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Facilitators and barriers to research participation: perspectives of Latinos with type 2 diabetes

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Abstract

Background: Latinos constitute 17% of the US population and are one of the largest ethnic groups; however, only 7.6% participate in research studies. There is a disproportionately high number of Latinos living with type 2 diabetes mellitus and are at increased risk for cardiovascular events. Research to elicit facilitators and barriers for participation in research and effective recruitment strategies is limited.

Aims: This article reports the qualitative findings of a mixed-methods study examining perceived facilitators and barriers for research participation, and explores decision-making processes and ascertains ethnic values that influenced their decisions among Spanish-speaking Latinos with type 2 diabetes mellitus.

Methods: Semi-structured interviews were conducted with 25 participants (mean age 50.8 ± 9.4 years, 76% women and 28% employed). Participants were asked to elaborate on perceived facilitators and barriers to research participation. All interviews were conducted in Spanish. Transcribed interviews were analyzed through conventional content analysis.

Results: Three themes emerged from transcribed interviews: (a) lowering barriers to access health-related expertise; (b) language concordance; and (c) trusting relationships. Perceived barriers to research participation included work schedule, childcare, transportation and ethnic beliefs.

Conclusion: Strategies to support learning, language concordance and establishing trusting relationships among Spanish-speaking Latinos may be key to increasing Latinos in research studies.

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Declaration of conflicting interests

The authors declare that there is no conflict of interest.

Keywords

Latino; research recruitment; health disparities

Introduction

There are 53 million Latinos living in the United States of America (USA), representing 17.4% of the US population now, which is projected to grow to include 28.6% of the population by 2060.¹ Also growing is the disproportionately high numbers of Latinos living with chronic conditions. The American Heart Association identified three cardiometabolic risks: blood pressure, fasting plasma glucose and total cholesterol that increase the probability of vascular events or developing diabetes.^{2,3} Diabetes lowers life expectancy by 15 years and increases risks for atherosclerotic cardiovascular disease (CVD) by two to four times and tends to be more extensive compared to those without diabetes.^{4,5} Two out of every three people with type 2 diabetes mellitus (T2DM) will be diagnosed with hypertension and the odds for a stroke are 1.5 times higher; therefore, prevention and management of atherosclerotic CVD risks are major goals of T2DM management.⁶

The burden of diabetes and atherosclerotic CVD complications is distributed disproportionately, several ethnic and racial groups experience minor improvements due to the patients' contextual circumstances that include healthcare systems and the environment.⁷ Approximately 23% of US Latinos live in poverty, about one-third lack healthcare coverage, have lower rates of education attainment, and limited English proficiency compromises the delivery of care that ultimately impacts clinical outcomes.^{8,9} Data show that Latinos are 1.7 times more likely to be diagnosed with diabetes and three times more likely to start treatment for end-stage renal disease than non-Hispanic whites, with Latino women 1.5 times more likely to die of diabetes than non-Hispanic white women.¹⁰ Latinos experience worse glycemic control and a higher rate of diabetes-related complications (e.g. macrovascular events including myocardial infarction, hypertension and stroke, renal disease and death).¹¹ However, when it comes to representation in research studies (i.e. clinical trials) that could enhance clinical and psychosocial outcomes, Latino participation remains low. The National Institutes of Health reports that minorities make up 30% of enrollees in clinical trials and Latinos represent only 7.6% of those participants.¹²

Several factors including distrust, lack of healthcare coverage, lack of childcare, language barriers, work schedules, legal status, cultural differences, religion and family have contributed to the underrepresentation of Latinos in research studies.^{13–15} Investigators recruiting Latino research participants mitigate some of these factors with bilingual staff, free onsite childcare, in-home interventions or integration of ethnic foods, but there remains a gap of relevant strategies for a heterogeneous Latino culture.^{16,17}

However, there is a paucity of research that focuses on the participation of Latinos in studies to enhance clinical outcomes, self-management and psychosocial wellbeing in Spanish-speaking Latinos with T2DM, and little is known about the effectiveness of different recruitment strategies on representation in research among this subgroup of individuals. Moreover, there is sparse funding available to identify effective recruitment and retention

methods of ethnic minorities.¹⁸ Thus there is an urgent need to understand better the perceived facilitators and barriers for participation in research and find successful methodologies of recruitment that increase the representation of Latinos in research that could improve health and reduce the impact of chronic disease in this high-risk population.

The overall goal of this exploratory qualitative study was to elicit perceived facilitators and barriers for participating in a research study among Spanish-speaking Latinos with T2DM. The specific objectives were to explore their decision-making processes and ascertain values that influenced the decision to participate in research, in order to suggest strategies for enhancing the representation of Latinos in clinical trials that could result in enhanced clinical outcomes, self-management and psychosocial wellbeing.

Methods

One-to-one semistructured interviews were used to develop an understanding of the perceived facilitators and barriers to participation in an ongoing intervention study, which was designed to examine the impact of shared medical appointments and coached care on clinical outcomes, self-management and psychosocial wellbeing among Latino patients with T2DM. Latinos were recruited from a federally qualified health center, which provides comprehensive health services to medically underserved populations. The principal investigator of the study was also a primary care provider in the clinic. Eligibility criteria for the study included individuals over 18 years of age, uncontrolled diabetes (glycosylated hemoglobin >8.0), absence of diabetes complications (e.g. renal failure or amputation), communication deficits (vision or speech impairment), and willingness to attend six monthly meetings lasting 1–1.5 hours.

Participants were asked: (a) what motivated you to participate in the current research study? and (b) are there any reasons that made you reluctant to participate in the current research study? They were asked to explain their responses to determine factors in the decision-making process (e.g. language, ethnicity concordance) and to ascertain values that impacted decision-making processes to research participation. All interviews were conducted in Spanish by a single interviewer (JAH).

Data analyses

NVivo (version 10; QSR International, MA, USA)¹⁹ was used to organize transcript coding for easy retrieval. As with all qualitative data software, it is important to emphasize that actual coding/analysis is done by the research team. SPSS (version 22.0; IBM Corp., Armonk, NY, USA)²⁰ was used to calculate descriptive statistics of demographic data, frequencies of themes and inter-coder reliability. Due to the scarcity of data about perceived barriers and facilitators for participating in research for Spanish-speaking Latinos with T2DM, transcribed interviews were analyzed through conventional content analysis using inductive code generation.²¹ Each transcript was independently coded by two coders (JAH and LSE). Coders resolved coding disagreements through discussion. Codes were collapsed into higher-level themes organized around two related topics, facilitators and barriers to research participation and elements of the decision-making process.

Results

Twenty-five Spanish-speaking participants ranging in age from 31 to 66 years (M 50.8, SD 9.40) provided responses to the two open-ended questions. Nineteen (76%) were women and 16% completed high school. Four (28%) were employed and only 12% reported that their financial income was enough to make ends meet.

Three primary themes emerged from the transcribed interviews: (a) lowering barriers to access health-related expertise; (b) language concordance with the research team; and (c) the importance of trusting relationships. Illustrative quotes are presented in Table 1.

Lowering barriers to access health-related expertise

This feasibility study incorporated health coaching intervention into shared medical appointments for Spanish-speaking Latino adults with T2DM. In general, participants wanted to learn how to take better care of themselves to improve their diabetes. The combination of diabetes education with provider access was central to the decision-making process. Access to the provider facilitated open discussions regarding health and myths about diabetes. Participants also felt that the process to access clinical records (e.g. laboratory results) was simplified.

Some participants expressed that they were reluctant to participate in research not because they did not see the value, but because it was logistically difficult for them to complete the study procedures. To alleviate some of these barriers, the day and time of the study was based on participants' input during the recruitment phase. Two groups met on the weekend to accommodate individuals working full time or for transportation purposes. A weekday group was scheduled for weekend workers or those assisting family members at flea markets where independent vendors sell discounted goods to the public. Family members (e.g. spouse, siblings or adult children) were encouraged to participate in the activities. Although childcare was not provided, participants were advised that coloring books and crayons would be available. Moreover, childcare was defined in the context of each participant. It was not always the child–parent dyad who required childcare, rather it was a child–caregiver dyad. The child was either an extended family member (i.e. grandchild, niece or nephew) or the participant was hired to care for the child. Socioeconomic barriers were identified as obstacles to research participation. Although only four participants were employed, others would choose to work if the opportunity arose. These jobs included day laborer, babysitting, house cleaning or selling seasonal foods (i.e. tamales). There was no cost to participate in the study, yet enrollees identified financial constraints as a barrier. On further probing, they clarified that they would not be able to achieve goals, such as preparing healthy foods that they knew they could not afford. Transportation was also asserted as a barrier.

Participants elucidated cultural beliefs as barriers to learning. One example was an emotion referred to by participants as 'fatal' or an overreaction to an event such as the initial diagnosis of diabetes. Fatalism is a cultural belief that life events are beyond one's control and is conceptualized as negative beliefs and attitudes regarding health-seeking behaviors, screening practices and illness.²² Other cultural barriers included the belief that fright (*susto*) triggered diabetes, medications would harm the liver and kidneys, or out-of-control

diabetes may be due to witchcraft. Participants acknowledged that believing these myths was harmful because individuals would not seek any help. However, participants associated diabetes education as an integral intervention to dispel these cultural beliefs.

Language concordance

Language concordance was critical for these Spanish-speaking participants. Twenty-three (92%) of the participants were monolingual Spanish speakers. They expressed more satisfaction when they could speak directly to staff and felt better understood when the individual was bilingual. Participants identified the use of interpreters as a barrier to language concordance. They felt that interpreters could not fully explain all their feelings and symptoms. They felt lost in translation when a combination of Spanish and English was used to give them instructions.

Trusting relationships

Trust (*confianza*) was an overarching theme that influenced participants to enroll in the study. Relationships (*personalimo*) were associated with friendliness (*simpático*) and caring. Some of the participants knew the investigator as their provider and felt comfortable enrolling in the study. Other participants enrolled because their provider recommended the study as an opportunity to learn more about diabetes and improve their health. Each participant was scheduled an appointment with the investigator to explain the study, sign the consent and complete prescreening forms. Participants described this face-to-face interaction as individualized and more welcoming. The salient effect of this strategy added a personal touch to the recruitment phase of the study.

Participants identified a hurried attitude as a barrier to developing a trusting relationship. One participant explained that a hurried individual does not take the time to listen and tends to be self-centered. Participants found it challenging to build any type of relationship with such a hurried individual.

Conclusion

Recruitment of Latinos remains a challenging effort for investigators, but this may not be due to lack of interest in participation. A number of people saw value in participation. The study aimed to identify facilitators and barriers to explore decision-making processes and ascertain values that influenced their decisions. Decision-making is a multifactorial process. Based on interview responses, participants were willing to enroll in the study because it fulfilled a need that was important to them. The study offered an educational and supportive intervention to improve glycemic control and ultimately their health. The availability of the provider as part of the study added value because it removed barriers to access.

However, logistical and cultural barriers make it hard to participate and should be addressed. Logistical facilitators included bilingual/bicultural staff, convenient location, schedule and ease of bringing family members and children to the study. It is important to note that participants were queried on the best time to schedule the program, which gave them a sense of participating in the planning process. Recruitment of Latino participants obligates researchers to recognize the complexity of ethnic beliefs and norms in social and economic

contexts. However, Latino is a general term that encompasses a group of subcultures spread across the USA, each with distinct traditions. This is further complicated when assimilation involves cultural variations. It is unreasonable to define a set of interventions that is applicable to all subcultures, but it is prudent to clarify practices unique to the participants.

This study has some limitations, and the results should be interpreted with the understanding that Latinos comprise a heterogeneous population with diverse beliefs. One limitation is that participants in this sample were already enrolled in a research study, so each was motivated to participate. Information from non-enrollees was not captured, which would highlight more barriers to research participation. Despite these limitations, our findings provide researchers and clinicians with a better understanding of the facilitators and barriers to research participation in a sample of Spanish-speaking Latinos with T2DM to reduce atherosclerotic CVD complications and vascular events.

In conclusion, although the primary motivation to enroll in the study was based on learning, there was a consensus among the participants that language concordance with the research team was crucial. Along the line of transparent communication was an overarching theme of trust, much of which was associated with the provider who recommended the study. Future studies must consider collaborative studies that include research and clinical personnel together as an effective strategy to attract more Latino participants. However, the take-home message is that many Latinos may have a genuine motivation to ‘share their stories and help others understand their struggles’ and that investigators should lower barriers to allow this to happen.

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Table 1.

Themes with representative quotations.

| Theme | Quotations |
|---|--|
| Lowering barriers to access health-related expertise | |
| Facilitators to access | <ul style="list-style-type: none"> I brought my sister because she has prediabetes and wants to know how to take care of herself. Having [provider] here, [she] can answer questions, they [friends, neighbors, family] tell me to take this or that medicine or herb... I tell them no... I have diabetes and I have to ask my doctor. |
| Barriers to access | <ul style="list-style-type: none"> There are so many beliefs that people think cause diabetes... I was told that I have diabetes because of fright. One has to work... I take care of my grandson... so my daughter can work. I don't get paid, but it is the only way to help each other. |
| Language concordance | |
| Facilitators to concordance | <ul style="list-style-type: none"> ...my [clinic] provider is very good, but having someone who can understand me is much better and it is necessary... ...I know my diabetes care is important. I learn more when my provider explains it in Spanish and I can ask more questions about the information. |
| Barriers to concordance | <ul style="list-style-type: none"> ...my [clinic] provider uses words that I do not understand... knowing that you speak Spanish is better because you will understand me. ...I get pamphlets to read but I do not understand them.. I was told to have a family member help me review the information, but they are too busy with their own lives. |
| Trusting relationships | |
| Facilitators to trust | <ul style="list-style-type: none"> My provider recommended [the study] because it would help me with my diabetes. So that's why I am here. ...she was very nice and answered my questions. She changed the time of the study for me... my daughter can bring me on Saturday because she does not work. |
| Barriers to trust | <ul style="list-style-type: none"> ...I don't like to be rushed. it makes me forget things.... ...in the clinic, I see my provider for a few seconds. I am told that my diabetes is still uncontrolled and that I must stop eating too many tortillas, exercise more and now I must start insulin. I want to ask for more help but [provider] just tells me the same [instructions]. |