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Marleen Z. Jones-Pool
mmjonespool@gmail.com

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Perspectives of Type 2 Diabetes Patients on Their Interactions with Providers

Marleen Jones-Pool

Master of Public Health

Yale School of Public Health

Social and Behavioral Sciences

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Collaborators:

Khush Dhaliwal

Jessica Ainooson

Eleanor Cook

Clinical Advisors:

Anne Camp, MD

Elizabeth Magenheimer, APRN

Thesis Readers:

Danya Keene, PhD

Nicola Hawley, PhD

ABSTRACT

Effective patient-provider communication has been shown to help achieve optimal health results, particularly in patients with diabetes. While previous studies have identified patient-perceived personal barriers in communicating with their providers, this study highlights interpersonal factors in the patient-provider interaction that may contribute to effective health communication. As part of a larger mixed-methods study, 10 semi-structured interviews were conducted with patients with self-reported diabetes at a primary health center. These interviews sought to understand patient-perceived communication factors that influenced their interactions with their providers. Interviews were recorded and transcribed verbatim. Interview transcripts were then coded and analyzed utilizing a grounded theory approach. Findings identified elements of patient-provider interactions that patients valued most when communicating with their providers. Patients appreciated when providers took the time to listen in order to take a holistic approach to their health. Patients also highlighted the respect they had for a provider's authority in the decision-making process within the clinical setting. Findings suggest ways providers can improve their interactions with patients in order to provide the best care.

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BACKGROUND

Type 2 diabetes is a chronic health condition where the body is unable to use insulin well to keep blood sugar at normal levels (1). It is a prevalent disease in the U.S., affecting over 30 million people (1) and disproportionately affecting those in the Hispanic population. Between 2013 and 2015, 12.1% of Hispanics had diabetes compared to 7.4% of non-Hispanic Whites (1). An estimated 33% of U.S. adults had prediabetes (1), a condition where blood sugar is higher than normal but not high enough to be diagnosed as type 2 diabetes, and signals increasing risk of diabetes development in the future (2). Among Hispanics, the prevalence of prediabetes was approximately 32% (1). Proper blood glucose level control requires daily self-care behaviors, such as eating healthy, performing physical activity, taking insulin or medications, and checking blood glucose levels (3). Many patients have difficulty completing these tasks every day, which results in poorer health outcomes (3).

Proper diabetes management relies on a patient's ability to understand the signs and symptoms of disease, as well as their knowledge of proper self-administration of medications. These instructions are often relayed verbally and through print by providers, and require proficient health literacy skills (4). Methods of addressing inadequate health literacy include improving the delivery of health information through clearer communication, seeing that communication between patients and providers has been linked to diabetes outcomes, such as glycemic control(3,4,5,6). In one study examining audio recordings of patient encounters in primary care centers, researchers reported that providers are having conversations with their patients about diabetes self-care; however, the providers varied in their capacity to engage in support and problem-solving about this self-care (7,11). Interestingly, patient ratings of providers' communication effectiveness have been found to be a better predictor of diabetes self-

management than a participatory decision-making style (8). Participatory decision-making style means the provider is involving patients in the medical decision-making process (8). In this study, which consisted of over 1000 veterans receiving care for diabetes from over 20 VA medical centers in the U.S., researchers found that patient perceptions of open and clear communication with providers influenced patients' management of their illness more than the perceived involvement of patients in the decision-making process for their treatment plan (8). With complete and understandable information, patients have the necessary knowledge for their diabetes management that they can put into practice (8).

Previous qualitative studies have focused on patients and providers characteristics that influence communication on diabetes self-management topics. One study of patients and providers identified common barriers and facilitators to communication regarding diabetes self-care during medical appointments, including but not limited to, trust, open communication, and reluctance to share (9). In one study focusing on Latinx patients in a community clinic in Massachusetts, researchers found that patient's perceived limited capacity to manage diabetes differed from the provider's confidence in patient's ability to live a "normal life" with the disease (10). With this belief, providers emphasized long-term, general goals for diabetes management with their patients, as opposed to short-term, realistic goals for lifestyle change (10). These studies have highlighted the importance of individual and cultural factors in communication about diabetes self-care, but are limited in identifying factors in the patient-provider interaction that also may contribute to effective self-care communication (9).

Understanding interpersonal factors in the interaction would be beneficial, since it may help providers address and overcome some of the perceived barriers in communicating effectively with their patients, like lack of trust or reluctance to share. For example, some research finds that

approaching a patient in a non-accusatory manner can increase patient comfort in sharing information with their provider (9).

This paper draws on qualitative interview data to explore patient perceptions of provider communication. Qualitative data will provide insight into the particular factors patients value most when interacting with their providers. Interviews will also examine how these values shape patient's self-management of their diabetes. Results from the analysis will be used to make suggestions on how providers in clinical settings can improve their interactions with patients, and thus improve care.

METHODS

Study design

Semi-structured qualitative interviews were conducted with 10 patients with self-reported diabetes at the Fair Haven Community Health Center (FHCHC) in New Haven, CT between July and August 2018. FHCHC treats a predominately Hispanic population with high incidence of obesity and increased risk of diabetes and pre-diabetes. This study was part of a larger mixed methods study that examined patient-provider communication and its association with patient health behaviors and outcomes in both patients with and without type 2 diabetes. Patients at FHCHC were approached by research team members in the health center waiting room and asked to participate in the study. Survey participants who reported having a diagnosis of type 2 diabetes were then invited to participate in qualitative interviews to explore patient-provider relationship and diabetes self-management.

Twenty-one patients were invited to complete qualitative interviews. Patients who didn't currently receive care at FHCHC or didn't have self-reported diabetes were excluded. Interviews were scheduled immediately after the patient completed the study survey and expressed interest

in participating in an interview. If a date could not be decided at that moment, a research team member would collect the patient's contact information to schedule the interview at a future date. Patients were contacted via phone to schedule an interview. A final sample size of 10 participants was achieved. Individuals who didn't participate in the study missed their scheduled interview time or were lost to follow up during the study data collection period. All participants were women. Four interviews were conducted in Spanish. Written consent was obtained from each participant before conducting interviews. This study was approved by the Yale Human Subjects Committee and Fair Haven Community Health Center Institutional Review Board.

Data collection

Semi-structured interviews were conducted by the research team in a private room at FHCHC. The research team used an interview guide with open-ended questions on the following topics: patient trust in providers, communicating with providers, interacting with providers, and diabetes self-management. These interviews provided insight into patient-perceived challenges in communicating with their providers, particularly when it came to managing their health. The interviews also asked about patient experiences participating in the diabetes-related programs offered at the health center. Interviews lasted between 30-45 minutes and participants were compensated with a \$10 gift card to the New Haven Farmer's Market. The first author conducted all of the Spanish interviews and 2 English interviews. The rest of the interviews were conducted by other members of the research team. Members of the research team identified themselves as Yale University students to participants and did not have any prior relationships with participants. All interviews were recorded after obtaining written permission from the participants.

Data analysis

All interviews were transcribed by the research team. Transcripts were coded and analyzed in their original language. To analyze the interviews, the first author used an open coding approach to identify themes and concepts. Codes were then refined to ensure that each represented a distinct concept in patient-provider relationships. Major themes were identified from noticeable patterns found in the way participants described their communication challenges with their providers. Salient participant quotations were translated into English for this paper. Dedoose software was used for all coding.

RESULTS

When discussing patient perspectives of their interactions with providers, there were three major aspects of their interactions that participants with diabetes valued most when they received care at the health center: receiving holistic care from their providers, the authoritative role of the provider, and evidence that their provider is listening to them. Participants wanted their providers to take a holistic approach to their health, which can be achieved by listening to their concerns. Additionally, participants didn't only want their providers to listen, but also valued the provider's authority and expected providers to make informed medical decisions using the information shared by patients along with their medical expertise. The following sections describe how participants discussed these topics in their interviews.

Holistic care

Participants with diabetes appreciated when their providers checked in on other issues pertaining to their health and well-being more generally. For several participants, coming to see a provider meant more than just checking their A1C levels (average blood sugar level over a 3-month period) and telling them how to improve their diabetes management. For instance, one

participant stated how she was previously on medication for her anxiety and had recently returned to the clinic to get them prescribed once again. Instead, the visit resulted in a “stand-off” with her provider because the provider was only concerned with addressing her high A1C level during the visit, and did not attend to the participant’s concern of returning on her medications.

“She helps me very well but we’re at a standoff right now because I don’t need you to keep telling me that my A1C is at a 12. You know what I’m saying? ‘And I need to get my A1C down. And you need to change your diet. And you need to do this. And you need to do that.’ You need to sit back and listen to me, but you really don’t.” (Participant 2)

This isn’t to say that providers shouldn’t attempt to address issues with patient’s diabetes management. Diabetes, as a chronic disease, affects the lifestyle of the patient and its management requires that patients practice good self-care in their day-to-day life, like eating healthy and scheduling time to take medication and/or check their blood glucose, which is often not an easy task for all patients. Participants did want providers to listen and assist in the challenges associated with diabetes self-management. In the words of one participant,

“But then I had to start taking insulin shots, and that wasn’t a picnic. Me and my needle had to go to work together.” (Participant 8)

However, when sharing their personal experiences in managing their diabetes, participants spoke about their diabetes in the context of current events in their lives, and not as an isolated issue. For example, one participant, acknowledging that her A1C levels were higher than previously, shared that she had recently gone on vacation for several months and since then, has not been following a healthy diet due to familial and cultural influences on food choice. The provider went on to tell her that she needs to eat healthier and increased her metformin dosage, but didn’t ask the participant what was going on in the past few months that her A1C level had

increased. The participant knew it was because she was engaging in unhealthy eating behaviors and that she could address her high A1C level by returning to her original diet pre-vacation, but the provider didn't take the time to ask. Some patients attributed this lack of inquiry to the limited time they had with providers and felt that it wasn't sufficient time for them to voice their concerns. As one participant put it,

"I don't know. I just think the communication. I had communication with my primary care doctor, but because again it's the time. You're on a time. Depends if she was running on schedule or if she was behind. You know so, maybe like 25 mins to a half hour [each visit]. Not [enough time] to focus on the things that I wanted to be focused on."

(Participant 7)

Several participants communicated dealing with other health conditions besides diabetes, such as obesity, kidney problems, and heart problems. Participants reported dealing with mental health issues, including depression and anxiety. Having to deal with other problems in their lives, some participants expressed feeling overwhelmed having to manage several health issues at once. As one participant shared:

"Cause I still have so many [health] issues that I at one point, got so depressed I stopped going anywhere. I stopped everything. It gets overwhelming." (Participant 1)

As this suggests, patients dealing with many physical health problems at once noticed the impact these difficulties had on their mental health. Participant 1 in particular, dealt with the overwhelming feeling by stopping everything related to managing her conditions, which can have a toll on her physical health. By not treating her conditions, this participant was unknowingly increasing her risk of serious health problems, but to her, her current state of depression was more pressing than the slower, long-term effects of not managing her chronic

conditions. The participant expressed wanting to see her provider again soon to get help managing her health conditions.

Given that patients are dealing with so much, many of the participants valued when providers would address or at least provide attention to the problems that were most pressing to them as patients, especially those pertaining to their emotional well-being. Describing her positive relationship with her provider, one participant said:

“That is very important. That she always stays the same with me. So any problem that I have, that is affecting me, emotional whatever it may be, I can count on her, you know. I think that is a very important base [for the relationship]. Having confidence [in her], and I think I have it.” (Participant 4)

Patients mentioned that having a provider that focused on their whole being and could talk about anything besides just their diabetes was a way that they knew they could trust their provider with their health, thus improving their overall interaction with their provider.

“I just always know and feel that with any doctor or any caregiver that is always a great thing to have that open dialogue and communication. It’s a must. It helps me because it lets me know that 1. You care 2. You’re concerned about my health and everything. If I can get all that in one like how I found here with my you know... I think that’s what makes it go smooth.” (Participant 7)

Therefore, the interviews suggest that it is useful for providers to approach the patient holistically in order to improve their relationship with their patient and better care for their diabetes and health. In the interviews, participants addressed how providers should go about this holistic approach: by listening to them.

Providers listening to patients

Participants emphasized listening as an important and very valued characteristic in their relationship with their providers. A clinical encounter that focused on concerns voiced by patients allowed for the holistic care participants valued from their provider. To actively listen meant that providers knew everything that was going on with the patient and were constantly focused on patient concerns throughout the visit. As one patient described it:

“They hear me. That’s what I like about the doctor. When I speak out, that doctor is listening to me and focusing on what I’m saying because you can tell when a doctor listens to you and you’re just saying she’s focused on that. And you know that some doctors are zoned out or they just start writing and you don’t even know that it’s about you.” (Participant 10)

Participants were able to identify whether or not their provider was actively listening to them by the nature of the interaction. Some participants mentioned that they felt that their providers were not listening when they felt rushed or when they were repeating themselves often.

“Cause she doesn’t, like I said, she’s in for a few minutes and then boom out. So there’s no time for communication. Really can’t get much through.” (Participant 1)

Participants also noted that providers weren’t really listening when provider instructions were contradictory to patient feelings and experiences. One participant described an encounter when her provider was trying to take her off medication that she felt was helping her health.

“She was just more interested in getting me off of it than trying to explain to me why she wants me off of it so badly. You understand what I’m saying. We went along with that and let her do what she wanted to do, but was it against my judgement? Yeah because it was something that I felt that I needed but she felt that I didn’t really need it. But I felt that I

really did. So, who draws the line in that?... She listens. But we have a battle of wits.

When I say we have a battle, I don't have my medication, so who's winning? Is that fair to me? No, but it is what it is." (Participant 2)

In addition to verbal cues, participants discussed provider body language as a way to tell whether or not a provider was actively listening during an appointment. One participant described how her behavior changed when she interacted with a provider whose body language suggested they weren't listening to her:

"Because sometimes I feel that people be like can you hurry up and get to the point depending on who I'm sitting down talking with. Sometimes body language and facial expression tells it all. Sometimes when I get that body language, I won't even say anything. I just say "alright can we move onto something else?" (Participant 7)

As this example shows, some participants would disengage when providers did not listen to them and would *"just don't open up really"* (Participant 2) during appointments. For a few participants, this disengagement meant not showing up to appointments. Patients who stopped going to medical appointments run a risk of not getting the constant follow-up care they need to manage a chronic condition like diabetes. At appointments, when patients get their A1C levels checked, the provider determines action steps for the patient based on the assessment of their blood sugar levels. Yet patients are unable to receive the professional guidance they need to properly manage their diabetes if they miss an appointment, and in the meantime, sometimes may not know what they need to be doing to actively control their diabetes, as is the case with one participant.

“When I said that we’d do the 3-month appointment, it’s to check my A1C again. And I guess then she’ll tell me what to do. But in the meantime, don’t ask me. Nothing to do. Just wait.” (Participant 1)

Moreover, participants noted that it is important that providers take the time to listen before taking an authoritative position in the process of treatment decision-making. Many participants expected providers to listen to their concerns in order to provide guidance on action steps the patient should be taking for their health. For example, one participant shared how her provider used her experiences with a medication to make the decision to take her off of it:

“I let her give me the diagnosis and she listens to me when I tell her something... How I feel, how I react. Like the one she took me off, I told her that I had a lot of stomach pain. That when I took that pill, I did not feel well. And she told me ok we're going to eliminate it. She did not tell me ‘you have to take it because of this’.” (Participant 4)

Alternatively, another participant showed frustration that her provider wasn’t listening to her when making decisions for her health:

“She sets up things and tries to involve me. But you know, we bump heads cause you know, like I said she’s not listening. In her own way, she wants me to do what I got to do to comply to get my blood sugar down and blah blah blah blah. But are you really listening to me? It’s like she’s not. It’s not her fault. She’s forcing her idea on me, you know what I mean.” (Participant 2)

Overall, participants appreciated their providers making an active effort to listen to their interests when it concerned their health. Providers who let patients dictate the concerns addressed in a medical visit had more positive interactions with participants and could communicate recommendations that fit the needs of each participant, thus providing a more holistic approach

to patient health. Though participants expected their providers to give them the opportunity to direct the conversation to their specific needs, participants also valued the authority of their provider and depended on them for medical guidance on the issues they voiced, as detailed in the next section.

Authoritative role of providers

Many participants acknowledged that it was important to them that their provider take on an authoritative position during their medical visits at the health center. A few in particular were very clear that they expected their doctors to tell them what to do:

“She, she is the one who has to authorize. She is the doctor, the one who has to let me know things.” (Participant 6)

One participant noted that the authoritative position she expected from her provider provided her with the guidance she needed to practice healthy behaviors.

“She tells me what I have to do and I, then, do what she tells me.” (Participant 3)

By providing clear and direct instructions, participants felt that this took the burden of information seeking off of the patient. Participants recognized the provider’s knowledge as a valuable source of information that couldn’t be easily accessed elsewhere and may not lead to the same health results as doing one’s own research.

“They would make sure that they’re on top of my health, instead of me having to be on top of them. And sometimes you can’t get 100% results looking it up yourself. I’ve did that.” (Participant 1)

Several participants stated that they respected the provider’s authority because *“it’s obvious she’s licensed and knowledgeable”* (Participant 7). This expertise qualified providers to have the final say in many of the interactions patients were having with them. Participants usually

responded saying that they did whatever their provider tells them to do “*al pie de la letra*” [verbatim] (Participant 4), recognizing that their provider recommendations are for their health and that they would be “scolded” if they didn’t follow directions. To one participant, this was how she knew that her provider truly cared for her. To not tell a patient how to address their health needs meant that the provider wasn’t engaged in the patient’s health.

“You know, I like it because she admonishes me. Like that you see in a doctor how much interest they have in you as a patient.” (Participant 4)

However, some participants expressed frustration when providers would make recommendations without clear explanations that made sense to the participant. One participant considered vague responses like “*in the long run, it doesn’t benefit you*” insufficient when providers would switch her medications (Participant 2). Another participant, unsure why her provider told her not to get back on metformin, said she was just “*hanging in this place*” and felt “*in limbo*” (Participant 1), not sure of what steps she should be taking to manage her diabetes.

Participants responses varied in how they reacted to the unclear information from their providers. Some participants expressed feeling comfortable asking their providers questions when they were confused by the information shared by their provider, whereas others found it difficult to navigate this space. One participant voiced:

“She didn’t give me no explanation or anything so I said whatever it is it is. She’s the doctor and I’m the patient so I really don’t know what to do. And that was about the end of the conversation... I’m like in my mind guessing what they said or what should I do or I just don’t understand it period.” (Participant 10)

In other cases, participants mentioned taking initiative and looking up information online or going to other people for advice.

“During that time, I had a laptop. You ask the doctor some things, but then I have to experience it and read it for myself so that I can understand it.” (Participant 8)

In this example, the authoritative role of the provider is not necessarily being challenged, but instead supported by outside research conducted by the participant. Although providers can provide the necessary information to their patients, one participant felt that their health was still their personal responsibility regardless of the authoritative position of the provider.

“The information is out there. There are so many pamphlets – it’s out there, it’s whether you want it or not.” (Participant 9)

In these instances, participants asserted that they didn’t always rely on their provider for their health needs, highlighting that the authoritative position of the provider shouldn’t ignore patient responsibility when it concerns patient health. After discussing the ways she personally manages her diabetes with little guidance from her provider, one participant said:

“You have to learn to take care of yourself. Cause if you wait for people, it’s not happening. Nobody cares about you more than you.” (Participant 1)

DISCUSSION

This study identified patient-perceived factors and challenges in the interactions with providers that improved health communication and the care participants received in clinical settings. In this study, participants valued providers who took the time to listen to their concerns. By listening to patient concerns, providers were able to provide holistic care and use their authority as medical experts to make informed decisions for the patient’s health. When participants felt that these expectations weren’t being met by their provider, they often disengaged during medical visits, which has implications for the management of a chronic disease like diabetes that requires patients to perform daily tasks in order to properly control symptoms. Disengagement for these

participants led to further confusion and lack of knowledge related to health concerns. For some, this meant they weren't doing anything to proactively address their health. Other participants were more active in taking responsibility for their health and looking to other medical sources.

Findings from this study present possible solutions for common barriers to communicating diabetes self-care during medical appointments. Previous research has shown that communicating diabetes self-care information is difficult for providers when patients are reluctant to share information and don't trust providers, which can be attributed to individual psychosocial factors and interpersonal factors between patients and physicians (9, 12,13). Reluctant patients are more likely to report lower diabetes quality of life, and more diabetes-related distress and depressive symptoms (12). This study highlights some of the interpersonal factors that may be contributing to lack of communication on behalf of patients. As the results show, participants frequently disengaged when they perceived that their provider wasn't listening to them and addressing all of their concerns. Participants who felt more comfortable with their providers shared that they could open up to their provider about anything that was on their mind besides their diabetes. They also mentioned verbal and non-verbal cues from their providers that showed they were actively listening to the participants. Additionally, giving clear and thorough guidance on patient-identified problems was a way patients knew that their provider cared for them and their health. Seeing the provider take responsibility for a patient's health was reassuring to participants and helped build that needed trust in the patient-provider relationship. To increase trust and patient openness during medical appointments, providers need to provide a space for patients to voice their concerns without interruptions before they proceed to ask focused questions and share their recommendations (15).

The authoritative role of providers that patients appreciated in this study aligns with existing literature on the perceived responsibility of the physician. One qualitative study focused on providers' views of achieving diabetes treatment goals in their patients across Boston health centers, noted that physicians perceive that they are responsible for patients not achieving their goals (11). Physician barriers in properly treating patients include communication difficulties, such as explaining treatment recommendations, and time constraints, which sometimes lead to feelings of frustration and inadequacy in providers (11). Our interviews reveal that patients are aware of these provider barriers, and suggest that if providers take the time to listen to patients and give patients the opportunity to ask questions, then they will be able to more confidently communicate treatment recommendations to the problems that patients have identified during the medical appointment. Unfortunately, time constraints aren't an issue that can be easily addressed by patients or providers, and require institutional changes in the delivery of healthcare, like shifting smaller tasks to other members of the medical team other than the primary provider (18).

The findings of this study also present a nuanced way of thinking about shared decision-making in the clinical setting. In the literature, shared decision-making is defined as “an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences” (16,17). This is achieved by providers who provide information and support the patient as they consider the different options available to them (16). In other words, patients are expected to listen to providers and then make a decision based on the information presented to them. However, in our sample, some participant experiences show that an interactive medical visit is one where the patient provides the information to the provider and the provider makes informed decisions using what was shared by the patient and their medical

expertise. This suggests a different way of thinking about the process of shared decision-making, where the provider is expected to listen to patients and make a decision based on what was presented to them in combination with their medical expertise. This mode of shared decision-making also reduces potential burden patients may experience when given the responsibility to make an important clinical decision based on information they just received, and may not have fully processed or understood.

This study is limited by its small sample size. Given the unique demographic of the clinic, with a larger sample, analyses could have also explored cultural differences that may influence the way English- versus Spanish-speaking patients interact with their providers. In our Spanish interviews, there were a couple of participants with positive relationships with their providers who stated that their provider was like family to them. Because family plays an important role in Latinx culture and health (10), future studies with this population should consider how cultural values regarding the family unit may facilitate relationship building with a provider. Additionally, this study would have benefited from interviewing providers from the health center to identify ways that providers are currently addressing communication issues with their patients and the type of support they need from patients and other health system stakeholders, like other providers and healthcare institutions (14), to establish positive relationships that lead to better health outcomes.

The results of this study highlight interactional factors in the clinical encounter that can facilitate the communication between patients and providers. Understanding what patients value when interacting with providers has the potential to improve medical encounters by increasing patient comfort and trust in providers through positive interactions. Medical education emphasizes a patient-centered approach to health in order to ensure high quality care (13,19).

These findings draw attention to ways that providers can deliver this patient-centered care, not only to patients with diabetes, but to all patients they care for.

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