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Structural community factors and sub-optimal engagement in HIV care among low-income women in the Deep South of the USA

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Abstract

This study describes the ways in which poverty and other structural factors create a risk environment for sub-optimal engagement in HIV care among low-income women living with HIV in the Southern USA, contributing to existing health disparities. We conducted a qualitative study in 2012, involving in-depth interviews with 14 stakeholders (service providers and representatives of community-based organizations) and 7 focus-group discussions with 46 women living with HIV (89% African American). A thematic approach in the context of the social ecological model guided data analysis. Data were coded and analyzed using NVivo qualitative software. The findings suggested that structural community factors, such as poverty, poor employment opportunities, limited access to healthcare resources, stigma, transportation challenges and access to illicit substances, may work independently and in synergy to impact women's health seeking behavior and decision-making, thereby influencing their ability to engage in HIV care. Interventions designed to improve engagement in HIV care should address structural factors to bolster low-income women's ability to engage in care.

Introduction

HIV-infection continues to be a significant public health concern in the Southern USA (Adimora et al. 2014; Phillips et al. 2011; Sprague and Simon 2014). The states most

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severely affected by the HIV epidemic tend to have high rates of poverty, poor population health and poor health outcomes among individuals living with HIV (Reif, Pence, et al. 2014), signaling the need to critically examine the role of non-individual HIV risk factors in this region. The disproportionate burden of the infection among those living in poverty (Hodder et al. 2010; Livak, Prachand, and Benbow 2012; Pence et al. 2007) and in disadvantaged communities (Buot et al. 2014; Peterman, Lindsey, and Selik 2005) suggests that focused approaches addressing the social and structural determinants of health are essential to halt the spread of HIV infection (Baral et al. 2013; Dean and Fenton 2010; Poundstone, Strathdee, and Celentano 2004; Stratford, Ellerbrock, and Chamblee 2007; Sumartojo 2000; Wolde-Yohannes 2012) and reduce racial disparities in health (Adimora et al. 2013).

Many of these disadvantaged communities are predominately comprised of African Americans and other racial and ethnic minority groups. African Americans bear a significantly higher burden of HIV infection, having alarmingly higher rates (approximately eight times that of Whites) of new HIV diagnoses (CDC 2015), lower rates of engagement in care and poorer health outcomes compared to Whites (Reif, Pence, et al. 2014). Understanding the roles of race, poverty and other structural determinants in the HIV epidemic among women is particularly important, as they are more likely than men to live in poverty and are provided fewer educational and employment opportunities (Dale et al. 2014).

Despite decreasing HIV incidence rates among women in the USA, women (≥ 13 years of age) account for approximately 25% of AIDS cases (CDC 2014), compared to 7% in 1985 (CDC 1995). Further, the burden of the HIV epidemic is not homogenous among women – African American women are disproportionately affected, with less access to care, poorer health outcomes and an HIV infection rate approximately 20 times higher than that of White women (Haley et al. 2014). Studies have shown that women are less likely to engage in HIV care, tend to present for HIV care late during the stage of their illness (Aziz and Smith 2011; Mugavero et al. 2007) and have higher mortality rates compared to men (Riley et al. 2007). Engagement in care is now at the center of HIV prevention efforts as it is proven to be effective at both the individual and population levels (Eaton, Saag, and Mugavero 2014; Gunthard et al. 2014; Mugavero, Norton, and Saag 2011). This qualitative study seeks to understand the ways in which poverty and other structural community factors contribute to sub-optimal engagement in HIV care among low-income women living with HIV in the Deep South of the USA.

Methods

Conceptual framework

The social-ecological model was used to inform the design and data analysis of this study (Baral et al. 2013; McLeroy et al. 1988). This model highlights the importance of including structural and social determinants of health in prevention and support programs, which are often difficult to identify and address in purely biological models (Baral et al. 2013; McLeroy et al. 1988). The social-ecological model was appropriate for this study as it allowed us to explore the proximal and distal effects of structural factors such as poverty on

HIV risk behaviors and engagement in care among women living with HIV infection Baral et al. 2013; McLeroy et al. 1988; Mugavero, Norton, and Saag 2011).

Study setting and sample

Alabama is one of the poorest States in the USA Lichtenstein 2007; Sprague and Simon 2014), and has high rates of HIV and other STIs (Muzny et al. 2014; Reif, Whetten, et al. 2014). Participants in this study were stakeholders (n = 14) and women living with HIV (n = 46). Stakeholders were representatives of organizations that provide services to individuals living with HIV, disadvantaged women and the general community. Representatives of legislative, faith-based and business communities were also included among the stakeholders in this study. Stakeholders were 19 years old and resided in Alabama at the time the study was conducted. Women living with HIV who were eligible for this study were 19–64 years old, of low socio-economic status self-reported) and seeking care at selected recruitment sites in Birmingham. The recruitment sites included three major HIV clinics and a residential facility that provides support services to individuals living with HIV.

Recruitment and data collection

Purposive and snowball sampling were used to recruit stakeholders. Stakeholders who consented to take part in the study were asked to participate in an hour-long in-depth interview. We partnered with HIV service providers to recruit women who were living with HIV to participate in this study. Flyers were placed in the recruitment facilities and potential participants were asked to contact the first author (MW) or a representative at the recruiting site. The women who consented to participate in the study were asked to take part in an hour-long focus-group discussion (FGD). The number of participants in each FGD ranged from 5–9 women. Each participant was given US\$30 at the end of the FGD.

The main questions relevant to the analyses that were explored in the interviews and FGDs included:

1. What are the challenges to initiating HIV care and treatment among HIV-infected women?
2. What are the challenges to remaining in HIV care once linked to care among HIV-infected women?
3. What are the challenges to adhering to HIV medications among HIV-infected women?
4. How does being poor affect HIV-infected women's ability to engage in HIV care?

Participants were also asked to complete a brief questionnaire to assess sociodemo-graphic characteristics (age, education, employment, etc.). Women were specifically asked if lack of food or transportation challenges ever served as barriers to engagement in care. Ethical approval was granted by the University of Alabama at Birmingham and written informed consent was obtained from all participants before they were enrolled in the study. The interviews (n = 14) and FGDs (n = 7) were audio recorded and conducted by the first author (MW), in private rooms at the recruiting sites.

Data management and analysis

Audio-recordings were transcribed verbatim, excluding names or other personal identifying information. The data analysis incorporated both inductive (themes emerged from and grounded in the data) and deductive (informed by the socialecological model and the literature) coding (Elo and Kyngas 2008; Hatcher et al. 2013). A thematic analytic approach (Boyatzis 1998) was used to guide the identification of themes and presentation of the findings. The data familiarization process began with listening to the audiotapes and reading the transcripts. This was followed by the coding of the data based on the levels outlined in the socialecological model. The initial report that was generated from this process was reviewed by MW and JT, who then developed the codebook based on the themes that emerged from the data. The data were then recoded using the codebook, while ensuring consistency in the application of the codes.

The report generated from this process was reviewed and interpreted by the members of the team independently and collectively. This iterative process ensured the themes presented herein are grounded in the data generated from this qualitative inquiry. Collecting data from stakeholders and women living with HIV facilitated triangulation (examining data from multiple sources for consistency) of the findings. A high level of consistency of the data generated was observed in this process. This paper presents the findings that emerged from three levels (organizational, community and societal factors) of the five levels of the socialecological model, as these were significant overarching themes (structural community factors) that influenced engagement in HIV care as described by the participants. NVivo qualitative software (QSR International version 9) was used for the management, coding and analysis of the data. The findings are presented with supporting quotes from the participants designated by their pseudonyms, age, gender and whether they were a stakeholder or an FGD participant.

Results

A total of 60 participants (14 stakeholders and 46 HIV-infected women) were enrolled in this study. Most of the women living with HIV were African American (89%), unemployed (88%) and earned < US\$11,000 a year. The women were between 20–62 years old (mean 44.6 years $\pm$ 9.6) and 63% had high school level education or less. Of the women, 39% reported that they had missed an HIV care visit due to transportation challenges. The majority of the stakeholders were women (64%) and had a higher-level education (57% Masters degree or higher). Stakeholders were within the 29–60 years age range (45 $\pm$ 10.9) and included directors, social worker, managers, a chaplain and an HIV peer educator, 50% of whom were White.

The two main themes that emerged from the data were: (1) limited community resources and (2) stigma and access to healthcare services. Participants described how these factors worked independently and synergistically to adversely impact women's ability to engage in HIV care. Overall, similar themes and sub-themes emerged from both groups of participants (women living with HIV and stakeholders), with the exception of telecommunication challenges, which was only mentioned by stakeholders.

Limited community resources

The participants described a number of interconnected pathways in which limited community resources and opportunities contributed to sub-optimal engagement in HIV care. In describing these relationships five sub-themes emerged: (1) focus on basic needs, (2) lack of health insurance, (3) transportation challenges, (4) lack of housing and telecommunication and (5) risky environments: sex work and drug use. Focus on basic needs (competing priorities)

The participants explained that preoccupation with basic needs while living in poverty impaired ones' ability to see ones' health as a priority. In the presence of limited resources, decisions are often made to provide for basic needs rather than addressing matters pertaining to health:

You know, when you are poor, you are always, 24hrs a day, always involved in the business of being poor, how do I keep a roof over my kids' head, how do I get there school uniforms, how do I live basically day to day? [Myah, 37 year old African American woman, stakeholder]

When I'm on medication I have to eat a full meal to take my medicine, so it's always something that you could be lacking; whether it's food, money, medicine or whatever because of being poor. [Issa, 43 year old White woman, FGD participant]

The women also expressed a strong obligation to their family/children and explained that they have engaged in sex work and stole from stores to provide for them:

Ok as far as taking care of the kids or the living arrangement or just providing for your family you have to do what you have to do [selling sex, stealing]. And when I say that a woman have to do what she has to do I mean you have to do what you have to do. [Zena, 48 year old, African American woman, FGD participant]

Lack of health insurance

Most women participating in the study lived in poor communities with high rates of poverty, and limited educational and employment opportunities. The participants explained that being poorly educated reduces the likelihood of securing high-income jobs or jobs that offer health insurance benefits. Not having health insurance significantly affected their management of HIV infection and added to the complexity of their daily struggles for survival:

There are a lot of HIV doctors who like to say and you even see it in the press that um HIV is just a chronic disease it's just like diabetes you take a pill and you're good to go. If you are middle class with insurance it is just take one pill a day and you're good to go. It is just not that simple but when you are living in poverty or have children to take care of, living in the city of Birmingham without a car, living inside the city without a General Educational Development (GED) or a high school education it's HIV but it is so much more than HIV. I mean it becomes everything it surrounds everything and they struggle hard and they get sicker fast...They [low-income women] come into our system sicker than your healthy white middle class male with insurance who's gonna get tested you know every six months um or

every year so women are coming into our system with a higher viral load a lower t-cell count and everything... [Lanah, 42 year old White woman, stakeholder]

A few participants did not share this belief (lack of health insurance is a barrier to HIV care) and expressed that there are agencies that will assist with the cost of HIV medications, housing and other support services. However, a number of participants countered this argument, highlighting that although assistance is available, not everyone is aware of the services or how to access them. They further added that the process can be very long and complicated. Therefore, some individuals living with HIV may opt not to engage in care:

I was going to say funding. I have been asked to leave a clinic and go to another clinic before when they lost funding. They never called me back...they have a very long waiting list, and if you have your own transportation and things like that... [Phea, 41 year old African American woman, FGD participant]

In some instances individuals may deviate from their treatment regimen due to their inability to purchase their medication as prescribed:

Sometimes people make bad choices because of circumstances because they feel like that is the only choice that they have. They feel like I am going to make my medication stretch because I don't have enough money this month to make my co-pay or I do not have enough money to get to the clinic or whatever so therefore I am going to stretch my meds and only take 3–4 times this week even though they know that they will equate to illness, But they make the decision that even though they know that there is some risk. These are choices that people make. I do not think that people always have alternatives. I think sometimes it is the choice of two bad alternatives. [Asa, 29 year old White male, stakeholder]

In addition, a few participants also said that bouts of illnesses associated with HIV infection can result in losing both their income and health insurance benefits.

Transportation challenges

Almost all the participants reported that living in poverty created transportation challenges, which served as a significant barrier to engagement in care at multiple levels, including disconnecting women from employment opportunities and health resources:

There are no doctors in the Black Belt parts of Alabama. You can't get to a doctor there's no transportation there's no cars, the poverty is through the roof there are no jobs. So it's nobody can get out, nobody can come in, or nobody choose to come in. So I think that it's all the same thing. It's education level. It's knowledge. It's the ability to get out of their situation. It's the ability to move into a different community. All that becomes very stagnant. [Lanah, 42 year old White woman, stakeholder]

Service providers further explained that although women generally only need to visit the HIV clinic twice yearly, limited resources and transportation challenges still can significantly affect women's ability to be linked and engaged in care. Relying on family and friends for transportation when accessing healthcare could result in forced or unwanted disclosure of their HIV status. Thus many women opted to avoid healthcare:

I think, you know number one they have a problem in getting here. Because you know a lot of them have no transportation and because a lot of them don't have income they can't afford to ride the bus. They don't want to tell their family that they are going to the doctor, because the family is going to say, well why are you going to the doctor? And they don't want to answer that question. And we do have a lot of patients that are not very adherent to their medical care because of that.

[Abiah, 57 year old African American woman, stakeholder]

My biggest issue is getting back and forth to the xxx Clinic [Unidentified woman, FGD participant]

Lack of housing and telecommunication

Participants also said that being unemployed resulted in financial strain, leading to housing and telecommunication challenges, which negatively impacted engagement in care. A few participants expressed that challenges with housing (shelter, group home, sharing with relatives/friends or homelessness) may result in unwanted disclosure, loss of medications or being overwhelmed from efforts to find secure housing. Additionally, not having a telephone or a stable telephone number made it difficult for healthcare providers to remind clients about their doctor's appointments. All of these contributed to sub-optimal engagement in care, as illustrated in the quotations below:

Like [participant] said they are homeless and they get their drugs and they might leave them, forget them, somebody steal them because they thinking that they are narcotics, so you know that will affect adherence. [Eartha, 62 year old African American woman, FGD participant]

...they have housing issues-uncertain housing, they even have uncertain communication – they don't have a telephone maybe their telephone only works occasionally so they can't get communication with the clinic to get reminders telephone calls or assistance with medication. Those kinds of everyday practical things that play out to cause negative outcomes for these folks. [Rajah, 55 year old White male, stakeholder]

Risky environments: sex work and drug use

Many women reported having a history of drug use and explained that it was very easy to access drugs in their community. The women explained that they often engaged in sex work or relationships with undesirable partners due to financial challenges. These situations created an environment that fostered drug use and or trade, which in turn affected their engagement in HIV care:

Bottom line situation is that it all comes down to the money and being able to take care of what is left of our family. When money isn't there or money comes up short we have to provide for our families in any kind of means we possibly can even if it means selling [sex] just for joe-blow [man on the street] or whatever situation. [Edda, 44 year old African American woman, FGD participant]

They didn't save up too much money, because money is the trigger to go back out and use [drugs] and not take their medication. [Ulrika, 57 year old African American woman, FGD participant]

The only thing that stops you [from staying engaged in HIV care] is being on drugs. [Unidentified woman, FGD participant]

Stigma and access to healthcare

Participants reported that not having adequate financial resources dictates where the women seek HIV care – a government infectious disease clinic compared with a private doctor's office. Two types of stigmas associated with accessing healthcare were described: (1) stigma associated with accessing healthcare at facilities that were designated for the poor (stigma associated with being poor) and (2) stigma associated with accessing care at healthcare facilities that were solely designated for HIV care (HIV-related stigma).

With regard to stigma from utilizing health care facilities designated for the underserved, the following quotation illustrates this concept:

Like here, our facility is for the indigent in Jefferson County, but this also comes with a stigma attached to it. The stigma attached with it of being poor, or living in poverty or whatever, if I go to that hospital, people are going to look at me funny, the doctors are not going to care for me, this is what I hear, you know that there is no good doctors in indigent care hospitals or facilities. People who provide indigent care, we get the rejects. You know these are things that they say that keeps them from coming in to get, and hopefully with this new healthcare reform, you know people will go to the doctor. [Abiah, 57 year old African American woman, stakeholder]

Perception of sub-standard care at some HIV treatment facilities for the poor also served as a barrier to engagement in care:

It is horrible. It is absolutely just embarrassing. Know what you are dying from, and knowing that it is killing you and not being able to reach the resources what you need to help your self is downright embarrassing. And then to go to where there is a doctor that does not give you any kind of hope but, discourages you, it's pathetic. They did not treat me well, in fact they refuse me medication, they refuse treatment. There was a time when I had no transportation, there was a time I was homeless. They did not care about the fact that I did not have proper transportation to get here. They did not care about the fact that I was not on welfare, I did not have medical [insurance]. I did not have money for my prescriptions or anything like that. They didn't care. Even if – or a pharmaceutical company to pay for the bills, they would not help me because they were convinced that I was a loss cause-you've have half a breath to live and your toenail and finger nail in the grave so we are not going to deal with you. [Waiola, 28 year old African American woman, FDG participant]

Stigma from utilizing HIV-specific facilities was related to perceptions of poor treatment received from healthcare workers, increased risk of being seen by others, as well as sub-

sequent risk of unwanted disclosure and community stigma. Participants explained that taking that first step – walking into the lobby of an HIV care facility and risking being seen by others – can be a frightening experience that may deter individuals from engaging in care:

Because you are poor even if you do decide you have to access health care from public places verses a private doctor. Someone who has the financial means to access a private infectious disease doctor. You have to come in to state federal funded programs which are open to the public. Not wanting to be seen in those place, affect access to health care as well. [Sabah, 40 year old African American woman, stakeholder]

The women explained that the HIV care facilities in their communities are often designated specifically for HIV care only. Since these HIV treatment facilities were so designed or labeled, it was difficult to access care without risking the chance of unwanted disclosure. Due to fear of being stigmatized or discriminated against if seen visiting such facilities, individuals may choose to not seek care:

I was from a rural and the clinic for HIV was in a different clinic. And their section was in the back. So you had to go in there and sit in the back...so everybody knew you were going to the HIV clinic. If I come in and see somebody from my hometown I'm most likely to come in and walk out. [Calista, 48 year old African American woman, FGD participant]

Discussion

Our findings describe ways in which structural community factors may create a risk environment for sub-optimal engagement in HIV care among low-income women living with HIV in the Deep South of the USA. Community structural factors (poverty, limited access to resources [health care and employment opportunities], stigma, transportation challenges and access to illicit substances) appear to work independently and in synergy to adversely affect women's health seeking behaviors and decision-making, thereby potentially influencing their ability to engage in HIV care. The findings underscore the need to adopt a social-ecological perspective in the design and implementation of programs geared at improving engagement in HIV care and health outcomes among low-income women living with HIV (Arrivillaga et al. 2011; Baral et al. 2013; Mugavero, Norton, and Saag 2011; Roura et al. 2009).

Although HIV infection is now considered a manageable chronic disease, among women living in poverty the management of HIV infection is often complex and may impact all aspects of their lives. Challenges pertaining to meeting basic needs, such as satisfying hunger and taking care of their families, are at times given priority over taking measures to engage in HIV care. Other studies in the USA have shown that these challenges can contribute to sub-optimal engagement in care among women living with HIV (Aziz and Smith 2011; Phillips et al. 2011). Additionally, aspects of poverty such as food insecurity have been identified as significant barriers to suboptimal adherence to HIV medications (Kalichman et al. 2014; Surratt et al. 2014) and unsuppressed viral load (Wang et al. 2011). The findings from our study suggest limited access to resources such as employment and

educational opportunities further challenge women's ability to satisfy their basic needs and provide for their families.

Lack of formal employment opportunities in the women's communities seemed to foster an environment for easy access to risky occupations and illicit substances. While women may have been exposed to drug use or trade through sexual relations (sex work or sexual partners), some also became substance abusers, which negatively impacted their ability to effectively engage in HIV care. These findings are consistent with other studies demonstrating that substance use is associated with sub-optimal engagement in HIV care (Bruce, Kresina, and McCance-Katz 2010; French, Tesoriero, and Agins 2011; Nicholas et al. 2014).

Access to private health insurance among individuals living with HIV in the USA is very low (17%) and approximately 30% are uninsured (2010 estimates) (Snider et al. 2014). The uptake of HIV care and other support services needed to improve HIV-related health outcomes tends to be higher among individuals with comprehensive health insurance (Snider et al. 2014). Therefore, it was not surprising that participants in this study described a number of ways in which lack of health insurance resulted in sub-optimal engagement in care. Lack of insurance also meant that women did not always have the autonomy to choose their healthcare providers. Thus, when seeking care, women seem to wrestle with decisions regarding the use of healthcare facilities that were designated to the poor. Perceived stigma – thoughts about being judged by healthcare providers for being poor or receiving sub-standard care – prevented women from accessing care. Also, when seeking HIV care, women often had to use public HIV care facilities as opposed to private doctors due to the lack of health insurance. Using public HIV care facilities was associated with fears about unwanted disclosure, which would significantly increase the risk of being stigmatized in their communities. Fears of being ostracized by the community deterred women from accessing HIV care. These multilevel effects of not having insurance among women living with HIV infection emphasize the need for structural interventions to improve access to HIV care.

Unsurprisingly, most participants reported that transportation challenges played a major role in sub-optimal engagement in care among women living with HIV. These results corroborate findings from other studies that have emphasized the need for improved public transportation or patient transportation programs, especially in rural areas, to help individuals living with HIV to engage in care (Kempf et al. 2010; Sprague and Simon 2014). The issue of transportation also underscores the inherent problems in which healthcare is organized in Alabama, for example in some areas women have to travel long distances to access health-care, which has been found to contribute to reduced uptake of services (Pence et al. 2007). Provision of HIV care via mobile units or via telemedicine could potentially assist women in these communities. Given the stigma associated with HIV infection, careful branding of the program would be crucial for community buy-in and uptake. 'Wellness Services', wherein a package of healthcare services such as diabetes, hypertension, nutrition and sexual and reproductive health, including HIV/STI services, is offered via mobile units, could potentially reduce the effects of stigma.

Importantly, transportation challenges also indirectly affected women's ability to engage in care by preventing them from accessing jobs, a source of income necessary to provide for basic needs, a means of accessing health insurance and an opportunity to lift oneself out of poverty. Deprived of these opportunities, women may feel 'trapped' in their communities, thereby increasing their vulnerability to engaging in other sources of income such as drugs and sex work. Furthermore, many of the women in this study reported a history of substance use, which is also associated with sub-optimal engagement in care. Study participants also described relationships between education level, income and health. These findings support the literature arguing that addressing social determinants of health is essential for the improvement of health outcomes (Riley et al. 2012; Sharpe et al. 2012; Sumartojo 2000).

Although our study contributes to the understanding of the impact of structural community factors on sub-optimal engagement in HIV care among low-income women in the Southern USA, there are limitations that must be considered. First, this is a qualitative study involving a small non-random sample, hence the findings are not generalizable. However, participants were recruited at the three main HIV clinics in Alabama and a major residential facility that provides housing and support for HIV-infected women. Therefore, a wide cross-section of low-income women participated in the study. Second, the data are self-reported and therefore subject to recall and social desirability biases and the extent to which the participants were willing to share their experiences. However, involving both HIV-infected women and stakeholders allowed for triangulation of the data sources. The themes that emerged from the women and the stakeholders were very similar.

Overall, the findings of this study suggest specific ways in which structural community factors contribute to sub-optimal engagement in HIV care among low-income women in the Deep South. These structural aspects (transportation challenges, unemployment, limited access to healthcare, stigma, access to drugs, etc.) of the communities in which the women lived may directly or indirectly influence women's health seeking behavior and ultimately their ability to engage in care. These findings underscore the need for healthcare providers to consider the context in which women live when prescribing antiretroviral medication and helping women to engage in HIV care.

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