM who had previously received usual T1D education.

Materials and methods

Participants

For this study, we included pediatric patients aged 1–19 years of Somali ancestry with T1D of at least 6 months duration, who had previously received routine diabetes education and who live in the greater Minneapolis-St. Paul-Bloomington metro area, Minnesota. Patients followed at the University of Minnesota (UMN) Pediatric Diabetes Clinic and at Children's Hospitals and Clinics of Minnesota (CHCM) in the period from January 1st, 2017 to January 31st, 2018 were identified and recruited during routine clinic appointments by the treating providers at each institution with the assistance of a Somali interpreter. Hemoglobin A1c (HbA1c) data were obtained from the electronic medical record, including the HbA1c within the 3 months preceding enrollment in the study as their baseline HbA1c (pre-video HbA1c).

The study was approved by the UMN and CHCM Institutional Review Boards. Written informed consent and assent were obtained from parents/guardians (in English or Somali, based on participant preference) through an interpreter, and from participating children older than age 6.

Usual education

Our programs routinely deliver initial comprehensive diabetes education at T1D diagnosis, with ongoing education at subsequent follow-up visits. The initial education at UMN takes place in the outpatient clinic over several days and approximately 5–6 h, and covers all of the education topic areas recommended by the ADA [24]. This education is delivered one-on-one with a diabetes educator and in the case of Somali patients, in the presence of an interpreter. CHCM has a similar program, but it is generally delivered in the inpatient setting.

Focus groups to understand the needs of the Somali community

Two focus groups met at a Somali community center, each comprised of 8–10 interested Somali parents of children with T1D and patients aged 12 and older followed at UMN and CHCM (with or without their children), two pediatric endocrinologists, a diabetes nurse educator, a registered dietitian/certified diabetes educator (CDE), and a Somali interpreter. They were recruited by the study team through word of mouth in clinic, in the community and by telephone. Questions were put together by the study team, based in part on a previous survey done exploring cultural attitudes towards diabetes in the Somali community [5]. The principal investigators led the focus groups, although all study team members attended.

Somali participants emphasized the oral learning tradition of their culture, reinforcing that videos could be a useful format. We reviewed each traditional diabetes education topic with the focus groups, with a goal of uncovering factors that might be specific or unique to Somali understanding of or implementation of that area. Some examples of culturally specific areas of confusion that were discussed included "Is diabetes contagious?", "Can camel milk cure diabetes?", "Can you get used to insulin and become dependent on it?", "Does seeing the diabetes team psychologist imply that you are crazy?". The principal investigator documented the discussion themes on a white board and took notes. No formal analyses of focus groups discussions took place.

Creation of the educational videos

Ten individual educational video modules in the Somali language (1.5–14 min long) were developed, for a total duration of 60 min. The content of the educational videos was adjusted based on suggestions from the focus groups. Core topics typically provided as part of routine diabetes education were supplemented with relevant cultural information. Examples of the educational messages that the focus groups recommended embedding in the educational videos included: explaining that T1D can affect young children and that it's not caused by eating too much sugar (it is generally believed in the Somali community that it's a disease of old individuals and that it's caused by an unhealthy diet); mentioning that experiencing anger and/or sadness at diagnosis does not indicate lapses in faith or lack of submission to God's will; stating clearly that currently, the only treatment for T1D is insulin therapy, and that pills, special diets or milk are not acceptable forms of T1D treatment; explicitly explaining the honeymoon phase and what is expected during this phase very early on in the course of T1D diagnosis to avoid/mitigate the common thought that "diabetes is going away"; pointing out that each member of the diabetes team has a role that cannot be filled by any one team member, in an attempt to show -for example- that diabetes nurses are core members of the diabetes team and that our model is not centered around the physician as it may be in some parts of the world; and destigmatizing the psychologist as a team member and clarifying that a recommendation to see a psychologist does not mean that one is "crazy". Specific examples of commonly consumed Somali

traditional foods were used in the carbohydrate-counting education unit.

Video modules were developed for each educational topic using a combination of didactic presentations (e.g., a brief verbal explanation), visual instruction (e.g., demonstration of injecting insulin), and clinical role playing (e.g., recognizing and treating hypoglycemia). Actors in these videos included a Somali nurse, an interpreter, a registered dietitian CDE, and Somali community members. We carefully reviewed the Somali-language content of the videos with our interpreters for accuracy and social appropriateness. Please refer to Table 2 for the video module topics and their links.

Delivery of the educational videos

Parents alone were invited to participate if the child with diabetes was < 12 years, while the parents and the patients who were ≥12 years were included. We initially set up group video education events in Somali community centers, mosques, and clinic conference rooms. Only 8 patients and their families were interested in participating in group sessions. For the remaining 14 participants, based on informal patient/parent feedback, we conducted individual educational sessions. Each educational session lasted ~ 2.5–3 h, with ~ 60 min for the 10 videos, time for pre-video and immediately post-video questionnaires, discussion, and social breaks with food.

Diabetes knowledge tests (questionnaires)

Members of the pediatric diabetes team together with a Somali interpreter constructed a diabetes knowledge questionnaire consisting of ten questions that were formatted as: open-ended fill-in the blank, multiple-choice, and true or false. We chose to create a new questionnaire that covered usual diabetes knowledge topics and also offered opportunities for the participants to express their answers in their own words so we could better understand their comprehension of the topics. The purpose of the questionnaire was to examine the change in diabetes knowledge from baseline immediately after- and 3 months following video education (primary and secondary endpoints, respectively). The questionnaires included questions related to the following topics: What is diabetes?; glucose monitoring and target glucose and HbA1c levels; T1D treatment/insulin; hypoglycemia; hyperglycemia, ketones, diabetic ketoacidosis (DKA) and sick day management (which includes describing various glucose patterns, frequency of glucose checks, and when to test for ketones during illness); carbohydrate counting; and long-term diabetes complications. These topics were covered in the educational videos. Examples of specific questions include: "How long is an insulin pen or vial good for after you open and start using it?", "What should you always check if your child is sick?", and "When should you consider using glucagon for your child?".

All questionnaires were "graded" by the same person (M.S.) for consistency. Participants were given a point for each correct answer and no points for wrong answers or questions left blank. The highest possible score for the individual questionnaire was 10.

The diabetes knowledge questionnaire was translated into the Somali language using a certified translation service and administered to all Somali parents in English or in Somali (participant choice) by one of three individuals: the principal investigator (M.S.) and two coordinators she trained. Parents of all participants completed the questionnaire in the written form (either by writing the answers themselves, or -in the case of those with a literacy barrier- by orally providing answers to the interpreter who wrote the answers down for them). To make it easier for those with limited literacy, a trained Somali study interpreter read the questions and the answer options and demonstrated how to mark each answer. Patients aged ≥12 worked with their parents on answering the questionnaires (the children did not answer separate questionnaires). The questions were also available in written form in both English and Somali (participant choice). At the end of the video education, the questionnaire process was repeated to assess immediate changes in understanding (primary endpoint). As a secondary endpoint, the knowledge questionnaire was repeated 3 months later to assess retention. The 3-month questionnaire was administered in clinic, over the phone via an interpreter, or at the participant's home based on participant preference.

Table 1
Average hemoglobin A1c levels at baseline, and at 3 months post-education via the video modules.

	At Baseline(n = 21)	At 6 months after education (n = 18)	*p*-value
HbA1c, % (mean, SD)	9 ± 1.5	9.27 ± 1.9	0.56

HbA1c: Hemoglobin A1c.

Table 2
Somali diabetes education video module topics and their YouTube links.

	Module duration (min: *sec*)	**Video Module Topic**	**YouTube Link**
1	1:53	Introduction to the video series	https://youtu.be/JcV-KA_O9_E
2	5:37	What is diabetes?	https://youtu.be/RRPTyfUTjnk
3	1:47	Diabetes team, parent support groups, school and camp	https://youtu.be/aPCCHOQASkI
4	6:10	Glucose Monitoring	https://youtu.be/g6KJsGsJZzo
5	14:00	Insulin	https://youtu.be/HPxLlY0I2Lw
6	8:13	Hypoglycemia and exercise	https://youtu.be/LJUj0bk14EQ
7	8:13	Hyperglycemia, ketones, diabetic ketoacidosis, Sick day management	https://youtu.be/35YHDfKSDCI
8	7:49	Healthy eating and carbohydrate counting	https://youtu.be/YFd8O8fW1hY
9	6:50	Psychosocial adjustment, depression and anxiety	https://youtu.be/a1n7Njr6mLY
10	5:49	Long-term complications	https://youtu.be/r-LdOhACq50

Statistical analyses

Data were analyzed using R version 3.4.2. Descriptive statistics are primarily presented as mean ± standard deviation (SD). Pre- and post-educational session tests were scored using numerical values (highest possible score = 10). Paired *t*-tests were conducted to compare changes in diabetes knowledge (between pre- and post- education knowledge tests) at each timepoint. Due to a small sample size, no subgroup analyses or interactions were considered. P-values <0.05 were considered statistically significant. A similar approach (paired *t*-test) was used to compare pre- and 6-month post education hemoglobin A1c (HbA1c) levels (exploratory endpoint). Cohen's d effect sizes were calculated to determine if the changes were meaningful.

Results

Subjects

Somali youth with T1D comprise approximately 3 % and 6 % of the total CHCM and UMN clinic populations of youth with T1D, respectively. Sixty-seven Somali youth were eligible to participate. Twenty-two children of Somali origin aged 12.3 ± 4 years participated from both institutions (UMN and CHCM) during the study period; 11 from

each institution. All participants had autoimmune, type 1 diabetes mellitus. The mean time since diagnosis with T1D was 4.4 years (0.5–17 years). Twelve participants were ≥12 years old. Eight out of 22 were female (36 %). At least one parent per each participant was included. All parents were first-generation immigrants. Forty-five eligible children and adolescents (12.5 ± 3.9 years; 29 % female) between both institutions did not participate for various reasons (lack of interest, lack of response to recruitment, and logistical reasons such as childcare, school, and religious holidays). Most participants (n = 16; 73 %) had government-funded health insurance (Medicaid, Prepaid Medical Assistance). Only 6 participants (27 %) had private insurance (Preferred one, Atrium Health, Blue Cross Blue Shield).

Diabetes knowledge test results

Twenty-five diabetes knowledge tests (questionnaires) were completed pre-, immediately-after and 3-months after the video education. The questionnaires were completed by 25 parents of 22 children, including 5 sets where both parents of a child participated, and 2 sets of 2 siblings with T1D. Both parents for each of these two sets of siblings participated. Twenty-two questionnaires were included in analyses as 3 of the 25 questionnaires were excluded for the following reasons: pre-education questionnaire completely unanswered, immediate post-education questionnaire completely unanswered, or parent did not view the entire video education program. Each correct answer was given 1 point. Individual questions that were left unanswered received a score of zero for that particular question but the questionnaire was counted. Of the 22 questionnaires, 18 (82 %) were answered by mothers of participants while 4 (18 %) questionnaires were answered by fathers. All pre- and immediately post-video questionnaires were answered in writing (50 % by participants and 50 % with the assistance of an interpreter). Eight of the 22 participants (36 %) completed the questionnaires at a community center where the video education took place. The other 14 participants (63 %) answered them at home (during an in-person visit by the principal investigator or one of the two study coordinators at the request of their families). The 3-month post-video questionnaires were mostly completed in person in a written form (at home or in clinic), while 45 % were orally answered over the phone through a trained Somali speaking study team member". We opted not to repeat the questionnaire at 6 months, and to only obtain HbA1c data 6 months post-video.

Prior to watching the videos, the baseline (pre-video) score of the participants was 6.53 ± 2. Diabetes knowledge significantly improved immediately after watching the educational videos (7.85 ± 1.1, p = 0.012, Cohen's d = 0.58) (Fig. 1). Specific areas that were commonly not well understood at baseline (based on percent of participants who answered the relevant questions incorrectly or left them unanswered) included hypoglycemia, sick day management, and carbohydrate counting. The majority of participants scored better in areas of the description of T1D, glucose monitoring/glycemic targets, and insulin therapy in T1D (e.g. how long an insulin pen or vial are good for once they are opened and used, and how often to change insulin pump infusion sets, and that T1D is treated with insulin and not oral medications) (Fig. 2). The areas that showed the greatest improvement included hypoglycemia and sick day management. Areas where there was minimal improvement included glucose monitoring, glycemic targets, and carbohydrate counting (Fig. 2).

Three months after the video intervention, 21 parents of 22 children completed the follow-up questionnaires. The improvement seen immediately after video viewing persisted 3 months post education (baseline score 6.53 ± 2 vs 8.69 ± 0.8, p = 0.0008, Cohen's d = 1). Areas demonstrating persistently improved understanding included hypoglycemia recognition and treatment and sick day management. Areas where there were persistent misunderstandings included glucose monitoring and targets, and carbohydrate-counting.

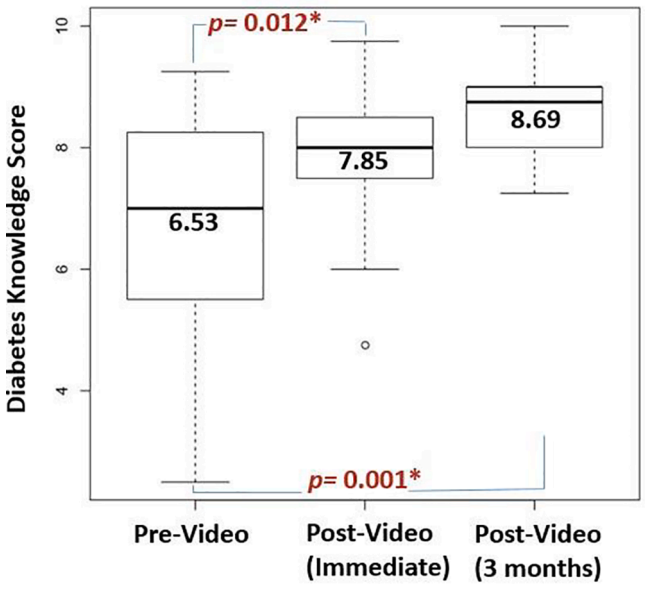

Fig. 1. Participant diabetes knowledge scores (n = 22) at baseline, 3- and 6-months post-video education. Participants were given points for each correct answer and no points for wrong answers or questions left blank. The highest possible score for the individual questionnaire was 10.

Diabetes management and metabolic control

We found no difference between HbA1c measurements at baseline and at 6 months after video education (Table 1). Linear regression models to adjust for change in diabetes knowledge score at the various time points did not make a difference (data not shown).

Discussion

To our knowledge, this is the first video-based T1D education program developed specifically for the Somali immigrant population. In this project, we developed educational videos in the Somali language and tested diabetes knowledge in 22 Minnesota Somali families (recruited over 1 year) with children and adolescents with T1D (1–19 years) who had already received our usual ADA-based T1D education. Their scores on a non-standardized diabetes knowledge test/questionnaire improved immediately after watching these videos compared to baseline (p = 0.012). Promisingly, this improvement persisted 3 months after watching these videos (p = 0.0008), suggesting retention of the knowledge. This study provides proof-of-principle to validate a specific approach that can be used as a template for education of diabetes and other conditions in Somalis, and in other immigrant populations.

Many US cities have experienced a wave of African immigration due to war and political upheaval on that continent. These immigrants often require a disproportionate amount of medical care. Diabetes care is complex for anyone, and this is compounded when there are barriers in language and literacy [3,25]. Literacy in general as well as exposure to modern diabetes medical practices may be low in Somali immigrant adults, complicating effective delivery of diabetes education and health outcomes [26]. In a study comparing diabetes management success in Somali adults with non-Somalis, the former group were less likely to meet glycemic goals [4] and similar findings have been reported in children [5]. It appears that our current diabetes educational practices are not effectively reaching these patients [4]. To address this health disparity, we developed an approach tailored to their unique culture.

Data from a study that provided prenatal videos in the Somali language was largely accepted by study participants, and suggested that culturally-tailored health education videos were preferred over written materials by Somali immigrants [19]. Our focus groups confirmed the

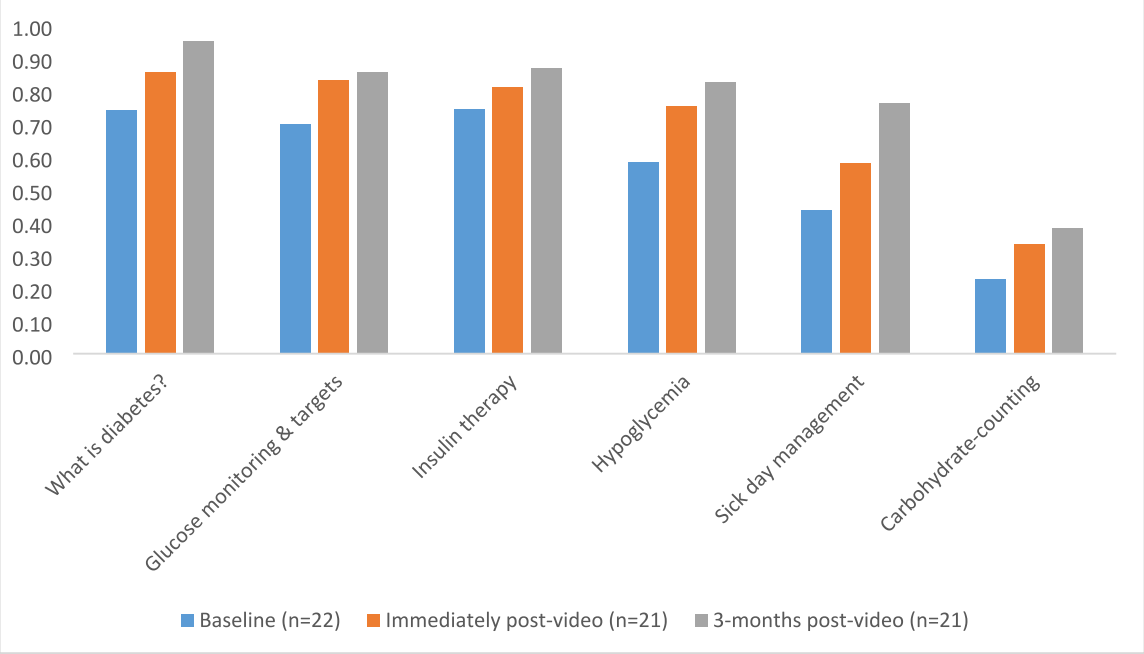

Fig. 2. Proportion of correct questionnaire answers on various education topics at baseline, immediately-post and 3-months post video education.

appeal of this approach. In this study, we relied on our Somali partners to help us create an educational program tailored to the Somali community and their unique cultural perspective.

While there appeared to be improvement in diabetes knowledge in general, this improvement was not uniform across the topics of education. For instance, there appeared to be better improvement in knowledge related to sick day management compared with the modest improvement in carbohydrate counting knowledge. The authors speculate that this may be related to low literacy and low numeracy in this population. We plan to place more emphasis on these topics in the future.

The authors acknowledge several limitations, and plan to address many of them in a future study. The sample size in our study was small, and recruitment was challenging. We believe that the positive Somali community reaction to our initial videos will help with future recruitment. When we began our study, we made assumptions that proved to be false; for instance, we observed Somalis to be highly social, and assumed that group sessions would be ideal for education and emotional support for Somali families with children with T1D. We initially set up group education events in Somali community centers and mosques, and subsequently at 2 different health care institutions. Participation was minimal (8 out of 22; 36 %) over a 5-month period; patients' families repeatedly requested private visits, which were met with much better participation (14 participants comprising 64 % of the 22 participants, over a 3-month period). It became apparent that the one-on-one clinic-based approach was more accepted. We are exploring the reasons for this, but the Somali community stigma of chronic disease and unwillingness to be publicly associated with diabetes anecdotally emerged as a major factor that needs to be addressed. Similarly, we initially planned to have patients and their families act in the videos, but we discovered they were not comfortable with this. While the videos that we created were generally well-received by Somali families, we were well aware that due to resource limitations their production was somewhat amateur. A few key education pieces are lacking such as a tutorial on insulin pumps and continuous glucose monitors, and an introduction to the importance of research in diabetes. Some aspects of diabetes care remained problematic for participants after the video program, and we will work to enhance these educational areas. Intervention acceptability data were not collected. Finally, the questionnaire used to test diabetes knowledge has not been validated. Thus, identifying meaningful changes in diabetes knowledge may be limited.

Ultimately, in a larger study, we plan to use an updated, enhanced and more comprehensive version of the audio-visual educational materials, to use an individual/clinic-based approach, to track education retention over a longer period of time than in this study, and to collect intervention acceptability data. Also, given that private home visits were preferred by many participants, in a larger future study, for feasibility, we plan to recruit potential participants in the privacy of their clinic room (or a consultation room in clinic to maintain clinic flow) where they could watch the educational video (the intervention), rather than in a group setting. As the questionnaires were meant to be self-explanatory, in a future larger study, we plan to administer them directly to participants in their preferred language, and to utilize the assistance of an interpreter (who normally accompanies non-English-speaking families to clinic) for those with a language or literacy barrier. We anticipate that an updated and fine-tuned program can be tested in a larger Somali T1D population nationwide and can potentially be used as a template for other African immigrant populations and other medical conditions.

Conclusions

In conclusion, culturally and linguistically tailoring diabetes education and delivering it in a visual-based manner to a Somali population resulted in improved diabetes self-management knowledge, with good retention. The effect of this program on HbA1c needs further study with a larger sample size. The materials we created are available free-of-charge around the globe including in Somalia.

CRediT authorship contribution statement

Muna Sunni: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Software, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing. **Jennifer Kyllo:** Data curation, Funding acquisition, Investigation, Methodology, Project administration, Resources, Visualization, Writing – review & editing. **Carol Brunzell:** Investigation, Methodology, Resources, Visualization, Writing – review & editing. **Janyce Majcozak:** Data curation,

Investigation, Methodology, Writing – review & editing. **Munira Osman:** Investigation, Resources, Writing – review & editing. **Abdirahman M. Dhunkal:** Investigation, Resources, Writing – review & editing. **Antoinette Moran:** Conceptualization, Investigation, Methodology, Project administration, Resources, Supervision, Visualization, Writing – review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

The authors wish to thank Dr. Salah Malin and Mr. Feisal Elmi for their insight into the Somali culture. We also acknowledge Marrissa Ludwig, RN, for her assistance guiding the education content of the videos. We are thankful for the parents of Somali children we follow in clinic for their feedback and suggestions. The authors wish to thank Weihua Guan, M.S., Ph.D. and Ellie Northrop for providing statistical support via the Biostatistical Design and Analysis Center (BDAC) at the University of Minnesota.

Research reported in this publication was supported by the National Center for Advancing Translational Sciences of the National Institutes of Health Award Number UL1TR000114. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Funding Statement

This work was supported by the National Center for Advancing Translational Sciences of the National Institutes of Health [Award Number UL1TR000114]. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

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