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BRIEF REPORT

Individual and structural factors influencing HIV care linkage and engagement: Perceived barriers and solutions among HIV-positive persons

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ABSTRACT

To meet the National HIV/AIDS Strategy's goals of reducing and preventing HIV transmission, understanding factors that shape HIV-positive persons' care-seeking behaviors is critical. Accordingly, this study examined factors that affect HIV care linkage and engagement. Six focus groups were conducted with 33 HIV-positive persons living in North Carolina. A variety of factors influenced care behaviors, including: structural and policy factors, relationship with HIV care systems, and individuals' personal characteristics. Participants also provided solutions for addressing specific factors to care. Improving clinical services and utilizing context-specific strategies can help facilitate greater care linkage and engagement.

As priorities of the National HIV/AIDS Strategy (Office of National AIDS Policy [ONAP], 2012), care linkage and engagement for HIV-positive persons are important steps in the reduction and prevention of HIV transmission. Care linkage and engagement refers to a systematic process of initiation and retention in medical and social services that results in improved health outcomes (Philbin et al., 2014). Given that approximately 20% of newly diagnosed HIV-positive persons are not promptly linked to care, less than half are receiving regular HIV care, and nearly 75% are not virally suppressed (Hall et al., 2013), improving HIV-positive persons' engagement with appropriate services is critical to prevent HIV transmission. If the benefits of care linkage and engagement are to be fully realized (Gardner et al., 2009; Hall et al., 2013), then addressing facilitating and challenging factors is essential.

HIV-positive persons experience multiple barriers to obtaining needed health care. Individual and structural factors (e.g., job instability, mental health issues, stigma) are prevalent and often hinder the use of health care services (Collins, von Unger, & Armbrister, 2008; Earnshaw, Smith, Chaudoir,

Amico, & Copenhaver, 2013; ONAP, 2012; Philbin et al., 2014). The criminalization and stigmatization of HIV associated with disclosure laws also challenge care linkage and engagement (Galletly, Glasman, Pinkerton, & DiFranceisco, 2012; Lehman et al., 2014). Due to these challenges, several strategies (e.g., co-located HIV primary medical care services, tailored clinic design and services) have been recommended to facilitate care linkage and engagement (Gardner et al., 2009; Philbin et al., 2014; Tanner et al., 2014).

The continued low rates of care engagement and viral suppression (Hall et al., 2013; Philbin et al., 2014) underscore the need for a thorough examination of the local context and factors that affect HIV care linkage and engagement to improve individual health and develop comprehensive care initiatives.

Methods

We conducted six focus groups with HIV-positive persons ($N = 33$) recruited from community-based organizations and HIV clinics in metropolitan Charlotte, North Carolina (NC), through invitations from organization and clinic staff. Individuals were eligible if they were HIV positive, over the age of 18, and receiving any type of service at the recruitment sites. Approximately equal percentages of women (45%) and men (48%) participated in the focus groups; two identified as male-to-female transgender. The average age was 41 years (range: 20–60 years). Most participants identified as African American/Black (73%), followed by Euro-American/White (18%), Asian American (3%), American Indian (3%), and mixed race (3%). Two participants identified as Hispanic or Latino, and 17 were parents.

Consideration of NC's social and political context, such as high urban HIV rates (North Carolina Department of Health and Human Services, 2012) and strict disclosure policies (e.g., mandatory counseling by HIV health care providers, requiring HIV-positive persons to disclose their status to sexual or needle-sharing partners) (Lehman et al., 2014), is important in understanding that our results are embedded within a unique environment. Open-ended interview questions (see Table 1) explored experiences with HIV care linkage and engagement, including factors affecting care access and utilization. Focus groups were digitally recorded, transcribed verbatim, and managed using Atlas.ti 6.2. The average focus group size was approximately seven participants (range: 6–10 participants) and lasted about 79 minutes (range: 56–103 minutes). We used content analysis to examine factors related to care behaviors using a multi-level approach, which guided the identification of individual and structural factors affecting care linkage and engagement. A second coder cross-coded a random sample (50%) of focus group transcripts to confirm the initial coding structure, which was subsequently reviewed by other team members. We applied the finalized coding structure to all transcripts and compared initial independent codings with any discrepancies

Table 1. Sample focus group questions.

Key constructs	Questions
Service Access/Utilization	• What was the hardest thing about getting into care when you were first diagnosed? • What do you think are the best things about the services you receive? • What could be improved about the services?
Barriers to care (linkage and engagement)	• What barriers to receiving care have you experienced? • How are the barriers different now than when you were first diagnosed with HIV? • What suggestions do you have for dealing with the barriers you mentioned?
Facilitators to care (linkage or engagement)	• After considering the factors that are barriers for getting into and staying in care, what things help you receive care? • How are these factors different now than when you were first diagnosed with HIV? • How are these helpful factors and barriers different for men and women?
Recommendations	• Based on the obstacles and things that help that you all discussed, what advice would you give to newly diagnosed individuals to help them get into and stay in care? • Do you have any suggestions on how to improve 'the system of care'?

resolved through discussion. The Institutional Review Boards at the University of North Carolina at Charlotte and Greensboro approved study protocols.

Results

Three primary themes emerged related to factors affecting HIV care linkage and engagement: (a) structural and policy factors; (b) relationship with HIV care systems; and (c) individuals' personal characteristics. Participants also provided suggestions for addressing specific barriers. Table 2 presents illustrative quotes and potential solutions related to each theme.

Structural and policy factors

Participants discussed structural and policy factors that directly and indirectly affected care linkage and engagement, such as access to health insurance and continual job instability. Government-funded health insurance issues were stressed in all focus groups. For example, a participant discussed limited resources to fund essential programs: "Pretty much everywhere … ADAP

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Table 2. Illustrative quotations on barriers and solutions for care linkage and engagement.

Factor	Barrier	Solution
	Structural and policy factors	
Insurance	I know like ADAP, here [clinic 2], they have a waiting list … Pretty much everywhere … ADAP is cut. (Male, Group 4 (G4))	I think if there was someone at that doctor's office … that is educated on HIV and knew all of the resources, that could come in after you have been told and walk you through it. (Male, G4)
Supportive Services	I get $77 a month, it's all I can earn and still keep my benefits. It's not going to help me get anywhere … I mean I'm literally stuck within the system … (Female, G3)	
Disclosure Laws	Everywhere you look [HIV is] criminalized, right? So, immediately you've got this stigma built up. You get called into the health department and have to sign a stupid form for them that says, 'I will not have unprotected sex.' So right there, they're labeling the person and not necessarily talking about the behaviors … (Male, G4)	We need to focus on the behaviors and not so much on, "How many people are you having sex with?" … It's like, well, let us get to that after we get to starting treating it, you know? (Male, G4)
	Relationship with HIV care systems	
Clinical Environment	You know, it's not like [clinic 1]. You want some environment that's more family oriented. More so, [clinic 2] is a big facility … I don't think their doctors have that one-on-one relationship with their patients … (Male, G4)	But I think when you get with a doctor and they are able to just be honest and real and transparent with you, then you can just be your honest self. (Male, G4)
Supplemental Programs	Case managers – it's hard to get in touch with them … A lot of them have a huge caseload … like their caseloads are so much that they have to meet that person, go see this person, go see that person … (Male, G1)	So, I mean the support side of it, too. It's not so much the medical care, but mental health and even, as I have noticed, down to transportation. (Male, G4)
Geographic Location	Moving from South Carolina to North Carolina, everything just went … The thing I think saved it for me was I got really, really sick … [My doctor] thought I was going to die, so he put me on disability and then I was able to get into North Carolina … (Female, G3)	Transportation because, I mean, even though you got a bus, you got some people can't actually just can't. (Male, G1)
	Individuals' personal characteristics	
Stigma	I'm a brother, a Black male. It's hard out there for us because of the fact that it can be shared. You know, they afraid they are going to get in contact, that they are going to get the HIV. Or like giving a handshake, they hesitate, you know … (Male, G4)	But the churches are starting to embrace this and … if they would actually go to the churches or send out information, I think that would be helpful in actually breaking out the stigma. (Male, G4)
Negative Attitudes	That's the hold up with a lot of people. They really don't want to know and then by the time they go, they find out it's too late … (Male, G2)	And I think a mentor, just to be there for them and help them with the system and getting into care … to talk to them and walk them through the steps. (Male, G4)

[AIDS Drug Assistance Program] is cut" (Male, Group 4). Participants who were receiving supportive services expressed feeling forced to live a lower quality of life to remain eligible for services, such as lower wages, as exemplified by a participant: "I get $77 a month, it's all I can earn and still keep my benefits. It's not going to help me get anywhere …" (Female, Group 3). Additionally, participants described the intersection of NC disclosure laws and social injustices. They reported the HIV disclosure laws were stigmatizing, essentially criminalizing those infected with HIV by "labeling the person and not necessarily talking about the behaviors …" (Male, Group 4).

Relationship with HIV care systems

Participants reported care system characteristics (e.g., interactions with providers, clinic's geographic location) as relevant for care engagement. Participants were generally satisfied with their HIV care, characterized by friendly medical environments and "one-on-one" (Male, Group 4) interactions with providers, which enhanced their desire and ability to stay in care. However, participants' experiences with clinical service varied based upon provider training and geographic location, which prevented some from obtaining necessary care. Despite mostly positive experiences with supplemental programs designed to improve care, participants also described challenges, such as utilizing case management, given that "it's hard to get in touch with [case managers] … a lot of them have a huge caseload …" (Male, Group 1). Considering these large caseloads, inevitably, participants reported delayed responses, and at times non-response, from case managers.

Individuals' personal characteristics

Participants disclosed experiences with social injustices, which affected short- and long-term psychological stress and negatively affected care engagement. Specifically, identification as persons of color and sexual and gender minority status shaped their HIV care-seeking experiences. For example, an African American male discussed experiences with day-to-day discrimination: "I'm a brother, a Black male. It's hard out there for us because of the fact that it can be shared. You know, they afraid they are going to get in contact, that they are going to get the HIV" (Male, Group 4). Some participants described how the fluctuation between positive and negative attitudes surrounding their status caused psychological distress, affecting their ability to stay in care or decisions to disengage from care. For instance, some experienced denial of diagnosis, or a "hold up" (Male, Group 2), highlighted by difficulties in promptly seeking care after learning about their HIV status. This underscores mental and emotional health issues around care linkage and engagement.

Solutions

Participants suggested a variety of solutions to address these factors that spanned improved dissemination of resources and funding expansion to support care services (structural and policy factors), provider and staff training (relationship with HIV care systems), and integrative services (individuals' personal characteristics).

Participants recommended education and access to a resource list or contact person at diagnosis as a means to facilitate care linkage and disseminate local HIV-related service and resource information. For example, "someone at that doctor's office … that is educated on HIV and knew all of the resources, that could come in after you have been told and walk you through it" (Male, Group 4). They suggested these resources could help address access to insurance and supportive services (structural and policy factors), empower HIV-positive persons against stigmatizing disclosure laws (structural and policy factors), and direct them to supplemental services (relationship with HIV care systems).

Participants also described the importance of providers' training and authentic interactions with patients as important in facilitating care engagement (relationship with HIV care systems), suggesting that additional training opportunities for providers and staff could help ensure their approach to HIV care facilitates care engagement. A participant emphasized having providers who "are able to just be honest and real and transparent with you" (Male, Group 4). Finally, participants expressed a need for integrative – and ideally co-located – services, such as the importance of linkages between clinics and organizations, including community-based churches (individuals' personal characteristics). These organizations offer myriad support services (e.g., mental health care, transportation, housing, support groups) that are helpful in navigating fragmented health systems and expediting care linkage and engagement.

Discussion

Consistent with existing research (e.g., Philbin et al., 2014), our study findings highlight both the challenges to and opportunities for increasing HIV care linkage and engagement. Although the results were presented across different levels – structural, system, and individual – the issues overlap. Participants expressed overall satisfaction with clinical services. However, under-resourced clinics (e.g., case managers with large caseloads) and limited clinics in certain geographic areas reduced care options. Additionally, the instability, and at times inaccessibility, of government-funded services and programs highlight other resource-specific challenges to care continuity. Participants provided a variety of context-specific solutions to address these factors and improve

health outcomes (Gardner et al., 2009; Philbin et al., 2014). Within the current funding climate, working to coordinate services and efficiently and effectively allocate limited resources will help reduce service duplication.

The intersectionality of multiple identities and stigmas (e.g., racial/ethnic and sexual minority) and co-occurring health conditions (e.g., mental health issues) with their HIV status shaped, and at times complicated, participants' care-seeking behaviors (Collins et al., 2008). These experiences and psychological distress associated with HIV suggest that individual and structural stigmas are important to address in care linkage and engagement (Earnshaw et al., 2013). Individual stigma from family, community members, and providers can be reinforced by specific structural factors, such as NC's disclosure laws that require disclosure to sexual or needle-sharing partners (Lehman et al., 2014). Although these local policies are designed to reduce HIV transmission in NC, they may inadvertently undermine effective HIV prevention programming by limiting care behaviors and viral suppression efforts through criminalizing policies that promote disclosure fears to providers and hesitancy to obtain needed care (Galletly et al., 2012).

Amending policies and laws may have implications for both individual- and community-level health outcomes. Given the changing health care environment in the United States, determining how the implementation of the Affordable Care Act affects care engagement will be important, particularly with the potential changes to the Ryan White Program and the expansion of private health coverage, to ensure care quality and continuity for HIV-positive persons. Further, enforcing less stigmatizing policies for HIV-positive persons could improve care engagement, resulting in reduced viral load with individual- and community-level health benefits. Given the variety of factors that influence care behaviors, providing comprehensive care services is also a vital component to ensure access to HIV care and other needed services (e.g., mental health, reproductive).

Limitations

Our findings should be evaluated in the context of the study design. A small, geographically specific sample of HIV-positive persons was included, many of whom were connected to care (i.e., medical or social services) in some capacity and whose experiences may differ from those never engaged in care. Future studies should examine the factors affecting care linkage and engagement with more diverse populations.

Conclusion

To meet the National HIV/AIDS Strategy (ONAP, 2012), HIV prevention and care efforts should work to address issues across multiple, overlapping levels.

Specifically, they should consider how HIV-positive persons' intersecting identities, stigmas, and co-occurring health conditions may be reinforced by structural factors and affect care linkage and engagement. Solutions to increase care linkage and engagement rates included improved dissemination of resources and funding expansion to support care services, provider and staff training, and integrative and conveniently located services. Addressing the factors that shape HIV-positive persons' care-seeking behaviors is essential to develop and implement comprehensive HIV care initiatives and facilitate greater care linkage and engagement to improve individual and community health.

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