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Process Evaluation of the Intensive Diabetes Self-Management Program for Underserved Communities

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Abstract: Background/Objectives: This study assesses barriers to behavior change among underserved populations with type 2 diabetes enrolled in the intensive Diabetes Self-Management Education and Support (iDSMES) program. **Methods**: Thirteen participants (5 English speakers, 8 Spanish speakers), who had completed at least six months of the 1-year iDSMES program, were invited to join focus group discussions. Participants were asked about barriers, facilitators, and suggestions for promoting the program. **Results**: Barriers to effective diabetes self-management included financial constraints, lack of social support, stigma surrounding treatment, and miscommunication with healthcare providers. However, the iDSMES program's support system emerged as a major facilitator. Participants valued the relationships they developed with others facing similar challenges, which motivated them to keep working toward their health goals. **Conclusions**: The iDSMES program was successful in promoting behavior changes and improving health literacy. Addressing financial barriers in underserved communities is essential for supporting long-term behavior change.

Keywords: diabetes self-management education and support; focus groups; type 2 diabetes; social determinants of health; vulnerable populations

1. Introduction

Diabetes is a significant public health issue in the United States, affecting over 37 million people, with a disproportionate impact on underserved populations, including racial and ethnic minorities, individuals with low socioeconomic status, and those living in rural areas [1,2]. The unequal impact of diabetes on underserved populations is further exacerbated by disproportionate access to healthcare [3,4]. In the face of this, diabetes self-management education and support (DSMES) programs have been implemented in certain healthcare systems and are recognized as essential for improving health outcomes and quality of life for people with diabetes, particularly by promoting glycemic control and reducing complications.

The intensive Diabetes Self-Management Education and Support (iDSMES) program is a year-long educational health behavior intervention for people with Type 2 Diabetes (T2D) that was developed at an urban university in response to a dire need for diabetes self-management at the peak of the COVID-19 pandemic [5]. This preliminary study showed positive results with program completers (n=9) losing 8.8% of their initial body weight. The authors also observed a 10 mg/dL decrease in fasting blood glucose, a 1% decrease in hemoglobin A1c, an average of 10.5 mmHg decrease in systolic and diastolic blood pressure, and an average 110-minute per week increase in physical activity. Reimbursement for diabetes self-management is available from both commercial insurance plans and Medicare [6]. However, challenges to recruit and retain participants still exist.

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Our study is a focus group discussion (FGD) study, based on the barriers and facilitators related to chronic disease self-management discussed in the literature. Among various self-management programs, DSMES programs are mainly focused on the appropriate management of glycemic control through behavior changes, diet education, medication adherence, and understanding the potential complications of uncontrolled diabetes [7]. Such interventions have been shown to improve patient outcomes, diabetes-related knowledge, self-efficacy, glycemic control, and overall quality of life [7–9]. Despite the benefits of diabetes self-management programs, underserved communities often lack access to these programs due to various barriers, including financial constraints, transportation difficulties, and lack of awareness or trust in the healthcare system [4,10,11]. Existing literature has primarily focused on quantitative outcomes of DSMES programs, with limited qualitative insights into the lived experiences of individuals in these programs, particularly those from underserved communities. This study aims to fill this gap by exploring the social determinants of health that affect diabetes management among participants in the intensive Diabetes Self-Management Education and Support (iDSMES) program. Specifically, this study seeks to understand the barriers and facilitators of diabetes self-management as perceived by participants, thereby providing insights that can inform the design and implementation of more effective DSMES interventions tailored to the needs of underserved populations.

2. Materials and Methods

A focus group discussion (FGD) methodology was chosen for this study due to its effectiveness in exploring shared experiences and collective perspectives among participants who face common challenges, such as managing Type 2 Diabetes in underserved communities. Focus groups are particularly useful for generating rich qualitative data that can capture the nuances of participants' experiences, which might not be easily obtained through individual interviews or surveys.

The methodology involved two groups totaling 13 people with T2D. Participants who have completed at least six months of the 1-year iDSMES program were invited to take part in an FGD to assess their experiences and perceptions about the program. Inclusion criteria for the iDSMES program included: (1) enrollment in the iDSMES program, (2) age ≥ 18, (3) BMI ≥ 25 kg/m2 or ≥ 23 kg/m2 (if Asian), (4) diagnosed with Type 2 Diabetes, and (5) HbA1c > 7%. Study subjects were separated into two groups based on the participant's spoken language: one in Spanish (n=8) and another in English (n=5).

Data collection procedure and tool. Focus group discussion sessions were conducted in 2023 and each lasted 90 minutes. Each session was led by two bilingual medical students. Both students had prior experience working with populations with T2D, enabling them to engage effectively with participants and ensure that the discussions were both meaningful and respectful. Further, all interviewers had undergone lifestyle coach training prior to FGD sessions and received training on facilitating small group discussions.

During sessions, one student conducted the interview, and the second audio recorded and transcribed the participants' answers into Microsoft Word files. Participants were informed of their right to decline to answer any question and that they could leave the discussion at any time should they choose to. An open-ended topic guide (see Supplementary) was used to conduct FGD which consisted of nine questions asking participants about their overall understanding of the underlying causes of diabetes, main factors that facilitate or prevent diabetes self-care, their personal experiences living with diabetes, and opinions of the iDSMES program. The study was approved by the Institutional Review Board (#21-0210). Verbal consent was obtained from participants before the beginning of the sessions. Privacy and anonymity were ensured as the name of the participant was not required during the discussion. All study findings were also presented without any individual identifiers.

Qualitative data analysis. The audio recordings of the FGD were transcribed by the same bilingual medical students who conducted the sessions, ensuring accuracy in both the original language and translation to English. Transcriptions were completed within two weeks of the focus

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group sessions, allowing for timely analysis while the details of the discussions were still fresh in the researchers' minds. Spanish transcripts were transcribed and translated to English by a native Spanish speaker. A thematic analysis was conducted using an inductive approach, where themes were identified based on patterns and repetitions in the data. The transcripts were independently coded by two researchers, and any discrepancies were resolved through discussion. Data analysis was performed using QDA-Miner-Lite.

3. Results

This section may be divided by subheadings. It should provide a concise and precise description of the experimental results, their interpretation, as well as the experimental conclusions that can be drawn.

3.1. Participant Characteristics

Table 1 represents the baseline demographics of participants at the time of enrollment into the study. The average age is similar for both English and Spanish groups. While the Spanish group has a higher proportion of people without a high school diploma (75%>0.0%), the English group has a higher baseline BMI (34.8>31.8) and A1C (10.4%>9.4%) levels than the Spanish group.

Table 1. Characteristics of Focus Group Discussion Participants by Language.

	English (N=5)	**Spanish (N=8)**
Age (means, std.)	51 (5.1)	50.5 (12.6)
Female (n, %)	3 (60.0%)	4 (50.0%)
Race (n, %)		
Non-Hispanic White	2 (40.0%)	0 (0.0%)
Hispanic	3 (60.0%)	8 (100.0%)
Education (n, %)		
Less than 12 Grade	0 (0.0%)	6 (75.0%)
Grade 12 or GED	4 (80.0%)	1 (12.5%)
Some College	1 (20.0%)	0 (0.0%)
College Graduate	0 (0.0%)	1 (12.5%)
BMI (mean, std.)	34.8 (3.6)	31.8 (6.6)
A1C % (mean, std.)	10.4 (2.6)	9.8 (2.0)

3.2. Thematic Analysis of Qualitative Responses

The study identified valuable determinants of health for people with T2D living in underserved communities. First, challenges with cultivating healthy behaviors were frequently raised by participants as a major obstacle in T2D self-management. Second, socioeconomic barriers, such as lack of transportation, low income, and difficult work schedules presented themselves as significant hindrances to participants' ability to self-manage their diabetes. Third, participants noted that self-awareness about the importance of diabetes self-management, including health behavior modifications and knowledge about the disease and treatment, is a fundamental part of the treatment process. Fourth, lack of social support was emphasized as a potential hindrance to adopting healthier behavior modifications. Fifth, the stigma that surrounds diabetes treatment highlighted a primary reason many people with diabetes delay or refrain from joining self-management programs. At the end of the FGD, we also asked participants about the benefits of the iDSMES program had on them and what specific suggestions they have for us to improve and expand the program.

3.2.1. Barriers to Diabetes Self-Management

1. Health Behavior Factors Contributing to T2D; Challenges with practicing healthy behaviors, in terms of diet and physical activity, were frequently raised by participants as a major obstacle in

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T2D self-management. Unhealthy eating habits, such as regularly choosing high-fat, high-sugar, high-salt, or low-fiber foods, low levels of physical activity, and being overweight were often raised by participants as major risk factors for T2D. For example, a man from the Spanish FG reported: 'When we came to this country, the whole lifestyle that one had in his country changes, and you forget about that and eat whatever there is and a lot of fried foods, and that is what leads to diabetes the most' (Spanish #2).

2. Socioeconomic Barriers to Self-Management; Socioeconomic barriers, such as lack of transportation, low income, and rigid inflexible work schedules presented as important factors limiting self-management ability. Lack of transportation impeded participants from staying as engaged with the program/classes as they would like: 'Sometimes the problem is not having a car ... that was the problem for me' (Spanish #2). Additionally, for those participants living off the island, the commute proved costly with several attesting: 'gas is expensive and it's an issue sometimes' (English #2). Lack of access to healthy food is further exacerbated by the financial strain making healthy choices can entail, with participants often expressing: 'healthy food is so expensive (…) the doctors tell me I can't eat this or that and yet the food bank only offers rice, bread, bananas, etc.' (English #2). Even though most participants have access to local food banks, they are often stocked with foods that are not diabetic-friendly. Regarding inflexible work schedules, one participant reported: 'I have her [lifestyle coach] send me a [text] message in Spanish and English to show my boss that I have an appointment … It's just that sometimes they don't believe me and think that I just don't want to work' (Spanish #3).
3. Self-Awareness and Diabetes Management; Lack of knowledge about their medical condition is a common limitation to diabetes self-management ability. One participant reported: 'I didn't know I had diabetes; I got a bump on my toe (…) I went to St. Vincent's, and they diagnosed me with diabetes (…) but if it hadn't been for the toe, I never would have realized I had diabetes (Spanish #4). However, at the 6-month mark of the program, most participants developed an overarching self-awareness that implementing healthy behaviors, and becoming informed about one's condition, were imperative for successful self-management and avoiding complications. For example, a woman from the English FG reported: '(…) you also have to change what you're eating. It's not a miracle. You have to go with a diet' (English #3). Another participant expressed: 'Having information to find out what is hurting you and what can help you. I have the case of my mother, she died of sugar complications (…)' (Spanish #1). However, despite the health behavior training by the program's coaches, some individuals complained of not receiving enough information from their respective health providers, reporting: 'I get overwhelmed because I feel like I am not being educated properly (…) I just feel like I don't know when to check my insulin, when to check my sugars, or when to eat what' (English #5), making guidance from health providers all the more important to ensure successful self-management.
4. Lack of Social Support; Living with T2D is challenging when participants feel a lack of social support. For example, a participant shared: 'Sometimes our own family is not interested in us [or our health], nor are they interested in taking care of themselves' (Spanish #2). Another participant recognized unhealthy eating habits do not help manage T2D but reported: 'When I eat a salad or something healthy, everybody makes fun of me' (English #1). Additionally, friends and family members can negatively affect self-management ability by encouraging unhealthy behaviors. For instance, a participant shared: 'I have friends that always invite me to go drink, but when I try to invite [him] to this program, he tells me, "Why would I go there?" He tells me I'm crazy for coming to this program and that I'll die either way' (Spanish #5).
5. Stigma Surrounding Diabetes Self-Management Education; Fear of seeking help was frequently reported by participants as an important factor in deterring people from joining diabetes self-management programs. There seems to be a stigma surrounding diabetes self-management education in that people think they'll be mistreated or harmed in some way, with some participants sharing: 'My mother-in-law is very fearful, and she thinks that they will always be poking her' (Spanish #5). Another participant added: 'It is that we do not know what we are

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going to face. We think that in each meeting they are going to poke our fingers and that they are going to scold us, but I have not seen anything like that (Spanish #1).

3.2.2. Facilitators of Diabetes Self-Management

1. Effects of the iDSMES Program; Overall, the program has received positive feedback from participants. Individuals attribute their success in maintaining adequate diabetes control to the health behavior training sessions and the information/resources they have been provided through the program. A participant shared: 'The program has helped me a lot, it has helped me lose a few pounds and to think differently about how to eat' (Spanish #7). Many have experienced weight loss, fewer hypoglycemic episodes, better eating habits, and increased physical activity, with one participant reporting that through goal setting and exercise: 'I already lost 10 pounds. With the help they have given us and the advice, I have lost weight (…) it was a goal that [lifestyle coach] and everyone set for us' (Spanish #5). Encouragement from the lifestyle coaches stood out as a driving force to keep participants motivated and it was greatly appreciated by all. It demonstrated the importance of social support, providing a safe space to talk, and goal setting in developing individual empowerment for successful self-management. A participant reported: 'When I entered this program, [lifestyle coach] told me that I have a chance [to improve my health] (…) Before I ate whatever and now I don't. They told me how I have to eat (…) The routine and the advice they have given us have been good for me. My sugar has never gone down (Spanish #4). 'We are like a big family when we meet' (English-1). Finally, a meaningful aspect participants recognized is their power and duty to control their diabetes, with one individual sharing: 'We have realized that it is something that can be fought (…) it's something that if we do our part, that's the best way to combat it' (Spanish #6).
2. Ways to Improve the iDSMES Program; Developing trust between lifestyle coaches and participants is a key component for success in the program. It could increase participants' compliance, and thus, breaking the stigma and fear associated with diabetes self-management programs should be prioritized. Suggestions made by participants to expand the program were to increase advertisements and create campaigns to invite more people to join, with a focus on making the message clear: that diabetes self-management programs are a safe space created to improve a person's overall well-being and teach one the tools to navigate this condition effectively. Additionally, participants also voiced they'd like for a diabetic food bank to be created. For example, a participant mentioned: 'It's difficult to follow a diabetic diet when the food given at the food bank is filled with sugar, fat and is low in fiber' (English #2). Thus, making fresh produce and offering more diabetic-friendly options would strongly benefit participants. Lastly, another suggestion participants made was to make information less overwhelming, expressing that it can be frustrating to be given a "book's worth of recipes." Quality over quantity matters.

3.2.3. Research Team's Reflections

Some aspects were not mentioned by most participants but still emerged from the discussions. The main difference between the groups was on the delivery end. During the English FGD, participants expressed frustration with the lack of consistency when it came to lifestyle coaches, reporting they'd prefer to be seen by a few individuals instead of many different coaches. Additionally, participants from both groups pointed out stress as a challenge to self-management, reporting: 'Stress is a lot of it. I don't know when to eat. I only eat once/day and my sugar is crap' (English #5) or 'I can eat a cake, but a problem of stress is going to hurt me more than the cake' (Spanish #2).

4. Discussion

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Overall, our findings show that the iDSMES program is an effective tool for participants to learn to improve glycemic control, weight, health literacy, and quality of life. However, as evidenced by the participants' feedback in our study, despite knowing how to self-manage their diabetes, patients from underserved communities continue to face barriers beyond their control. This makes it difficult to implement self-management principles in their daily lives. Other studies investigating diabetes self-management programs have yielded similar results such as challenges to implement lifestyle modifications [12], lack of transportation [13], and lack of social support [14].

The predominant benefit gained from the iDSMES program that participants in both groups expressed was the development of relationships with others in similar situations and who are dealing with similar difficulties in controlling their disease. Many participants described their group as a "family" and drew motivation to continue working towards their goals from fellow participants, exemplifying the incredible support system that was created through the program. Many studies conducted both within and without the United States have emphasized the enormous importance of social support in making health behavior changes [12,14,15].

The perceived program impact is that it will have a lasting effect on participants' ability to self-management in the future, with many describing their experience as having a lifelong impact. This is a particular benefit of longitudinal diabetes education programs such as the iDSMES, with research showing that these programs yield greater A1c control than do short-term or single-event programs.8 Besides, the consensus among participants' responses was that their overall experience with the program was positive and many found the sessions helpful in managing their medical condition. Participants in both groups experienced weight loss, were better informed, and found a social support system outside their homes, with many describing instructors as approachable. All in all, the participants' main desire was for our institution to continue its efforts in educating and empowering individuals from underserved communities to manage and control diabetes.

Financial difficulties can be a prevalent limitation to making healthy choices for patients with low socioeconomic status, especially when considered in conjunction with the elevated cost of treating diabetes due to the necessity of medications, testing supplies, and healthy food [16]. For instance, our FGD study found the lack of transportation access to attend group sessions and the availability of diabetes-friendly food pantries as important barriers of particular significance. Both elements are well-represented in the current literature [17,18]. Financial assistance in the form of bus tokens, taxi/uber vouchers, or gas reimbursement could allow participants to attend diabetes education sessions more reliably. Likewise, our FGD participants suggested developing a diabetes food bank to make healthy food more readily available for underserved populations which is aligned with the suggestions from the literature [19,20].

In addition to financial concerns, our study revealed a lack of social support as a major impediment for the iDSMES program participants. The utmost importance of social support in successful glycemic control in people with diabetes has been extensively documented [21–23]. Diabetes self-management can leverage the social aspect of health behavior changes by encouraging the participation and attendance of family and friends of participants. Unlike other studies that have delivered individual-level sessions, our program was implemented at a group level and all participants complimented the supportive lifestyle coach, further exemplifying that a supportive environment is critical for diabetes self-management. As this program is one year long, participants will be more motivated to adopt and carry out healthy behaviors with sufficient social support.

Lack of effective communication is not unusual for patients and clinicians to have differing approaches and priorities when it comes to treatment [24]. This can also be further complicated by patient distrust in the healthcare system, especially among vulnerable populations, and language discordance between low English proficiency patients and monolingual [25]. Continued emphasis on patient-centered care, training clinicians on effective communication techniques, and appropriate use of qualified interpreters for low English proficiency patients by clinicians can serve to mitigate this barrier [25–27]. Unfortunately, providing training for clinicians can be a difficult task given their time constraints and overwhelming responsibilities; instead, providing education on the existence of

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diabetes self-management programs could allow for a cooperative relationship that would augment the goal of glycemic control in people with diabetes while taking into consideration the restrictions that clinicians face.

A key strength of the study was the cultural competency ingrained in the study's design. We chose to conduct classes and FGD sessions in English and Spanish to reflect the diversity of the community we serve. To avoid bias, FGD sessions were led by researchers who had not been directly involved as lifestyle coaches during the previous six months. The themes found in both FGD sessions were independently reviewed by the four researchers, all of whom were bilingual, to avoid human error and bias.

We acknowledge the limitation of having a small sample size and recognize that this may limit the generalizability of our findings. However, the themes identified in our study provide valuable insights into the specific barriers and facilitators experienced by participants in the iDSMES program. While the data may be limited, it still contributes to the broader understanding of how social determinants of health influence diabetes management in underserved communities.

5. Conclusions

The iDSMES program was successful in promoting health behavior changes and improving health literacy regarding the management of diabetes. The results of this study reaffirm that diabetes self-management programs are a useful tool to allow participants to take control of their health to make positive long-term behavioral changes that improve the outlook of the course of their disease. However, financial barriers remained a prominent factor that prohibited either full participation in the program or consistent application of behavioral changes to participants' daily routines. Our FGD respondents particularly pointed out access to both transportation and quality food as major barriers. Health systems should recognize the impact and importance that diabetes self-management programs have on patient care and long-term outcomes and therefore focus on increasing funding for these programs. This could take the form of gas or transportation vouchers to allow participants in need to attend all sessions. Another investment could include funding diabetes-friendly food pantries with whole grain and sugar-free food options. Increased partnership between health institutions and members of the local community in this way will help build trust, prevent future illness, and improve quality of life. Future research should investigate how the implementation of financial assistance to participants of diabetes self-management programs affects adherence to health behavior modifications, long-term outcomes, and perceived barriers to care.

Supplementary Materials: The following supporting information can be downloaded at the website of this paper posted on Preprints.org. Document S1: Guideline for Focus Group Discussion.

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Abbreviations

The following abbreviations are used in this manuscript:

iDSMES	intensive Diabetes Self-Management Education and Support
DSMES	Diabetes Self-Management Education and Support
T2D	Type 2 Diabetes
FGD	Focus Group Discussion

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