Patient Voices: Doctors and Diabetes Management

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ABSTRACT

OBJECTIVE: To assess the challenges of managing diabetes experienced by clients of a community-based social services organization via qualitative interviews; to develop recommendations for more effective diabetes education programming at the organization based on themes identified in the interviews.

METHODS: Staff at Progreso Latino in Central Falls recruited clients with diabetes and prediabetes to participate in interviews during the summer of 2019. Each interview used a structured question set and was conducted in the participant's preferred language of Spanish or English. Investigators analyzed the interview transcripts and identified predominant themes.

RESULTS: Analysis of fourteen interviews yielded four predominant themes: uncertainty about diagnosis and treatment, fear as part of the discussion with providers, language barriers, and cultural barriers.

CONCLUSIONS: To strengthen diabetes education programming at a community-based organization, we recommend utilization of community health workers, development of culturally appropriate dietary recommendations, and creation of educational videos in clients' preferred languages.

KEYWORDS: diabetes, community-based organization, Spanish, interview

INTRODUCTION

The American Diabetes Association (ADA) recommends that all people receiving a diagnosis of diabetes should be engaged in diabetes self-management education and support, either in healthcare or community-based settings, to gain the skills and understanding for living successfully with diabetes.[1] However, not every program is well suited to every participant. Indeed, a 2018 review demonstrating the efficacy of diabetes self-management education programs notes the importance of tailoring a program to its target audience's cultural needs.[2] In its official statement, the ADA also makes mention of the importance of addressing cultural needs among other factors when designing diabetes programming.[1]

While many agree on the importance of continuing diabetes education after an initial diagnosis is made, how this education can be optimized for Spanish-speaking and other non-English-speaking communities is uncertain. A study of health literacy found that self-efficacy, "the belief or confidence in one's ability to have influence over events in one's life," may be even more critical than health literacy in determining health outcomes; as such, increasing diabetes self-efficacy in Spanish-speaking patients may decrease disparities in diabetes outcomes between Spanish-speaking and English-speaking patients.[3] Self-efficacy is an essential objective of diabetes self-management education and support programs in general.[4] Additionally, qualitative research offers an opportunity to amplify the voices of these patients, which might not otherwise be heard, and provide important insight into their experience with the disease.[5]

The goal of this study was to develop recommendations for more effective diabetes programming at a community-based social service agency with predominantly Spanish-speaking clients. By relying on the voices of community members in creating recommendations, this study aimed to improve the organization's diabetes education programming and strengthen the self-efficacy of its clients.

MATERIALS AND METHODS

Study Participants

This study was conducted in the summer of 2019 at Progreso Latino, a social services organization serving the Hispanic and Latino community in Providence County and throughout Rhode Island. Such a study is in line with Progreso Latino's mission to promote personal growth and self-sufficiency among Rhode Island's Latino and immigrant communities through a variety of programming.[6] The state's Hispanic- and Latino-identifying population rose almost 40% in the 2010s, comprising 16% of the state's total population, or over 170,000 people, at the time of this study.[7,8] Forty-three percent of the population of the state's largest city, Providence, and 64% of the population of Central Falls, home to Progreso Latino, identify as Hispanic or Latino.[7] For this study, Progreso Latino's Wellness Center staff recruited participants from among their clients and regular visitors via flyers and face-to-face invitations. The Center regularly holds health screenings, organizes health fairs, and hosts

workshops on various health and lifestyle topics. Progreso Latino's clients with diabetes or prediabetes were considered eligible for the study.

Interviews

All interviews occurred in person at Progreso Latino. Each interview was conducted in the participant's preferred language of either Spanish or English. A structured interview question set was developed in conjunction with Progreso Latino's Wellness Center staff to direct the conversations. The interview guide included questions relating to participants' experience of receiving the diagnosis of diabetes or prediabetes, the experience of managing the disease, experience with healthcare and healthcare providers in Rhode Island, and interest in additional diabetes education programming. The study was approved by the Brown University Institutional Review Board.

Data Analysis

Each interview was recorded and transcribed in its original language. Analysis of the interview transcripts followed the Immersion/Crystallization method.[9] A group of five bilingual investigators, consisting of two internal medicine physicians, one geriatrician, one community health worker, and one medical student read and independently analyzed transcripts in their original form to identify salient themes. The transcripts were divided among readers such that at least three different investigators analyzed each interview. At an analysis meeting, all five of the investigators discussed and interpreted common themes, offering demonstrative quotations. The investigators then considered these results and agreed on four themes to be the most significant and predominant.

RESULTS

Participant Characteristics

Fourteen participants with a mean age of 70.3 years (range 40-87) represented three countries of origin: Colombia, Guatemala, and the Dominican Republic. Participants had lived in the US between 2 and 49 years. Twelve participants preferred to interview in Spanish, while two participants preferred English. Additional information about participants is provided in **Table 1**.

Table 1. Participant demographics.

Self-identified gender	
Male	14.3%
Female	85.7%
Interview language	
Spanish	85.7%
English	14.3%
Mean age (SD)	70.3 (14.9)
Country of origin	
Colombia	64.3%
Guatemala	21.4%
Dominican Republic	14.3%
Years living in U.S. – Mean (SD)	29.7 (13.7)
Level of education	
< High school	69.2%
High school or GED	15.4%
> High school	15.4%
Years since diabetes diagnosis – Mean (SD)	11 (8.19) (Range 0–31 with two participants unable to remember)

Predominant Themes

Four predominant themes emerged: uncertainty about diagnosis and treatment, fear as part of the discussion with providers, language barriers, and cultural barriers. Many participants described the uncertainty surrounding the original diagnosis of diabetes. Though many were aware of diabetes because of their family members' experience with the disease, participants indicated that their understanding of the disease at the time of diagnosis was relatively limited. When asked what they were told by their doctor at the time of diagnosis, many participants recalled being prescribed medicine without understanding the disease process. As one participant put it, *"The doctor simply told me that I had diabetes, that I could control it with medicine. And since then, I've been taking metformin, and it controls it for me."* (See **Table 2** for original text of quotations.)

In response to the interview prompts about what was discussed with the medical provider when first diagnosed with diabetes, one participant, laughing, explained, *"That I had diabetes. I hadn't known it, but he told me, and he prescribed me medication."* In some cases, that uncertainty about the diagnosis and the management persisted to the time of the interview: *"I think I'm prediabetic. I'm not sure what that means."*

Other recollections from participants' early encounters with providers noted fear was used to motivate them: "*The only thing he says to me is that I shouldn't eat hardly anything, and that I should take my injections and take my pills because he knows diabetes progressively destroys every part of you."*

In those controlling their diabetes with lifestyle changes and pills alone, that fear often manifested in the threat of insulin. One participant commented on glucometers and insulin by noting: "*I have that little machine, but I don't use it because it scares me a lot. I put my hand out to the nurse like this, but dying of fear…The nurse said to me, because I felt so scared, she said, "What are you going to do when you have to use insulin?" I told her, "Well, I don't know what is going to happen because you have to inject the insulin yourself."*

Participants often noted the difficulty created by language barriers between them and their providers especially when discussing diabetes and its management. Even with

Table 2. Predominant themes identified by analysis and representative quotations in original language.

Themes	Representative Quotations
Uncertainty	*El doctor…me dijo simplemente que tenía diabetes, que me la podía controlar con medicina. Y desde eso estoy tomando metformin, y me la controla.* *Que yo tenía diabetes. Yo no lo sabía, pero él me dijo y me recetó mis medicinas.* I think I'm prediabetic. I'm not sure what that means.
Fear	*Lo único que me dice [es] que no coma ni nada, y que me ponga la inyección y me tome las pastillas porque sabe que la diabetes le va destruyendo a uno todas las cosas.* On glucometers: *Yo tengo ese aparatico pues yo no lo uso porque me da mucho miedo. Yo pongo la mano así pero muerta del susto a la enfermera.…La enfermera me dijo que como yo sentía tanto miedo ella me dijo,* "¿qué va a hacer usted cuando tenga que usar insulina?" *Yo le dije, "Bueno no sé qué va a pasar porque la insulina la pone uno mismo."*
Language barrier	*Por un lado [la doctora de medicina general] me atiende, pero por otro ella no habla español…me siento incómoda porque yo quisiera decir lo que yo siento…pero [tengo que decir] a mi hija, "dile a ella esto y esto." Ella le dice lo que ella quiere.… [A veces] yo creo que es de la cabeza de ella porque no es lo que dije.* On finding a language concordant physician: *Pues [mis hermanos] controlan [la diabetes] porque están en Santo Domingo y allá ellos tomen su medicamento, pero toman muchas plantas de la tierra, natural, y entonces, pues ellos, su diabetes está bien. Yo cuando estoy en Santo Domingo, que tomo muchas plantas, no tengo que tomar pastillas, yo tomo muchos tés y esos, todo bien.* *…y yo lo conseguí muy buen médico… yo digo "ay, que bueno que le encontré" porque él habla español, yo no hablo inglés. Entonces pues tú vas adonde él, y tú le dices "yo me siento esto," y él trata de hacer lo que sea para ayudarte. Entonces, pues aunque no es receta, vamos a decir tés o cosa, pero [él me ayuda] más que mucho.*
Cultural barrier	On food: *Es…la cultura de nosotros, cómo crecimos desde niño, la comida que consumíamos…a esta altura de la vida de nosotros, cambiar radicalmente esa forma de comer es muy difícil, es bien difícil.* *…pero el mismo americano no se cuida.… El mismo americano sufre la misma enfermedad que nosotros porque también su comida es algo que no está para cambiarse los de la noche a la mañana. Como siempre nos están diciendo la comida chatarra lo que más come el americano, ¿sí?*

an interpreter present, a language barrier can affect the content and duration of the discussion. Regarding her doctor, one participant explained: "*On the one hand [my PCP] pays attention to me, but on the other she doesn't speak Spanish… I feel uncomfortable because I would like to just tell her how I feel…but [I have to tell] my daughter, tell her this and that. She tells her what she wants to.… [Sometimes] I think it's coming from her head because it's not what I said.*"

Several participants indicated that the challenges associated with the language barrier are commonly compounded by challenges associated with another barrier, that of cultural differences, when it comes to diabetes management. Various participants noted how their doctors' unrealistic expectations for changes in their diets reflected a lack of understanding of the food they prefer and its greater significance: "*It's our culture, how we grew up since childhood, the food we ate…at this point in our life, radically changing that way of eating is very hard, it's quite hard.*"

Further, identifying a person's preferred foods as problematic can come off as unnecessarily judgmental or condescending. As this same participant pointed out: "*…but the same American doesn't take care of himself…That very American suffers the same disease that we do because his food is also something that can't be changed overnight. Like they are always telling us, junk food is what the American eats most, right?*"

Conversely, Spanish-speaking participants who have found Spanish-speaking providers and providers with a more open approach to cultural differences note a high level of satisfaction. As one participant explained: "*Well [my brothers] control their diabetes because they are in Santo Domingo, and there they take their medicine, but they also take many plants of the earth, natural, and then, well, their diabetes is good. When I'm in Santo Domingo, and I take lots of plants, I don't have to take pills, I take many teas and such, and all is well…and I found a really good doctor… I say, "Oh, it's great that I found you" because he speaks Spanish; I don't speak English. Then, well, you go to him, and you say to him, "I feel this," and he tries to do something to help you. Then, well, even if it's not a prescription, let's say teas or something, but he helps me more than most.*"

DISCUSSION

This is, to our knowledge, the first study designed specifically to understand and address the needs of Rhode Island's Hispanic population with diabetes. In doing so, it follows in the footsteps of other community-based observational and interventional studies of groups with diabetes such as Benavides-Vaello, Brown, and Vandermause's interview-based study of Mexican-American women in South Texas[10] and Kim et al.'s self-management education intervention in the Korean American community in Maryland.[11] The existence of such studies underscores the importance of understanding the challenges of living with diabetes experienced by specific communities in order to offer the best interventions to each community.

Our investigators identified four salient themes present in the interview transcripts: uncertainty about diagnosis and treatment, fear as motivation, language discordance with providers, and poor cultural understanding by providers. In their review, Cersosimo and Musi also identified poor understanding of diagnosis/treatment, language discordance, and cultural barriers as difficulties associated with diabetes management in Hispanic/Latino patients.[12] Participants in this study and others eliciting patients' experiences in healthcare have noted the multitude of difficulties of communicating via a personal interpreter.[13] As our participants made clear, interactions with even the most patient and attentive physicians can be hindered significantly by a lack of language concordance. Further, language discordance has been shown to measurably impact diabetes management; data from the DISTANCE trial revealed participants with language-discordant physicians were more likely to have poor glycemic control than those with language-concordant physicians.[14]

Cultural understanding may be just as crucial to successful diabetes interventions. Culturally tailored diabetes education programs serving a variety of groups have been well-received and successful in improving diabetes management among participants.[15,16,17] One study examining a program designed for the Mexican American community of Dallas, Texas attributed its success to the program's leader, a community health worker, and suggested that community health workers are crucial to reaching people in underserved areas.[15]

Fear as motivation seems to be well known to patients and practitioners. In one study, physicians reported fear of insulin among their Hispanic patients.[18] In their review, Fu, Qiu, and Radican found that fear of insulin or fear of injection has a negative impact on successful diabetes control.[19] Indeed, though fear is not a positive motivator, it appears that physicians have not removed it from their practice.

This study is limited in its scope by the relatively small number of interviews collected and the small number of countries of origin represented among participants. Progreso Latino serves members of Rhode Island's Latino and immigrant communities,[6] who number in the hundreds of thousands;[7] tens of thousands of these Rhode Islanders live with diabetes,[7,20] and the 14 participants in this study are certainly not representative of the full diversity of experience among this large population. However, the sample size does accomplish this study's qualitative goal of amplifying multiple voices that reveal common experiences among the population of interest.

Notably, our study did not directly reveal additional challenges associated with the control of diabetes that others have seen in Hispanic/Latino communities, such as lack of access to healthy food or health insurance.[12] However, the participant population was very representative of Progreso Latino's regular visitors with diabetes. As such, the results of this study are well suited to this organization's needs. Similar recruitment and interview methods could be employed at other organizations to yield similarly well-suited results.

With these principles and the patients' voices in mind, our investigators make the following recommendations for diabetes education programming at Progreso Latino. To address the issues of uncertainty, language barriers, cultural barriers, and fear as motivation we recommend increasing the number of liaisons between community and health organizations. Spanish-speaking community health workers that can interpret both language and culture are ideally suited to meet people with new diabetes diagnoses at Progreso Latino and educate them about making practical adjustments to habits and lifestyle. To complement this, we recommend culturally appropriate methods of education about dietary changes. This could include distributing a cookbook with healthy recipes and holding cooking demonstrations with clients and their families. Lastly, we recommend providing clients with educational videos in their preferred language to allow for continued learning at home; this can further address the uncertainties of diagnosis and management of the disease. Changing habits in the face of a new diagnosis is difficult for every patient, but the results of these interviews suggest that these measures could potentially ease those difficulties for Progreso Latino's clients.

These recommendations will form the basis for adaptations that Progreso Latino makes to its existing programming. The organization's Wellness Center has already begun to publish supporting materials on its website, including informative bilingual videos. It has also distributed a cookbook with accompanying nutritional labels entitled *Savoring Health: A Healthy Latinx Cookbook*, available in print and online.[21] In order to gauge the effectiveness of these adjustments to programming, another study should be conducted that examines satisfaction, enhanced self-efficacy, and improved health outcomes of Progreso Latino's clients with diabetes.

This study provides a model in Rhode Island for involving community members in the design of community resources for their benefit by eliciting their experiences via interviews. Doctors must interview their patients daily, provide

individualized counsel, and engage in shared decision making to produce the best outcomes; it is in these interviews that the truth of experience is revealed. Community-based organizations can reach these same people outside the constraints of the doctor's office and are able to continue this conversation, reinforce the teaching about a new diagnosis, and empower their clients to take charge of their care. Other studies have shown that listening carefully to their voices and adjusting resources available to them accordingly is both feasible and essential; with that in mind, it is our duty to do so for our local communities.

References

1. Powers MA, Bardsley J, Cypress M, Duker P, Funnell MM, Fischl AH, Maryniuk MD, Siminerio L, Vivian E. Diabetes Self-Management Education and Support in Type 2 Diabetes: A Joint Position Statement of the American Diabetes Association, the American Association of Diabetes Educators, and the Academy of Nutrition and Dietetics. J Acad Nutr Diet. 2015 Aug;115(8):1323-34. doi: 10.1016/j.jand.2015.05.012. Epub 2015 Jun 5. PMID: 26054423.
2. Chatterjee S, Davies MJ, Heller S, Speight J, Snoek FJ, Khunti K. Diabetes Structured Self-Management Education Programmes: A Narrative Review and Current Innovations. Lancet Diabetes Endocrinol. 2018 Feb;6(2):130-142. doi: 10.1016/S2213-8587(17)30239-5. Epub 2017 Sep 29. Erratum in: Lancet Diabetes Endocrinol. 2018 Feb;6(2):e2. PMID: 28970034.
3. Hahn EA, Burns JL, Jacobs EA, Ganschow PS, Garcia SF, Rutsohn JP, Baker DW. Health Literacy and Patient-Reported Outcomes: A Cross-Sectional Study of Underserved English- and Spanish-Speaking Patients with Type 2 Diabetes. J Health Commun. 2015;20 Suppl 2:4-15. doi: 10.1080/10810730.2015.1061071. PMID: 26513026.
4. Tang TS, Funnell MM, Oh M. Lasting Effects of a 2-year Diabetes Self-management Support Intervention: Outcomes at 1-year Follow-up. Prev Chronic Dis. 2012;9:E109. doi: 10.5888/pcd9.110313. Epub 2012 Jun 7. PMID: 22677159; PMCID: PMC3457752.
5. Sofaer S. Qualitative Methods: What Are They and Why Use Them? Health Serv Res. 1999 Dec;34(5 Pt 2):1101-18. PMID: 10591275; PMCID: PMC1089055.
6. Mission & History. Central Falls, RI: Progreso Latino, Inc; cited 2022 Jan 31. Available from: https://progresolatino.org/about-us.
7. U.S. Census Bureau QuickFacts: Rhode Island. Suitland, MD: U.S. Department of Commerce; cited 2022 Feb 8. Available from https://www.census.gov/quickfacts/RI.
8. Fitzpatrick, E. R.I. Latino Population Grew by Nearly 40 Percent in the Past Decade, Census Shows. The Boston Globe [Internet]. 2021 Aug 13. Available from: https://www.bostonglobe.com/2021/08/12/metro/ri-latino-population-grew-by-nearly-40-percent-past-decade-census-shows/.
9. Borkan, JM. Immersion/Crystallization. In: Crabtree BF and Miller WL, editors. Doing Qualitative Research. Thousand Oaks, CA: SAGE Publications, 2012, pp. 179–197.
10. Benavides-Vaello S, Brown SA, Vandermause R. "Can You Keep It Real?": Practical, and Culturally Tailored Lifestyle Recommendations by Mexican American Women Diagnosed With Type 2 Diabetes: A Qualitative Study. BMC Nurs. 2017 Jul 6;16:36. doi: 10.1186/s12912-017-0232-4. PMID: 28694738; PMCID: PMC5500922.
11. Kim MT, Kim KB, Ko J, Murry N, Xie B, Radhakrishnan K, Han HR. Health Literacy and Outcomes of a Community-Based Self-Help Intervention: A Case of Korean Americans with Type 2 Diabetes. Nurs Res. 2020 May/Jun;69(3):210-218. doi: 10.1097/NNR.0000000000000409. PMID: 31972848; PMCID: PMC7266039.
12. Cersosimo E, Musi N. Improving treatment in Hispanic/Latino patients. Am J Med. 2011 Oct;124(10 Suppl):S16-21. doi: 10.1016/j.amjmed.2011.07.019. PMID: 21939794.
13. Brooks K, Stifani B, Batlle HR, Nunez MA, Erlich M, Diaz J. Patient Perspectives on the Need for and Barriers to Professional Medical Interpretation. R I Med J (2013). 2016 Jan 4;99(1):30-3. PMID: 26726861.
14. Fernandez A, Schillinger D, Warton EM, Adler N, Moffet HH, Schenker Y, Salgado MV, Ahmed A, Karter AJ. Language Barriers, Physician-patient Language Concordance, and Glycemic Control among Insured Latinos with Diabetes: The Diabetes Study of Northern California (DISTANCE). J Gen Intern Med. 2011 Feb;26(2):170-6. doi: 10.1007/s11606-010-1507-6. Epub 2010 Sep 29. PMID: 20878497; PMCID: PMC3019330.
15. Prezio EA, Cheng D, Balasubramanian BA, Shuval K, Kendzor DE, Culica D. Community Diabetes Education (CoDE) for Uninsured Mexican Americans: A Randomized Controlled Trial of a Culturally Tailored Diabetes Education and Management Program Led by a Community Health Worker. Diabetes Res Clin Pract. 2013 Apr;100(1):19-28. doi: 10.1016/j.diabres.2013.01.027. Epub 2013 Feb 28. PMID: 23453178.
16. Carter BM, Barba B, Kautz DD. Culturally Tailored Education for African Americans with Type 2 Diabetes. Medsurg Nurs. 2013 Mar-Apr;22(2):105-9, 123. PMID: 23802497.
17. Choi TST, Walker KZ, Palermo C. Culturally Tailored Diabetes Education for Chinese Patients: A Qualitative Case Study. J Transcult Nurs. 2017 May;28(3):315-323. doi: 10.1177/1043659616677641. Epub 2016 Nov 17. PMID: 27856820.
18. Lipton RB, Losey LM, Giachello A, Mendez J, Girotti MH. Attitudes and issues in treating Latino patients with type 2 diabetes: views of healthcare providers. Diabetes Educ. 1998 Jan-Feb;24(1):67-71. doi: 10.1177/014572179802400109. PMID: 9526327.
19. Fu AZ, Qiu Y, Radican L. Impact of fear of insulin or fear of injection on treatment outcomes of patients with diabetes. Curr Med Res Opin. 2009 Jun;25(6):1413-20. doi: 10.1185/03007990902905724. PMID: 19422281.
20. BRFSS Prevalence & Trends Data: Explore by Location. Atlanta, GA: U.S. Department of Health & Human Services; cited 2022 Mar 6. Available from: https://nccd.cdc.gov/BRFSSPrevalence.
21. Health & Wellness. Central Falls, RI: Progreso Latino, Inc; cited 2022 Jan 31. Available from https://progresolatino.org/health-wellness.

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Disclosures

None

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