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Improving HIV Care Engagement in the South from the Patient and Provider Perspective: The Role of Stigma, Social Support, and Shared Decision-Making

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Abstract

Initial linkage to medical care is a critical step in the HIV care continuum leading to improved health outcomes, reduced morbidity and mortality, and decreased HIV transmission risk. We explored differences in perspectives on engagement in HIV care between people living with HIV who attended (Arrived) their initial medical provider visit (IMV) and those who did not (Missed), and between patients and providers. The study was conducted in two large majority/minority HIV treatment centers in the United States (US) south, a geographical region disproportionately impacted by HIV. The Theory of Planned Behavior informed semistructured interviews eliciting facilitators and barriers to engagement in care from 53 participants: 40 patients in a structured sample of 20 Missed and 20 Arrived, and 13 care providers. Using Grounded Theory to frame analysis, we found similar perspectives for all groups, including beliefs in the following: patients' control over care engagement, a lack of knowledge regarding HIV within the community, and the impact of structural barriers to HIV care such as paperwork, transportation, housing, and substance use treatment. Differences were noted by care engagement status. Missed described HIV-related discrimination, depression, and lack of social support. Arrived worried what others think about their HIV status. Providers focused on structural barriers and process, while patients focused on relational aspects of HIV care and personal connection with clinics. Participants proposed peer navigation and increased contact from clinics as interventions to reduce missed IMV. Context-appropriate interventions informed by these perspectives are needed to address the expanding southern HIV epidemic.

Keywords: HIV, care continuum, care engagement, stigma, social, qualitative research

Introduction

For people living with HIV, engagement in HIV care is a critical step that leads to improved health outcomes, reduced morbidity and mortality, and decreased HIV transmission risk.[1–5] Initial linkage to care, represented by attending a first medical provider visit in a clinic, is a key step in the care continuum. Linkage to care has an impact on long-term engagement with HIV care and the likelihood of achieving virologic suppression.[5] The National HIV/AIDS Strategy's 2015 update names early and effective linkage to care as a key quality metric for HIV care.[6] Unfortunately, the gap between those who are diagnosed with HIV and those who are engaged in care remains the largest of the care continuum: 86% of people living with HIV are aware of their diagnosis, yet only 69% are linked to care and 40% are retained in care.[7] To realize the promises of life-sustaining antiretroviral therapy for all people living with HIV in the United States (US), the barriers to care engagement must be understood and addressed.[8]

Initial linkage to and engagement in care are particularly important in the southern US. The south has 52% of all new

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diagnoses of HIV infection in the US, but significantly lower rates of linkage to care when compared with the northeast or west[9,10] and 47% of all US HIV deaths.[11,12] Health disparities in care engagement also exist for African Americans and Hispanics, where stigma, lack of access to care, and other barriers may impact effective engagement in HIV care and treatment.[13–15] Considering the current profile of the US HIV epidemic, engagement in care initiatives is urgently needed to target people of color living in the south. Implementation science, which endorses the use of qualitative research methods to understand individual, institutional, and community barriers to engagement in care, may be particularly useful in designing interventions to reduce missed medical visits and increase engagement in these vulnerable populations.[16,17]

Data suggest that targeted approaches to vulnerable populations, such as the Outreach, Care, and Prevention to Engage HIV-Seropositive Young Men of Color Initiative (a special project of national significance), can lead to low rates of missed visits (11.4%) although certain subgroups, such as Hispanics and those with advanced HIV disease, may not benefit from this approach.[15] Evidence-based interventions to reduce missed visits include increased case management, enhanced personal contact, motivational interviewing, automated appointment reminders, and shortening time between initial contact and medical provider visit.[4,18–23] However, to appropriately adapt and target these interventions to the context of people of color in the south, more data are needed on the perceptions of engagement in care for people living with HIV and for providers in these areas.

In two large safety net clinics serving majority African Americans and Hispanics living with HIV in Dallas and San Antonio, Texas, 26% of individuals who linked to clinic through an initial case management visit missed their initial medical provider visit (IMV).[24] Patients with less case management contact and those who were unemployed were more likely to miss their IMV. Attending the IMV was associated with increased overall engagement in care and fewer gaps in care, while patients who did not complete their IMV within 90 days of case management intake were unlikely to ever engage in care in the clinic.[24]

To adapt interventions to the needs of majority/minority clinics in the south, we conducted a cross-sectional qualitative study to examine facilitators and barriers to attending HIV medical care from patient and provider perspectives in these same two large Texas safety net clinics. Our goal was to ascertain differences in perspective between those who engaged in care and those who did not and to solicit clinic provider perspectives to more effectively embed interventions in the context of these two clinics.

Methods

Study design

A qualitative study using in-depth, semistructured interviews was conducted to explore facilitators and barriers to engagement in care for people living with HIV in two large, public HIV treatment centers in Texas. Two populations were interviewed: people living with HIV receiving care at one of the two HIV treatment centers (patient participants) and care providers from the same two HIV treatment centers (provider participants). A provider focus group with M.D. providers was also conducted, which explored the same themes as the individual interviews.

Study population and setting

All participants were recruited from one of two publicly funded HIV treatment centers: Parkland Health and Hospital Systems in Dallas, Texas, which provides care to more than 5000 people living with HIV, and University Health System in San Antonio, Texas, which provides care to more than 3000 people living with HIV. Both clinics serve a majority/minority client population, with the majority in Dallas being African American and the majority in San Antonio being Hispanic. Both clinics offer comprehensive HIV care, including case management, counseling, nursing support, and an on-site pharmacy, and both receive funding from the federal Ryan White HIV/AIDS Program.

Patient participant inclusion and sampling design

For patient participants, inclusion criteria were as follows: ≥18 years of age, living with HIV, attended at least one case management intake visit at one of the two treatment centers, English speaking, and able to give informed consent. The investigators chose to exclude Spanish-speaking participants from this study because care engagement in Spanish-speaking people living with HIV, who are more likely to be recent immigrants, has been shown to differ from English-speaking Latinos.[25] A separate interview guide would be necessary to address topics of patient/provider language barriers, the role of documentation status, care engagement, and culture/acculturation, and a separate recruitment strategy would be needed to sample this subpopulation (<10% of the overall clinics' clients), which was beyond the scope of this analysis.[26,27]

From each site, 10 patient participants were interviewed who missed their IMV following their case management intake visit, defined as no-show for the IMV without cancelation by patient or provider (Missed). Ten patient participants per site were interviewed who attended their IMV, defined as attending their IMV following their case management intake visit (Arrived), for a total of 40 patient participant interviews. Patient participants were recruited consecutively from a weekly list of IMV attendance, with purposive sampling by site to ensure representative distribution of age, gender, race/ethnicity, diagnosed <6 months, late to care (new diagnosis >6 months ago but never in care), and re-entering care.

Provider participant inclusion and sampling design

Provider participants were recruited from the same HIV primary care clinic and were selected to gain insights from a diversity of providers with varied backgrounds, roles, and skill levels, which might address engagement in care or patient intake in the clinic. Nine providers were included in individual interviews, and an M.D. provider focus group included four providers. The focus group was convened based on M.D. provider preference and did not include any providers who were supervisors of others present, to ensure that participants felt free to express concerns or barriers to care engagement in the clinic.

Procedures

An initial semistructured interview guide for patient participants was created after a relevant literature search for factors influencing engagement in care, particularly initial linkage to care, in underserved populations. The guide used the Theory of Planned Behavior,[28–30] which explores behavioral beliefs, control beliefs (regarding factors that facilitate or hinder performance of the behavior), and normative referents (perceptions of societal norms and others' opinions regarding the behavior) at the patient, clinic, and community level to assess perceptions of care engagement and barriers to care initiation. Patient participants were also asked what types of interventions they would suggest to increase care engagement and reduce missed IMVs. The patient interview guide was piloted with two individuals experienced in case navigation within this population, to test the duration of interview and receive feedback on appropriateness of questions and prompts. The provider interview guide was structured similarly to the patient interview guide, using Theory of Planned Behavior and assessing barriers and facilitators to care engagement at the patient, clinic, and community level. Providers were also asked to suggest interventions to increase care engagement and reduce missed IMVs.

These interview guides were reviewed by the investigators and iteratively revised throughout the data collection period to address new themes or questions that arose. In-person interviews were conducted by a single investigator at each site for consistency and lasted ∼60 min per participant.

Data analysis

Interviews and the provider focus group were audio-recorded and transcribed verbatim by a professional medical transcription service. Interviewers at each site assessed the transcripts for accuracy by comparing them with the initial audio recording and made edits to the text as needed. A qualitative analysis team of five investigators (B.S.T., A.N., J.M., J.T., L.F.) constructed a code list based on themes from the literature and the Theory of Planned Behavior. A single investigator (L.F.) conducted the initial coding in ATLAS.ti Version 7 (Berlin, Germany), generating new codes as needed. The study team used Cohen's Kappa for two raters to index an inter-rater reliability of 1.00, with a benchmark goal of more than 0.70. A second investigator (J.T.) was trained and worked in tandem with the primary coder. A continuous dialog was maintained with input from both researchers to reach coding consistency. J.T. coded a subset of three transcripts independently and his results were compared for congruency with those of the primary coder. At this point the benchmark Kappa was reached, an *a priori* code list of 83 preliminary codes was created in ATLAS.ti, and the single primary coder completed coding the remaining transcripts. Codes were subsequently collapsed into 11 macrocodes, or code families.

The five-person qualitative analysis team used the constant comparative approach for analysis, consistent with Grounded Theory.[31,32] Open coding involved the research team examining code frequency and the quotes assigned to each code for both patient and provider interviews. Any differences of opinion regarding coding were reconciled by consensus. Axial coding sorted these codes into themes consistent with the Theory of Planned Behavior: attitudes, subjective norms, perceived behavioral control, and intentions. Codes that did not fit into one of the constructs of the Theory of Planned Behavior were grouped into independent themes. These additional themes included the following: structural barriers to engagement in care such as transportation, lack of housing, lack of insurance, financial hardship, bureaucracy, and wait times at the clinic.

These themes were examined for co-occurrence between patients who missed (Missed) and participants who arrived (Arrived) at their initial medical visit, and between patients and providers. Themes were organized into network families, and differences in these families between participant types (Arrived vs. Missed, patient vs. provider) were explored. The qualitative analysis team then used selective coding to understand how differences in themes between the subgroups—(1) Arrived versus Missed, and (2) patients versus providers—might impact initial engagement in care and influence future interventions.

Feedback of findings to consumers, providers, and community-based organizations

Investigators (B.S.T. and A.N.) shared study findings with consumer groups of people living with HIV ($n=2$), individual community-based organizations (CBOs) ($n=2$), community meetings including the staff of organizations involved in HIV care engagement ($n=3$), and groups of HIV and primary care providers ($n=4$). Participants in these discussions were asked for feedback on the findings, particularly whether the themes and differences in themes by subgroup resonated with their lived experiences.

None of the audience members at any of the feedback sessions voiced disagreement with the themes or study findings. Consumers strongly expressed their belief that stigma plays a role in missed visits and failure to engage in care and encouraged exploration and expansion of that theme. The investigators incorporated this feedback into further analysis of stigma descriptions between missed and arrived patients. Primary care providers noted the difference in patients' descriptions of interventions or preferred care, which focused on relational aspects of care, and providers' descriptions within the same themes, which focused on process of care. Investigators took notes regarding feedback at each session and used the feedback to inform selective coding and understanding of the data.

Ethical approvals and role of the funding source

The University of Texas Health Science Center-San Antonio and the University of Texas Southwestern Institutional Review Boards independently reviewed the study and deemed it not regulated research as defined by the Department of Health and Human Services and Federal Food and Drug Administration regulations. As per this protocol, participants were provided with an information sheet about the study, but written informed consent was not required. Patient participants were compensated for their time with a $20 gift card to a grocery store chain. Providers were not compensated.

Results

Participant characteristics

Patient participants. We conducted qualitative interviews with 40 participants: 20 patients who attended their

IMV following a case management intake visit (Arrived) and 20 who missed their IMV (Missed). The characteristics of this sample are outlined in Table 1 and are representative of the patient population at both sites.

Provider participants. Provider interviews were conducted with 13 providers, individually or through one focus group of 4 physicians at the Dallas site, including front desk staff ($n=1$), nurses ($n=1$), nurse case managers ($n=1$), social work case managers ($n=4$), physicians assistants or nurse practitioners ($n=1$), and physicians ($n=5$).

Commonalities in perspective between patients who arrived and missed their IMV

The stratified analysis of Arrived compared with Missed demonstrated many shared themes in these two groups (Table 2). Both Missed and Arrived groups expressed a high level of perceived behavioral control, believing that they were able to determine whether they attended their initial medical visit. *Total control. I know if I keep coming, taking my treatment, other than that* <HIV>, *I'm healthy, and I'm still healthy even with that!(San Antonio, Arrived).* Some in the Missed group described that they were in control of visit attendance but were just ''not ready to'' engage in care: *I can see that they are trying everything they can to help me, and I've just been stubborn (San Antonio, Missed).*

Both Missed and Arrived groups expressed strong normative beliefs regarding the lack of information and education regarding HIV within the community. In this context, normative beliefs are the patients' perceptions of others' beliefs regarding HIV infection or the need to engage in care. For example: *My mother, her friends [...] They don't know how it's contracted or nothing. They're afraid that they're going to eat behind you or use a spoon or fork you done used (Dallas, Arrived).* Participants from both groups noted similar control beliefs, the factors that facilitate or impede care engagement behaviors, regarding structural barriers to arriving at the initial medical visit. Most commonly mentioned were transportation, lack of housing, lack of insurance, financial hardship, bureaucracy, and wait times at the clinic. Facilitators to engagement that were expressed by both groups included positive relationships with physicians, including shared decision-making, community-based organizations' ability to ameliorate structural barriers such as transportation and housing, and support from family and friends.

Table 1. Characteristics of Purposive Sample for Patient Participants, by Initial Medical Visit Attendance Status

Characteristic	*Arrived* n = *20*	*Missed* n = *20*
Gender		
Male	13	14
Female	6	5
Transgender	1	1
Race/ethnicity		
White/Anglo	6	3
African American	7	7
Hispanic	7	10
Age		
18–29 years	8	6
30–49 years	7	11
≥50 years	5	3
HIV risk factor		
Heterosexual sex	7	7
Men who have sex with men	9	9
Injection drug use	2	4
Perinatal infection	2	
Engagement in care status		
Newly diagnosed (≤6 months)	2	3
Late to care (new diagnosis >6 months ago, never in care)	1	2
New to clinic (transferring from other care facility)	13	4
Return to care (out of care >12 months)	4	11

Notable differences between patients who arrived and missed their IMV

Of patient participants, 95% noted that living with HIV had a profound and negative impact on their intrapersonal relationships with friends, family members, and partners. However, the content of these narratives differed between Missed and Arrived groups: six Missed described direct experiences with discrimination from family members, friends, or medical providers as a result of stigma, whereas only two Arrived described direct discrimination. *They <fellow shelter residents> was treating me so bad like, 'Ew, I don't want to sit by her! Oh no! She this, she that. Oh, don't touch her!' or 'I don't want to touch her' (Dallas, Missed).* In contrast, normative beliefs surrounding perceived or internalized stigma, where patients described anticipating stigma and withdrawing from a social setting because of it, were more common in the Missed group (7) than in the Arrived (4). *They don't understand it, they think just by touching you that you can catch it. That's why a lot of times you just have to be private and keep things to yourself, you know (San Antonio, Missed).* Arrived also more frequently described experiences overcoming stigma (8) than Missed (5) *My life is more important than a thought (San Antonio, Arrived)*; *I'm not AIDS! You know, I am me! (Dallas, Arrived)* (Table 2).

A specific type of perceived stigma, fear of being identified in the waiting room while attending appointments, was common among Missed. One San Antonio participant specifically described seeing someone they knew and missing an appointment because of it:

> *Because I've been to the point where one time, and I'm just going to be honest, one time I came in here and there was so many people! And I spotted someone I knew! And they got up like they were getting to come at me, and I just turned around and went out and went to the elevator real quick before they got to me, and I called and told them I was cancelling the appointment. It just bothers me! (San Antonio, Missed)*

A notable difference in the normative referents between Missed and Arrived was that half of the Arrived group expressed worry about what others in the community would think of their HIV status. One participant described this as a motivation to engage in care so that he would receive treatment and not appear ill. *I would think that it would be even more reason to seek medical care so that you're not*

TABLE 2. COMPARISON OF PERCEPTIONS OF CARE ENGAGEMENT BETWEEN PATIENT PARTICIPANTS WHO MISSED THEIR INITIAL MEDICAL PROVIDER VISIT (MISSED) AND THOSE WHO ARRIVED TO THEIR INITIAL MEDICAL PROVIDER VISIT (ARRIVED)

Theme	*Description*	*Representative quotes–(site, attendance status)*
Common themes between Missed and Arrived		
High perceived control (18 Missed, 17 Arrived)	• Both Missed and Arrived groups believed that they controlled whether they engaged in care or not. • Missed described control regarding engagement and that they were choosing not to engage in care	*I'm taking care of me!–(Dallas, Arrived)* *Total control. I know if I keep coming, taking my treatment, other than that* <HIV>, *I'm healthy, and I'm still healthy even with that! –(San Antonio, Arrived)* *I have 100% control if it's what I want. –(San Antonio, Missed)* *I can see that they are trying everything they can to help me, and I've just been stubborn. –(San Antonio, Missed)*
Normative referent of community misinformation regarding HIV (16 Missed, 16 Arrived)	• Community members have little knowledge of how HIV is spread • Lack of understanding of treatment	*My mother, her friends just don't say nothing. They don't know. They don't know how it's contracted or nothing. They're afraid that they're going to eat behind you or use a spoon or fork you done used. –(Dallas, Arrived)* *I don't think they think that the medication works. Well, me, personally, I didn't.–(Dallas, Missed)* Re. her best friend: *She doesn't believe I have it because of the stigma. But she works at a urgent care so I think she is finally understanding how it works. You know, I try to explain to her, but she was being like, "You're just going to die! Why are you still alive?" Like I told her how long I've had it, so she's just like, "Oh!"–(San Antonio, Arrived)*
Structural barriers to care (18 Missed, 17 Arrived)	• Transportation • Lack of housing and issues with keeping diagnosis confidential and medications safe in communal housing • Lack of insurance and financial hardship • Bureaucracy and wait times at clinic	*That only thing that would come to mind why somebody would stop seeking like treatment would be because they don't have the means to get around.–(San Antonio, Arrived)* *I think that is very important because as of right now, with me being homeless, a home is something that is most needed, because I mean without the home your own lifestyle is not even stable. –(San Antonio, Missed)* *I was doing my research on everything, and it's like medication are expensive. I wouldn't be able to afford just a month's supply of medication, if any HIV medication! I'd have to pay for it. –(San Antonio- Missed)*
Facilitators to care engagement (20 Missed, 20 Arrived)	• Support from family and friends • Support from community-based organizations for transportation and housing • Positive relationships with physicians including shared decision-making	*So it's like I think the most important thing out of all of this is for a patient who has HIV not to feel alone. I think that would be the most important thing because feeling alone can take everything. –(San Antonio, Missed)* Re. family support: *I believe I can touch the moon with their encouragement.–(Dallas, Arrived)* *I am with <local AIDS Service Organization> and they are helping me out with transportation, and they're doing everything they can.–(San Antonio, Missed)* *A stable relationship with your doctor will keep you comfortable with coming and opening up to the doctor, letting them know everything they need to know to make you better.–(Dallas, Missed)*
Differences between Missed and Arrived		
Experiences of stigma Discrimination (6 Missed, 2 Arrived) Perceived stigma (7 Missed, 4 Arrived) Overcoming stigma (5 Missed, 8 Arrived)	• Missed more likely to describe experiences with discrimination or enacted stigma • Missed more likely to anticipate discrimination or stigma and withdraw from care or relationships in anticipation • Arrived describe experiences of overcoming stigma or developing a self-affirming attitude in the face of stigma	*They <fellow shelter residents> was treating me so bad like, "Ew, I don't want to sit by her! Oh no! She this, she that. Oh, don't touch her!" or "I don't want to touch her."–(Dallas, Missed)* Overhearing ER nurses discussing reluctance to enter her room because of her HIV status: *Y'all are supposed to be nurses, professional care and y'all are sitting here talking about who is going to go in there and clean out her trash can! –(San Antonio, Missed)* *You're walking out of a building that is known for getting care for HIV or AIDS. And you know, someone who is not in that building sees you, or may know you or something, they know what you're there for.–(Dallas, Missed)* *They don't understand it, they think just by touching you that you can catch it. That's why a lot of times you just have to be private and keep things to yourself, you know.–(San Antonio, Missed)* *I'm not AIDS! You know, I am me! –(Dallas, Arrived)* *My life is more important than a thought. –(San Antonio, Arrived)*

(*continued*)

Table 2. (Continued)

Theme	*Description*	*Representative quotes–(site, attendance status)*
Normative referent: Worry about what others think about HIV (1 Missed, 10 Arrived)	• Worry about what others thought about their HIV status or that others would perceive they are living with HIV was more common in Arrived • One participant described this as a motivation to engage in care	*Hopefully, it's nobody I work with <who will find out>, hopefully it's not my family, or knowing that it will get back to my family.–(Dallas, Arrived)* *Like I'm basically a weapon on legs. –(Dallas, Arrived)* Response to "Does worrying about what others think of your HIV keep you from coming into care?" *No, not really. It actually encourages me to want to get care…Yeah, to get back on* <ART> *and do what I need to do.–(San Antonio, Arrived)*
Depression (9 Missed, 5 Arrived)	• Missed more likely to describe personal experiences with depression, particularly after HIV diagnosis	*Because I know I had missed some a couple of times from suffering with depression way back then, and like one time I missed a whole month. And I just cried every day, and different stuff started happening, and I got kind of sick.–(San Antonio, Missed)*
Lack of family support (8 Missed, 4 Arrived)	• Missed more likely to describe lack of family support • Arrived more likely to describe positive experiences with family support	*And when you don't have <family support> it's like…it's so easy for you not to. When nobody even cares anyway why would I?–(San Antonio, Missed)* *Because if it wasn't without <my family> I would probably just give up, or would have. –(San Antonio, Arrived)*

Themes are described and representative quotations presented, first for themes that were common between Missed and Arrived, and then those where perceptions differed between the two groups.

susceptible to people knowing that you're HIV positive by the way you look(Dallas, Arrived). In contrast, only one of the participants who missed the initial medical visit expressed worry about community opinions of people living with HIV. Patients who missed their initial medical visit were also more likely to describe personal experiences with depression (9 Missed vs. 5 Arrived), erroneous beliefs about treatment (e.g., it was not necessary if you feel well and the medications do not work, 2 Missed vs. 0 Arrived), and lack of family support (8 Missed vs. 4 Arrived). *And when you don't have <family support> it's like…it's so easy for you not to. When nobody even cares anyway why would I? (San Antonio, Missed).*

Patient and provider perspective differences

Providers expressed many of the same normative beliefs, attitudes, subjective norms, and opinions regarding barriers and facilitators to care engagement as the patient participants. However, some themes demonstrated differences in perspectives between providers and their patients, particularly with regard to the need for relational versus structural support (Table 3). For example, in the perceived control theme, patients and providers both described the need for a collaborative care environment, with shared decision-making, but patients were the only ones to emphasize that the visits should be free from medical jargon. *You know, when you take the time out to include me as a person in your assessment of things, and I know what you're talking about, yes, it's important and I want to be a part of that, if I understand! (Patient).* Perceptions of the clinic environment also differed, with patients generally satisfied with the clinic, regardless of Missed versus Arrived status, and focused on the need for a respectful clinic environment and being listened to by providers. Patients also mentioned a profound fear of being recognized by others at the clinic, as noted above. Providers strongly believed that clinic wait times, lack of appointment reminders, and paperwork were barriers to engagement, but patients only occasionally mentioned these factors.

Similarly, when discussing the need for support from family, friends, and the community, patients usually spoke about emotional support. *I see my kids and they make me want to be stronger (Patient).*

Providers emphasized the need for family to provide support to overcome structural barriers, such as help with transportation and housing. *Because if you have a good family support, guess what? Your own family is going to provide that transportation. They're going to go above and beyond, if they can understand and if they can accept it (Case Manager).* Finally, as described above, patients almost universally described experiences with stigma and often told personal stories of discrimination and fear. Providers did not tend to mention stigma as a barrier to care, and when they did, providers felt that it could be overcome through individual counseling or education.

Suggestions for interventions to reduce missed IMVs

All participants, providers and patients, were asked for recommendations about ways that the clinic could reduce missed IMVs and increase engagement in care. Responses were similar across all participant groups and fell into two categories. Structural interventions were suggested, including text messages, phone call reminders regarding appointments, and mobile Apps to remind patients of upcoming visits. Patients emphasized that these interventions should be tailored to the needs and comfort level of the individual with technology. For example, a patient participant suggested that text message-based interactions with the clinic would only be appropriate for those younger than 30 years.

The second intervention category was relational, through implementation of a peer navigation program. Several patients

Table 3. Notable Similarities and Differences in Perspectives on Missed Initial Medical Visits Between Patients ($N=40$) and Providers ($N=13$)

Theme	*Description*	*Representative quotes*
Perceived control and staying in care Both patients and providers Patients	• Stress the importance of visits • Collaborative care • More physician contact by phone or text • Physicians should not use medical jargon or talk down to patients	*You're with us now. You're going to keep coming back.–Physician on need to encourage engagement* *I describe this as a team effort! It's just not the doctor, it's you working with the doctor making those decisions, talking things through, treatment plans.–Patient* *You know, when you take the time out to include me as a person in your assessment of things, and I know what you're talking about, yes, it's important and I want to be a part of that, if I understand!—Patient*
Perceptions of the clinic environment Patients Providers	• Satisfied with clinic, focus on receiving respect, and being listened to by providers • Focused on bureaucracy, wait times, lack of appointment reminders	*They are so nice! I mean I can get here having the worst day and just feel better because they make you…they have that positive energy about them!–Patient* *I mean if I get a call for a dental appointment… I don't know why our patients can't get a call.–Physician*
Support from family, friends, community Patients Providers	• Need for emotional support • Need for support to overcome structural barriers (transportation, housing)	*I see my kids and they make me want to be stronger.–Patient* *use if you have a good family support, guess what? Your own family is going to provide that transportation. They're going to go above and beyond, if they can understand and if they can accept it. They become acceptive to the situation and that would be something that is say, ''Okay, transportation, I will be the one to take you to your appointment.''–Case Manager*
Stigma Patients Providers	• Personal experiences of discrimination, fear • Stigma can be overcome through counseling or education	*I don't want to have to realize how people are going to act different…* *—Patient on friends' potential response to HIV status disclosure* *They don't like conflict or to be looked at like a leper, you know. And so I think that's something where counseling might help people in those situations, to help them understand better, I guess, the social aspect of it and so that they won't be afraid to go to see <HIV care providers> based on that.–Clinic front desk staff*

and providers had very positive prior experiences with peer navigators in other clinics. Participants felt that this type of support would help overcome the fear and stigma that might keep individuals from engaging in care and fill the gap for patients who had little social support from family and friends. One provider described the impact that a discussion with a peer navigator had on a patient newly diagnosed with HIV: *They are talking to someone who has had HIV for 20 years and just coming to the visit glowing because they didn't know they'll still be doing fine in 20 years from now (Provider).*

Discussion

These data provide unique insights into the differences in perspectives between patients who initially engage in care, by attending their first medical provider visit and those who do not, as well as key distinctions between perceptions of motivations and barriers for care engagement between patients and providers. Patients in the Missed and Arrived groups had many shared perspectives, including a strong belief in their own control over engagement in care, normative beliefs in a lack of knowledge or ''ignorance'' within the community regarding HIV transmission and treatment, and acknowledgment of structural barriers to and facilitators of HIV care, which would impact initial medical visit attendance. However, distinct differences in perspectives were noted between Missed and Arrived groups: Missed were more likely to have experienced discrimination or ''enacted stigma,'' whereas Arrived described experiences overcoming stigma; Arrived were more likely to worry about what others think about their HIV status; and Missed reported more depression and lack of social support. When compared with patients' perspectives, providers were more likely to focus on structural barriers to care such as lack of transportation and housing, and programmatic facilitators to care including shorter wait times, reduced bureaucracy, and text reminders. Patients, regardless of visit attendance status, were more likely than their providers to focus on relational aspects of HIV care: the need for emotional support, respect, and collaborative decision-making with providers.

These novel findings suggest that those who miss their initial medical visit may need additional support for depression and social/relational support to help overcome lack of family support and their concerns regarding discrimination or unintentional disclosure of their HIV status in a healthcare setting. The differences in patient and provider perspectives highlight how essential it is to integrate input of people living with HIV in intervention design for engagement in care initiatives. A provider-designed intervention would address structural barriers to care, but these changes may have little impact without improvements in the relational aspect of care emphasized by the patients. As such, these findings have significant implications for the design of patient-centered interventions for care engagement in this population.

As seen in this study, prior research on care engagement supports the importance of structural barriers to engagement and survival in majority/minority populations living with HIV. Data from North Carolina show that non-white/non-Anglo-Saxon race/ethnicity is associated with suboptimal longitudinal engagement in care.[33] Structural barriers to care, including food insecurity and housing or financial instability, are associated with both lack of retention in care and mortality,[14,34,35] and the number of barriers to care noted by patients in South Africa has been associated with mortality over time.[34]

The negative impact of individual/interpersonal barriers to care seen in this study is supported by research linking depression with medical appointment nonadherence among men who have sex with men in Boston,[36] and heterosexuals in New York City.[37] Support from family and friends was important for care engagement in this study, and has also been recognized as a facilitator to care engagement in other settings.[14,38,39] Similarly, lack of knowledge regarding HIV care has been cited as a barrier to care in other studies, and was associated with delays in care engagement in Latinos living along the US/Mexico border.[40,41]

However, several findings in this study offer new insights into the challenge of care engagement not previously described in the literature. HIV-related stigma is a well-acknowledged barrier to care throughout the globe, found commonly in communities of color and social and gender minorities.[13,35,37–40,42] The vast majority of patients interviewed for this study, regardless of Missed or Arrived initial visit status, described experiences with stigma and the profound impact that living with HIV had on their personal and professional relationships. In this study, the structured sample design allowed for comparison of perspectives between Missed and Arrived groups and revealed distinct differences in their descriptions of stigma. Patients who missed their visit were more likely to describe experiences with discrimination, some in the context of seeking medical care. Patients who arrived were more likely to describe feeling stigmatized in the past, but the steps they had taken to overcome stigma or changes in self-efficacy allowed them to seek care regardless of stigma. Although most patients acknowledge stigma, how it is experienced varied, and these data suggest that experiences of discrimination have a profound impact on care engagement.[43]

These findings are particularly interesting in light of responses to questions about concern for what others think about their HIV status. In the Theory of Planned Behavior, normative beliefs, or what individuals believe about the expectations of others, help inform behavioral intention, which leads to behavior change.[28–30] In this study, we explored whether or not patient participants were concerned about what others thought of their HIV, and found that those who expressed worry about others' opinions regarding their HIV status were more likely to attend their IMV. In fact, several participants spoke of this worry as a normative belief that led to them engaging in care because they did not want people knowing that they were living with HIV because they looked sick. Although this type of normative belief could be considered negative, and a product of stigma, for several patients it was a facilitator of engagement in care.

Although internalized stigma and a desire to hide one's HIV status are barriers to care in some studies,[37–39] a series of questionnaires on barriers to care in 470 Hispanics/Latinos living with HIV along the US/Mexico border revealed similar findings to our study. Participants in this exclusively Hispanic/Latino survey sample who were ''concerned that people might think badly of you because you were HIV+'' entered into care more quickly, whereas those who did not express this concern were more likely to have delayed entry into medical care after their diagnosis.[41] Similarly, the same Russian study that found stigma to be a barrier to care also found a fear of death from AIDS was a facilitator to care engagement.[39] In our study, discrimination or ''enacted stigma'' is a barrier to care engagement, whereas concern about others' opinions about HIV or ''internalized stigma'' is a facilitator, highlighting the complex impact of stigma on people living with HIV. It may be that those who see treatment as a way to hide their HIV status see the clinical care setting as a safe space, whereas discrimination, particularly in a medical setting or in populations that often experience race or sexual orientation-based discrimination,[43] renders the HIV clinic unsafe.

Our findings also differ from other engagement in care studies in that the majority of our participants, regardless of engagement in care status, expressed high self-efficacy and perceived behavioral control. Traditionally, low self-efficacy is associated with medical appointment nonadherence,[36] and interventions that enhance self-efficacy are promoted as tools to improve engagement.[44] Our patient participants also did not express many negative experiences within the clinic, dissatisfaction with services, or community-level barriers to care engagement other than stigma, differing from other studies where these barriers were prominent.[39,45]

Data presented here are also unique in highlighting key differences in perspectives between patients and providers in the same clinic setting. Although there were many commonalities, our patient participants were more focused on relational aspects of HIV care as facilitators to engagement, such as respect from providers, trust in one's doctor, and patient inclusion in the decision-making process. Several other studies have shown relational aspects of HIV care to be important for care engagement in communities of color.[13,39,42,43] In a survey of racial/ethnic minority adolescent men who have sex with men, 67% of participants felt that being respected by their providers helped them keep their medical appointments.[15] Latinos in this sample were less likely to report feeling respected and significantly more likely to miss medical provider visits than non-Latinos.[15] Collectively, these data demonstrate the importance of including relational interventions in efforts to increase care engagement.

Patient and provider participants in this study had strong opinions regarding interventions to improve engagement in care. Many suggested individual-level structural interventions, such as text messages, phone call reminders regarding appointments, and mobile Apps to remind patients of upcoming visits, but patient participants emphasized that these should be tailored to the individual patient's comfort level with technology. Appointment reminders have been shown to improve medical appointment attendance in young men who have sex with men in New York.[15] Many of the US Centers for Disease Control and Prevention (CDC) recommended evidence-based interventions: strategies from the Antiretroviral Treatment Access Study (ARTAS),[18] enhanced personal contact,[21] and Virology FastTrack,[46] incorporate reminders as a component of their strategy. Outreach coordinators have also been used successfully to re-engage people who are lost to care through letters, phone calls, and home visits.[47] Use of a multi-modality App-based intervention, PositiveLinks, was associated with increased virologic suppression and reduced perceived stigma.[48,49] This type of intervention, which gives appointment reminders, provides an additional line of communication between patient and provider, and includes an anonymous virtual support group for peer to peer support, may be particularly well received in our context as it incorporates many participant suggestions into one intervention. Reduced wait times for the initial medical visit, a second structural intervention suggested by providers in this study, has been shown to be associated with engagement in care in our prior work and in other settings.[24,35]

However, patient participants also emphasized the need for relational interventions. In particular, they requested interventions that would enhance their sense of a trusting relationship with their providers and a safe, supportive clinic environment. We previously demonstrated that more frequent case management appointments were associated with improved attendance at the IMV in this setting,[24] and patient participants in this study expressed the important role case managers play in their ability to engage in care. This aligns with many existing evidence-based care engagement interventions, which emphasize the role of support from case managers and patient navigators.[18,21,35,44,50] For example, participants working with linkage to care specialists in Wisconsin focused on the emotional support and a ''feeling of worth'' they gained from the program.[51] The relational intervention that was most appealing to patient and provider participants in this study was support from peer navigators. Several providers who had worked at clinics with peer navigators in the past spoke about how peers can provide structural support, such as appointment reminders and linkage to community resources, and also relational support that emphasizes the healthy future ahead of those living with HIV who engage in care. This message can be particularly valuable in stigmatized populations, where peer navigators' life experience can assist others in overcoming their reluctance to enter care.[35,52,53] Recent studies suggest that interventions that include peer navigation, when combined with other engagement modalities, can help patients re-engage and remain engaged in care.[52,53] We believe that the data from this study suggest that a combined intervention that addresses structural barriers to care and also provides relational support in the form of peer navigation would be appropriate in our patient population.

This study has several limitations. First, patient participants who were interviewed were contactable and willing to be interviewed, so the perspectives of those who are unreachable are not included. However, data from our study and other investigations on engagement in care over time suggest that many people who miss their initial provider visit go through cycles of engagement,[24,33] and we captured many of those perspectives. The study design is cross sectional, and we did not capture changes in individuals' perspectives over time. Thus, the results are subject to recall bias and it is unclear whether participants' perspectives before linkage to case management may have been different. Finally, our study excluded non-English-speaking people living with HIV. Investigators felt that a separate sampling strategy would be needed to glean sufficient perspectives from this relatively small subset of the clinics' population (<10%). Other studies have shown that early stakeholder engagement of Spanish-speaking Latinos and community outreach is important for recruitment.[27] A different semistructured interview guide addressing issues of documentation status, language barriers, and acculturation would be more appropriate for this population, as indicated by studies of barriers to care for Latino immigrants.[26]

Despite these limitations, the findings presented here have clear implications for the design of population-appropriate interventions to improve initial engagement in care in two large publicly funded HIV clinics in the south. This population is particularly important for engagement interventions because Texas, and much of the southern US, is currently the epicenter of the US epidemic.[54] Data suggest that 61% of new infections in the US come from people who are diagnosed with HIV but not retained in care.[55] If we can successfully engage these individuals in care over time, we will reduce their risk of the poor outcomes associated with missed visits and lack of care engagement, and may reduce the incidence of HIV infections in a region where HIV infections are on the rise.

We find that structural barriers to care, stigma, depression, and family support are all key barriers to care engagement in a majority/minority underserved population, and that interventions involving increased communications with the clinic, peer navigators, and appointment reminders would be welcomed by this population. We also find that providers recognize engagement in care as a key problem and propose ways to address structural barriers to care, but that patient perspectives are needed to incorporate the relational facilitators to care engagement. More data are needed to help predict those at high risk for difficulty with care engagement,[56,57] and to leverage data to care initiatives and integrate services available within the clinical setting and those in the community. Data from specific subpopulations, such as non-English speakers, are also important. These interventions, informed by qualitative and population-specific data such as those presented here, may result in better attendance at initial medical visits and improved long-term care engagement and outcomes.

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