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U.S. Healthcare Experiences of Hispanic Patients with Diabetes and Family Members: A Qualitative Analysis

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Abstract

Hispanics in the U.S. experience significant health disparities. Using focus groups conducted in Spanish, we explored the perspectives of 172 Hispanic adults regarding their healthcare experiences. Many participants were female (64.5%) and primarily from Mexico (80%). Four major qualitative themes emerged: 1) provide us with information, 2) want attentive and respectful relationships, 3) want better care, and 4) perceived discrimination. Suboptimal patient-provider interactions were described. Research is needed to explore interventions that address these issues. Incorporating person-centered care principles and practices such as clear and understandable communication, culturally competent care, and customer service skills may benefit provider interactions with Hispanics.

Keywords

Hispanics or Latinos; patient-provider communication; person-centered care; discrimination

Hispanics living in the U.S. experience significant health related disparities compared to non-Hispanic Whites (U.S. Department of Health and Human Services [USDHHS] & Office of Minority Health [OMH], 2017; USDHHS & OMH, 2016). For example, Hispanics are more likely to have uncontrolled diabetes, develop end-stage renal disease, and die from diabetes than non-Hispanic Whites (USDHHS & OMH, 2016). Hispanics with diagnosed hypertension are less likely to have the condition adequately controlled or to receive fibrinolytic medication when having a myocardial infarction as compared to non-Hispanic Whites (Agency for Healthcare Research and Quality [AHRQ], 2016). Data indicates that Hispanics are less likely to report having cancer screening tests such as a mammogram or colonoscopy, or to receive A1C checks, or have a usual source of care than Whites. Hispanics encounter social determinants of health that negatively impact their ability to access healthcare services such as being uninsured, low-income, low health literacy and

limited English proficiency. These barriers contribute to poor health outcomes, delays in seeking medical care, and/or overutilization of emergency services (AHRQ, 2015).

Person-centered care has been identified as a means to improve health outcomes and reduce health disparities and is critical for chronic disease management (AHRQ, 2016). An essential aspect of person-centered care is effective communication between patients and healthcare providers. Prior research indicates that healthcare provided in one's primary language can positively impact patients' health status and A1C levels among minority populations (Piette, Bibbins-Domingo, & Schillinger, 2006). In contrast, when language discordance is present between patients and healthcare providers, there is decreased comprehension and interactive communication which may result in poor quality healthcare and patient dissatisfaction (Schenker et al., 2010; Sudore et al., 2009). Effective communication is impacted by patients' health literacy level. Persons with limited health literacy tend to ask few questions and have greater difficulty following physician's directions or participating in shared decision making (Sudore et al., 2009). Therefore, tailoring communication to the patient's health literacy level is essential for patient safety and improving health outcomes as well as informing and empowering patients (Rossi et al., 2015; Sudore et al., 2009).

For patients from culturally diverse backgrounds, culturally competent healthcare is an essential aspect of person-centered care (Hawley & Morris, 2017; OMH & USDHHS, n.d.). Lower feelings of discrimination have been reported by Hispanics when they have perceived healthcare providers to be respectful and sensitive to their culture (Becerra, Androff, Messing, Castillo, & Cimino, 2015; Nápoles et al., 2012). Greater patient satisfaction and trust have been reported when patients perceive they have been treated respectfully by the healthcare community regardless of insurance status, English language proficiency, or race/ethnicity (Becerra et al., 2015; Calo et al., 2015; Tajeu et al., 2015).

The purpose of this study was to explore the perspectives and U.S. healthcare experiences of Hispanic adults living in North Carolina. Understanding their perspectives is important given the health disparities experienced by this population and that Hispanics are an increasingly larger segment of the state's population. Adult Hispanics in North Carolina are more likely to be foreign-born and of Mexican origin (Pew Research Center, 2014). Further, they have higher rates of limited English proficiency, lack health insurance, achieve lower educational attainment, and experience lower annual household income than non-Hispanic Whites (North Carolina Department of Health and Human Services Division of Public Health & State Center for Health Statistics, 2015, November; Pew Research Center, 2014). Hispanics in North Carolina may encounter greater language obstacles when seeking healthcare such as fewer available trained interpreters and less bilingual healthcare providers, which can impact quality of care and lead to long wait times and patient dissatisfaction (Calo et al., 2015). The information learned from this study may be useful in influencing chronic disease management, healthcare providers, and organizational policies.

Methods

Sample and Setting

Hispanic adults with type 2 diabetes and their family members that were part of a larger culturally tailored, diabetes self-management intervention study were invited to attend focus groups to discuss and share their perspectives of U.S. healthcare experiences. Participants had been recruited from Hispanic churches and community-based health clinics. This report presents the findings of the focus groups. Information regarding the larger study has been published elsewhere (Hu, Wallace, Amirehsani, McCoy, & Silva, 2016). Informed consent was obtained. The study was approved by the Institutional Review Board of the University of North Carolina at Greensboro.

Data Collection and Analysis

A qualitative inquiry approach using focus groups was utilized to allow freedom of expression to explore participants' perspectives and experiences with the U.S. healthcare system (Kreuger & Casey, 2015). The focus groups occurred at the completion of the intervention study. This allowed time for the research team to build relationships with participants. A semi-structured interview guide was used for the focus groups that were conducted in Spanish by a trained bicultural, bilingual, native Spanish-speaking moderator. The session began by asking the open-ended question "How can the healthcare community—doctors and nurses—work better with the Hispanic community?" Focus groups lasted 20 to 30 minutes and discussions were audiotaped and transcribed verbatim in Spanish by three bicultural, bilingual research assistants. Transcriptions were verified and compared to audiotapes for accuracy by two bilingual team members, translated into English and then translated back to Spanish. Final English translations were verified and compared for contextual meaning by two bicultural, bilingual team members and the first author who is bilingual.

The transcripts were analyzed independently and systematically using the constant comparative method to identify codes and themes by the four research team members (Kreuger & Casey, 2015). Line by line text was reviewed with an iterative process to identify trends and patterns. Then, the research team met to discuss and review all codes for consensus and placed them into broad categories and identified emerging themes. Coding discrepancies were resolved through group discussions until consensus was reached (Kreuger & Casey, 2015). Saturation of themes was noted. Descriptive statistics were used to analyze the sample characteristics.

Results

Eight focus groups (N=172) were conducted and ranged in size of 14 to 24 persons. Many participants were female (64.5%) and the mean age was 46 years (*SD* 12.9) (see Table 1). Most participants were foreign-born (95%), with the majority of persons emigrating from Mexico (80%). The average length of time reported living in the U.S. was 17.6 years (*SD* 8.2). All participants spoke Spanish. This sample of adult Hispanics reported social

determinants of health healthcare access barriers of being uninsured (67%), having less than a high school education (66%), and low annual household incomes.

Four themes emerged from the focus group data. The themes were: 1) provide us with information, 2) want attentive and respectful relationships, 3) want better care, and 4) perceived discrimination.

Theme 1: Provide Us with Information

Participants voiced concerns about not receiving adequate health information. They discussed wanting and needing information about their diseases, how to properly take medications, and learning better ways to self-manage diabetes. The lack of information for some participants led to self-medication, emergency department visits, and poor outcomes.

Doctors should be more informative, because sometimes we go to the doctor and if you don't ask they don't tell you. They should inform you because sometimes we don't know what the appropriate questions are that we need to ask. (female, age 26)

Doctors should give us more information about the consequences and symptoms of whatever disease that we are predisposed to... they (doctors) don't inform you of what could happen in a month or a year if you don't take care of yourself. They should give us more information on how to control what is happening to us or give more solutions for what is happening to us...dedicate more time to us, because here, it's almost like doctors are mute. They don't inform you of anything... Sometimes you have to self-medicate because the doctors don't talk to you. (female, age 42)

... I would ask the doctors that when they prescribe something to us that we have not tried before or something that we need that is new, they should take enough time to tell us how to administer it, what we should do with it and what it is for... they were going to change my medicine, but just like someone here said, they come for only 5 minutes and never explain how you are going to take it or why. I ended up in the emergency room because not even the doctor told me how I should take and use the medicine. I was told the nurse was going to come, so this is also for the nurses. The nurse came and took me out to the pharmacy and stopped there and told me they were taking a while so she would come back. She left and never came back... The end result was that I had to go to the hospital and I still feel bad. I haven't been able to control my blood pressure and sugar levels. (female, age 65)

One participant voiced her opinion that everyone needs to be more proactive about asking for the information they need and not be shy about asking healthcare providers questions.

Thank God I have always paid attention, because I always try to ask a lot of questions. I ask, I ask, I ask so they have to tell me what is happening with me. And if it is with my husband or my children the same thing happens. But there are people that are shy. There are people that stay quiet. (female, age 55)

Theme 2: Want Attentive and Respectful Relationships

A common theme was the desire for doctors and nurses to take a personal interest in the patient and ask questions. Participants voiced wanting providers to listen to patients' concerns and to take those concerns seriously and be treated respectfully. Some participants perceived that doctors seemed more interested in financial gain than providing care.

Attentive and respectful communication.

I would like the doctor to take more interest in the patient. To talk with his patients. I mean, to ask you "How do you feel?" to examine you from head to toe like he is supposed to do. If he sees, for example, something wrong then ask "What is wrong?" I would like the doctor to be more of a friend to the patient than a friend to the money. (female, age 49)

Doctors should show an interest in people because sometimes they just ask you one thing and then they are already diagnosing you without taking specific things into account....they have preconceived notions in their mind, they don't listen to the patient. They think you are wrong when you are talking about your symptoms... They have the idea that they know everything and only what they think is what is really true. (male, age 53)

Participants described unfriendly and rude encounters with nurses and front office staff which negatively impacted their office experience.

...The nurses should be friendlier or the people working at the front desk when they provide information. They should be nicer because sometimes they are very rude and they say, "I already told you this. This is the way it is." They don't give you any other explanation. (female, age 48)

Want time with the doctor.—Participants described experiences with healthcare providers that were rushed and did not allow enough time to ask questions or receive health information.

I also think the doctors should dedicate more time to their patients. There are doctors that make us wait for two hours in the waiting room and when the doctor comes it's only ten minutes with us before they get us out. They don't give us a lot of information, they don't talk enough about what we have, about what we should do...The doctor should dedicate a little more time to us. (female, age 40)

Theme 3: Want Better Care

Participants questioned the quality of the healthcare they received. Long wait times to be seen and difficulty obtaining timely appointments with regular providers or specialists were described and sometimes resulted in negative health consequences or delayed care. Other participants described not being able to see the same provider for follow-up visits resulting in perceived unnecessary changes in diabetes medications. Lastly, experiences of not receiving timely diagnoses were described that resulted in repetitive emergency room visits, physical suffering, and financial cost.

Long wait times and lack of timely appointments.

I was waiting for the doctor for two, almost three hours, and my sugar levels dropped and I felt very bad. There came a point when I had to leave and I switched doctors, but it was the same thing. (male, age 45)

When you arrive at the clinic, they should help you more quickly and sometimes they should provide more interpreters for those of us that do not speak English very well so you can leave quicker. (male, age 36)

One participant described having a positive experience with a clinic that was receptive to working with Hispanics.

I would like it if there was a clinic here where I live like the community clinic in the next town, because at that one, they take care of you very well.... There if I ask for an appointment, they give it to me for the next day. The doctors attend to me very well and they speak Spanish, the nurses are very nice. But here I can't find a clinic like that. There is one, but when you ask for an appointment they give it to you for a month later. (female, age 40)

Lack of provider continuity.

Each doctor attends to the patient in a different way and they give you certain medications and you are taking them exactly as directed and then at the next appointment, we have a different doctor who says, "No, this is not right. We are going to change your medication."... There are times that you are feeling good and then they go and take away the medication, change the days that you have to take it and that is when you have highs and lows (blood sugar levels)... they should respect the medical opinions of the other doctors that were previously treating that patient and they should pay attention to why the medication was prescribed in the first place and why they are giving it the way they do. (male, age 59)

Perceived poor quality care at a cost.

My husband broke two ribs and went to the hospital. They took an x-ray and said that he didn't have anything wrong. They said, "Go home and go back to work as usual."... On Monday he went to work for a while and at night he could not take it anymore, he was dying. We took him again to the same hospital. They gave him an MRI and they said, "You have two broken ribs." How then could they have sent him to work and then charged us two emergency room visits? And whose fault is that? (female, age 51)

Theme 4: Perceived Discrimination

All focus groups described situations of perceived discrimination related to not having health insurance or being Hispanic.

Insurance-based discrimination.—One participant, a husband, described the inability to get an appointment for his wife for a mammogram from a program for the uninsured.

I called twice...He (person answering the phone) asked what kind of insurance she had and I told him that she doesn't have any kind of insurance. Then I told him I was under the impression that in this case these services are free. He tells me, "Yes, it is true, but we need to know what insurance she has." Then I tell him, "She doesn't have any insurance." He says, "Wait a moment." Two or three minutes pass, he returns to the phone and says, "Ah, we are really sorry but the machine is broken. We don't have any machines available at this moment." The strange thing was that after I told him we didn't have any type of insurance he told me the machine didn't work. But he should have told me the moment I asked about the service and said something like, "Look we are very sorry but we don't have the machine available." (male, age 67)

You go to the doctor and the first thing they say is, "Do you have insurance?" You say, "No." "Okay, it is one hundred and ten dollars." You have to pay in advance or leave your card here. It is one hundred and ten dollars plus the tests." And if you have insurance, because it has happened to me, I almost always had insurance you get treated wonderfully. They will send you to get tests done. If you don't have insurance they will give you medicine and you leave and that's it. But the bad thing is they charge you the one hundred dollars. You might as well just leave. (male, age 49)

Racial/ethnic discrimination—"Is it because I'm Hispanic?"

What happens also is that there are doctors that you go to visit, to consult with, and they look at you like they don't want to help you. It is like they are treating you because they are obligated to, you know? It's like just by being Hispanic they are discriminating against you or something like that. (male, age 63)

I went to the cardiologist and the cardiologist checked me out and my sugar level that the primary doctor had apparently already sent to him and the cardiologist told me, "No, no, everything is fine. There is no problem with you. In one year I want to see you here again."... Three days after seeing the cardiologist who told me everything was fine, I had a heart attack and three or four days later they were operating on me. No matter how much I asked the doctors how they could know if everything was functioning like it should or to explain to me if the medication I was on was working like it should, when in reality it wasn't working, the doctor says, "Everything looks good." (male, age 63)

Discussion

Our study data revealed both positive and negative healthcare experiences as perceived by this sample of Hispanic adults. Participants voiced not knowing what questions to ask and wanting doctors to provide more health information to improve care for their specific health conditions. This finding is similar to that noted by Sarkar et al. 2011 in a study with physicians and limited English speaking patients with chronic cardiac conditions. In that study, poor communication was common and patients failed to receive understandable information regarding changes in their medications and health condition (Sarkar et al.,

2011). Poor communication was greater when there were cultural and languages differences between patients and providers. Additionally, physicians were unaware of barriers to medication use because they did not ask patients about any issues (Sarkar et al., 2011). Schenker et al. (2010) reported similar findings among limited English proficiency patients with diabetes. Suboptimal patient-provider interactions were associated with physicians not understanding patients' problems in carrying out treatments and perceptions of discrimination (Schenker et al., 2010).

Quality communication between patients, family members, and providers is essential for determining an accurate diagnosis, developing a collaborative treatment plan, and patient empowerment. Patients and family members require understandable health information that can be applied to manage their diseases. For example, improved glycemic control and engaging in diabetes self-care activities have been associated with patient empowerment (Rossi et al., 2015).

In this current study, participants voiced wanting more health information. Only one participant described her willingness to keep asking for information until it was obtained. This "shyness" about not asking their doctor for more information may be related to Hispanic cultural values of wanting a positive personal relationship with their doctor, and avoiding interactions that can be perceived as discourteous (Reininger et al., 2014). Since the current study sample of Hispanics were immigrants, many with limited English proficiency and social determinants of health access barriers, they may have felt vulnerable asking for information in a forthright or persistent manner. The lack of asking questions may have been due to the low health literacy of the study's participants, as the majority had less than a high school education.

The men and women in our study described a desire for attentive and respectful relationships with doctors, nurses, and office staff. The lack of perceived quality interactions made some participants feel disrespected, dissatisfied, and question the quality of care they received. These findings are similar to those found among Hispanics living along the U.S.-Mexico border area (Reininger et al., 2014). Perceptions of poor quality interactions with U.S. healthcare providers contributed to some Hispanics seeking care in Mexico (Reininger et al., 2014). Perceived poor patient-provider interactions have negatively impacted *confianza*, trust, with the healthcare team (Reininger et al., 2014; Schenker et al., 2010). Also, negative interactions with front office staff have been reported in previous studies with Hispanics contributing to feelings of disrespect, patient dissatisfaction, and perceived discrimination (Keller, Silberberg, Hartmann, & Michener, 2010; Tajeu et al., 2015). Patient-provider relationships built on respect, trust, and culturally competent care are critical to person-centered care (Hudon et al., 2012).

Rushed visits and little time with the doctor were described. This hurried environment contributed to perceptions of poor communication, poor quality of care, and impressions that doctors are not providing expected care. Similarly, among a sample of older Latinos, hurried office visits were associated with providers not eliciting patient information or providing health explanations and patients' perceived lack of culturally sensitive care (Nápoles et al., 2012).

Long wait times to be seen and the inability to obtain timely appointments were identified as concerns. In fact, one participant described developing hypoglycemia while waiting for his appointment which is a potentially serious situation. In a study by Calo et al. 2015 with Hispanics, long wait times were associated with the lack of interpreters which is similar to the current study findings. Long wait times have been associated with not having adequate Spanish speaking front office staff or difficulty making appointments over the phone (Calo et al., 2015). Similar to the experiences described by our study participants, persons without health insurance are less likely to receive timely care and more likely to go without needed healthcare due to difficulties obtaining appointments, resulting in negative consequences (AHRQ, 2015). Tajeu et al. 2015 described implicit bias among front office staff as possibly playing a role in long wait times; where some patients are passed over and others given differential treatment based upon race/ethnicity. Another reason for long waits maybe due to under resourced healthcare facilities that provide care to underserved communities (Tajeu et al., 2015).

The lack of provider continuity was cited by participants as a problem for managing their diabetes. Having an ongoing patient-provider relationship and partnership is central to person-centered care and improvements in chronic disease management (Hudon et al., 2012). In the current study, the reasons for the lack of provider continuity are not clear. It is unknown if a lack of sufficient Spanish language services, turnover of providers at safety-net healthcare facilities, overbooked appointment schedules, or patients not requesting appointments with a specific provider were the causes. Perceived discrimination, both insurance-based and due to being Hispanic, was described, similar to findings of other studies with Hispanics in various regions of the U.S. (Calo et al., 2015; Han, Call, Pintor, Alarcon-Espinoza, & Simon, 2015; Keller et al., 2010; Reininger et al., 2014). Persons without insurance or having publically supported health insurance have reported greater difficulty getting a timely appointment and higher odds of forgoing needed care as compared to those with private insurance (Han et al., 2015).

The current study's participants attributed their ethnicity as a possible reason why providers did not listen to their problems or provide adequate explanations about their health status and treatments. Nápoles et al. 2012 had a similar finding with Spanish speaking older Hispanics in California describing feelings of discrimination and perceptions of receiving less culturally competent care from providers and office staff. Hispanics who reported perceived discrimination in healthcare settings indicated greater mistrust in healthcare providers, going without needed services, discontinuing important treatments, and dissatisfaction with services (Becerra et al., 2015; Calo et al., 2015; Keller et al., 2010).

Conclusion

The perspectives of Hispanic adults' and family members' healthcare experiences are revealing, troublesome, and consistent with previous studies. Culturally competent strategies are warranted to improve patient and family education, patient-provider communication and interactions, quality of care, and reduce perceived discrimination. Future research is needed to explore interventions that address these issues and their impact on health disparities experienced by Hispanics.

Practice Implications

Greater emphasis on person-centered care principles may benefit chronic disease management and improve patient-provider interactions for Hispanics (American Diabetes Association, 2017). Strategies are needed to assist patients and family members to become knowledgeable, skilled, and empowered partners in their care. Healthcare providers at all levels may require additional training and evaluation in providing culturally competent care, customer service skills, and communication focused on listening, asking, and explaining. Encouraging self-advocacy skills may be important for Hispanics.

Providing culturally and linguistically competent care includes understanding implicit and explicit biases that may exist and promotes treating all patients with dignity and respect (OMH & USDHHS, n.d.). Healthcare agencies may need to evaluate the adequacy of their Spanish language services in all areas of patient care and compliance with the National CLAS Standards (Calo et al., 2015; OMH & USDHHS, n.d.). In order to avoid misunderstandings, misdiagnoses, and medical errors, it has been suggested that primary care providers should utilize the services of trained health interpreters, as physicians and medical students may overestimate their language skills (Fernández & Pérez-Stable, 2015). Developing alternative appointment scheduling strategies to prevent long wait times may positively impact patient satisfaction, prevent feelings of discrimination, prevent delays in seeking treatment, and avoid hypoglycemic events in patients with type 2 diabetes. Valuing patients' personal time is crucial to positive customer service relations. Regardless of the strategies selected for action, the growing Hispanic population requires additional efforts to promote shared decision making and improve health outcomes (Hawley & Morris, 2017).

While this study provides important findings, there are limitations. The sample, comprised mostly of Mexican Hispanic immigrants living in North Carolina, may limit the generalizability of the findings to other Hispanic subgroups or those living in other regions of the U.S. Though participants referred to seeing "doctors," they may have been receiving care from nurse practitioners and physician assistants. Similarly, references to "nurses" were not clear if participants were referring to medical assistants or registered nurses. Lastly, recall bias may have played a role as participants described previous experiences with the healthcare community.

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Table 1.

Baseline Characteristics (N = 172)

Characteristic	N (%) or Mean $\pm$ SD (Min, Max)
Type 2 diabetes	
Yes	103 (60)
No	69 (40)
Health insurance	
Yes	55 (32)
No	116 (67)
Orange card ^d	1 (<1)
Foreign-born	164 (95)
Length in U.S. (years) if foreign-born	17.6 $\pm$ 8.2 (0.2, 51.0)
Country of origin	
United States	8 (5)
Mexico	137 (80)
Puerto Rico	6 (3)
El Salvador	2 (1)
Guatemala	4 (2)
Costa Rica	1 (<1)
Dominican Republic	3 (2)
Ecuador	2 (1)
Honduras	1 (<1)
Nicaragua	6 (3)
Panama	2 (1)
Education	
Less than 12 years	114 (66)
High school	45 (26)
Some college	5 (3)
Technical or vocational training	8 (5)
Completed college degree	0
Graduate education	0
Annual household income	
Less than \$10,000	83 (48)
\$10,000 to \$19,999	42 (24)
\$20,000 to \$29,000	25 (15)
\$30,000 to \$39,000	7 (4)
\$40,000 to \$49,000	4 (2)
\$50,000 to \$59,000	0
\$60,000 or more	1 (<1)

Characteristic	N (%) or Mean $\pm$ SD (Min, Max)
Don't know	10 (6)
Language(s) spoken at home	
Spanish only	129 (75)
Spanish and English	29 (17)
Spanish and Sign language	2 (1)
Spanish and Tarasco	9 (5)
English only	1 (<1)
Tarasco only	2 (1)

^aNote.

Orange card is a county health program for the uninsured.