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Qualitative Assessment of Barriers and Facilitators to HIV Treatment

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The advent of effective treatments for HIV has offered millions of people living with HIV (PLWH) the opportunity to improve their longevity and quality of life (Jelsma, MacLean, Hughes, Tinise, & Darder, 2005). A necessary prerequisite for accessing these treatments is enrolling and subsequently remaining in clinical care. Levels of engagement in HIV care can be seen on a continuum: “a spectrum of patient care, ranging from initial diagnosis to full engagement in care” (Cheever, 2007, p. 117). For reasons that remain underexplored and poorly understood, a sizable portion of PLWH in the United States do not fully engage in HIV care, defined here as enrolling in care in a timely manner and subsequently attending care at the recommended intervals for monitoring and follow-up. Across all points on the continuum of care there are considerable proportions of PLWH in the United States who are *not* engaged in care. A reported 20% to 40% of PLWH in the United States are presently unaware of their HIV infection, 20% to 40% of PLWH who are aware of their HIV infection do not enter care in a timely manner, and approximately 33% of those who enter care do not use it at the recommended intervals (Mugavero et al., 2009). Clearly, efforts are needed to better understand barriers and facilitators to engaging in HIV care in order to develop and implement effective interventions that will promote higher rates of utilization over the care continuum.

Presently, considerable efforts through national initiatives to promote routine rapid HIV testing in adult health care settings target reducing the number of individuals who remain unaware of their HIV status (Centers for Disease Control and Prevention [CDC], 2007). Arguably, however, knowledge of HIV infection is a necessary but insufficient condition for better control of HIV at a personal, community, or epidemiological level. Effective medical treatment and persistence in HIV care are needed to achieve and sustain viral suppression,

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which could further reduce transmission risk and would offer a host of benefits to the health and longevity of the individual. Presently, however, barriers and facilitators to staying in HIV care once initiated are underexplored in the literature, limiting the empirical guidance needed to develop and implement effective retention-in-care interventions.

Barriers and facilitators that have been identified in the literature to date include structural aspects of care, availability of support services, and personal factors (Rumptz et al., 2007). Challenges to engaging in HIV care related to poor or no insurance coverage have been identified, particularly among African Americans (e.g., Molitor et al., 2006; Naar-King et al., 2007). Further, barriers to engaging in care identified to date have included factors associated with the process of interacting with care providers and agencies, including longer wait times from a request for an appointment and the actual appointment (Mugavero et al., 2007), absent or poorly implemented case management (Tobias, Cunningham, Cabral, et al., 2007), issues associated with transportation (Reif, Golin, & Smith, 2005), and negative interactions with care providers (e.g., perceived poor empathy, engagement, and validation on the part of the provider; Mallinson, Rajabiun, & Coleman, 2007). At a personal factors level, mental health issues, active drug use, negative or low health-beliefs about getting care, as well as avoidance and denial of HIV status have been identified as influential factors in the initiation of and subsequent persistence in HIV care (Cunningham, Sanchez, Li, Heller, & Sohler, 2008; Giordano et al., 2005; Konkle-Parker, 2010; Konkle-Parker, Amico, & Henderson, 2010; Reif et al., 2005; Stewart, Cianfrini, & Walker, 2005). Additionally, Stewart et al. (2005) found that the health status of PLWH may be improved by assessing and addressing social issues such as social isolation, life stressors, and housing. While correlates of engagement in HIV care have been well identified in terms of those related to the treatment offered (structural as well as process oriented) and the person in need of treatment (substance use, health beliefs, avoidance), and factors related to both the system and the person (e.g., patient-provider relationships), there are few comprehensive descriptions from the patient's perspective that examine the factors associated with attendance to HIV care, especially in the Deep South. As noted by Doherty, Leone, and Aral (2007), the proliferation of HIV among minority populations in the Deep South is heightened due to factors such as lack of viable employment, quality education, access to medical care, decent housing, and overall community infrastructure. These factors may further hamper the ability of PLWHs to attend regularly scheduled medical care visits. Just as unique cultural characteristics (i.e., rural poverty, historical racism, conservative religiosity, lower education and literacy levels, and poor overall health status) of the socioeconomic milieu in the Deep South promote factors that influence medication adherence (Konkle-Parker, Erlen, & Dubbert, 2008), appropriate use of HIV health care services may be similarly impacted. We conducted five focus group sessions with PLWH from a clinic in Mississippi to explore factors associated with HIV medical visit adherence among PLWH in the Deep South. The main purpose was to determine the barriers to and facilitators of consistently attending HIV medical care visits among a group of PLWH who had successfully negotiated enrolling in HIV care.

Methods

Participants

A convenience sample of 25 participants was recruited from a local public infectious disease clinic in Mississippi for participation in focus groups concerning HIV care. Fliers informed potential participants about the nature of the study, which was considered exempt from informed consent by the University of Mississippi's Institutional Review Board. Participants had to be at least 18 years of age and English-speaking.

A total of five focus group sessions, each lasting approximately 1.5 hours, were conducted in a private room in November, 2009. Prior to the beginning of each focus group, the participants completed a demographic questionnaire and helped develop guidelines outlining how the focus group would be conducted. The participants were strongly encouraged to maintain confidentiality regarding group members' identities and focus group discussions. A licensed clinical psychologist, who was guided by a semi-structured set of questions, facilitated each focus group. Each question was read to the group by the facilitator, with clarifications and follow-up questions used as needed. The purpose of the questions (e.g., *What is your opinion about making regularly scheduled HIV care visits when not having health or medication problems?*) was to identify the main facilitators and barriers to remaining in HIV care once initiated. After each group, the facilitator shared impressions with the full research team.

Analyses

Data from demographic questionnaires were used to characterize the sample with descriptive statistics. The digital recordings of each focus group were transcribed verbatim and distributed to three research team members for confirmation, editing, and analysis. Team members included the facilitator, the observer, the principal investigator, a PhD-prepared nurse practitioner with many years of HIV clinical experience, and a psychologist with experience in HIV-adherence research. The full research team discussed the identified barriers and facilitators that emerged from the recorded groups, assigned codes, and merged those codes into themes. Code development was done iteratively as a result of reviewing transcripts and discussions.

Results

The ages of the participants ranged from 24 to 54 years ($M = 40.4$ years). Participants were primarily African American (84%), male (60%), and of lower socioeconomic status (48% under the federal poverty line), which is representative of the clinic population from which the sample was derived.

Nine central themes (see Table 1) emerged from the collected data, each consistently included in most or all of the focus group discussions. Five main themes concerning barriers to care and four concerning facilitators of care were identified.

Barriers

Five themes described barriers to full engagement in care once initiated. The themes included: (a) the impact of competing demands (e.g., family, employment, childcare); (b) aspects of the system of care (e.g., qualities of health care provider, access to care, fragmentation of healthcare system); (c) the influence of stigma (e.g., changes to what others think about the individual, social isolation); (d) the experience of negative affect (e.g., fear of abandonment, hopelessness, denial); and (e) various beliefs about the need for or role of HIV treatment (e.g., questioning the need for health care when asymptomatic).

Competing demands—This theme emerged with the discussion of obligations, choices, or priorities that competed with attending medical care including: family, employment, childcare, other appointments, emergencies, substance use, and the desire to conceal use from care providers. For example: *".....and I knew that, ah, my urine would be positive with, with the drugs, and I knew that the doctors would, you know, know it, and I'd be ashamed...."*

System of care: This theme was related to the qualities of health care providers and staff, access to care, fragmentation of care systems, and privacy. As one participant said, “...if you feel like they are not responsive to you, you’re not gonna’ wanna’ go back and interact with them.”

Stigma—Stigma was expressed as a concern about the negative consequences of others knowing or finding out about one’s HIV status, including inadvertent HIV-status disclosure because of being seen going to clinic or at clinic. This was seen in the following statement, “...with the negativity and the thought that you gonna’ see somebody, you know, ...somebody gonna’ see you walking up to this office, you know.”

Negative affect—This theme included fear of abandonment, hopelessness, denial, shame, anger, fear, grief, or isolation that negatively impacted the participant’s motivation or commitment to self-care. For instance, “...when a person finds out that they are HIV positive, if they have been abandoned by their family, they may not care anyway. They may just lose all sense of hope.”

Beliefs about HIV health care—Participants discussed discounting the necessity of health care if currently feeling well and persistent negative beliefs about medical care in this theme. One said, “...a lot of African American men won’t go to the doctor because of the Tuskegee thing, they just won’t get regular checkups because of the distrust they have in the medical care system.”

Facilitators

Four themes emerged as facilitators for remaining engaged in care once initiated. These included: (a) support (e.g., peer navigation, family and friends, clinic staff); (b) activation around care (e.g., acceptance, empowerment, advocacy); (c) Positive aspects of health care visits (e.g., getting lab results, patient/provider rapport, being assured of best treatment); and (d) perceived vulnerability to negative consequences (e.g., avoiding the progression from HIV to AIDS, avoiding drug resistance, death). Participant quotes associated with these facilitators are listed below.

Support—This theme emerged from comments related to peer navigation, family and friends, clinical staff, and social influence. As one participant said,

.... you got to first build yourself up to the point to where you even want to go, and if you have friends, or even if ...you have told your family that, you know, that you have this illness, ...you have to know that this person is going to support you ...

Activation around care—Remarks that supported this theme included acceptance, empowerment, increased knowledge of HIV, advocacy, pursuing collaboration in treatment, and monitoring lab values. Some participants said, “I like to know my CD4 count.”

Positive aspects of health care visit—Participants discussed information about care visits, getting lab results, provider/patient rapport, being assured of best treatment, early detection, and feeling cared for. Positive information included statements such as:

... what I see motivates me to go to my regular scheduled visit is the fact that I have two kids, two daughters, and now I have a grandchild. So that grandchild basically, and the kids, are motivating me to continue to go to get [a] check up and my progress report and do well with myself.

Perceived vulnerability to negative consequences—This theme focused on getting sick and dying. One participant said, “...*my mom died from the virus, too. ... I took care of her, so that motivated me to wanna’ take care of myself cause I’ve actually seen the stages...*”

Discussion

This study qualitatively examined the barriers and facilitators associated with attending HIV medical care visits for PLWH in the Deep South. Five themes emerged for barriers to remaining engaged in care once initiated: (a) the impact of competing demands, (b) aspects of the system of care, (c) the influence of stigma, (d) the experience of negative affect, and (e) various beliefs about the need for or role of HIV treatment. Four themes emerged as facilitators: (a) social support, (b) activation around care, (c) positive aspects of health care visits, and (d) perceived vulnerability to negative consequences.

Many of the participants discussed having strong intentions to attend scheduled medical visits. However, the priority of attending to their own health care was often less than that of addressing immediate problems related to family and employment, or more acute immediate needs associated with addictions and substance use. Competing demand is a reality of substantial importance in this lower-income population. Social class is an important risk factor for HIV infection (Ickovics et al., 2002), and up to 45% of PLWH are unemployed (Rabkin, McElhiney, Ferrando, van Gorp, & Lin, 2004). The competition between accessing multiple services and securing or maintaining employment and attending HIV care appointments, while maintaining privacy concerning one’s HIV status was noted as a very real burden for many of the focus group participants. Previous research (Cunningham et al., 2008; Giordano et al., 2005; Konkle-Parker, Amico, & Henderson, 2010; Mallinson et al., 2007; Mugavero et al., 2007; Reif et al., 2005; Stewart et al., 2005) has also shown that factors such as interactions with health care professionals, poor mental health, and substance use limit patients’ abilities to adhere to the continuum of HIV care. Thus, it can be assumed that the aforementioned issues are experienced by PLWHs, regardless of geographical locale.

Social support was the facilitator most often mentioned by the participants. They believed that support from family, friends, and clinical staff all had a collective impact on a patient’s motivation to take the necessary steps to seek appropriate health care. They also felt that medical visits could be quite rewarding when discovering that their CD4+ T cell counts and/or HIV viral loads were at or above satisfactory levels and/or early detection of problems associated with the disease. Additionally, participants revealed that a combination of (a) education about living with HIV, (b) active involvement in the care process, and (c) acceptance of the HIV diagnosis resulted in a high level of engagement in care that facilitated attendance to medical visits.

Conclusion

Regularly attending scheduled health care visits is essential to the quality of life for PLWH. Despite some methodological limitations, this study shows that a wide array of issues (i.e., employment, family, etc.) are identified and easily discussed by PLWH as factors influencing whether or not a patient makes it to a scheduled medical visit. Future research in this area should focus on viable strategies to address multiple competing demands, promoting accurate knowledge of the role of HIV care, and fostering strong social connections between PLWH and the HIV care continuum. Socioeconomic conditions (i.e., racism, poverty, lack of education) in the Deep South can further confound the ability of

patients to regularly attend scheduled medical visits by strengthening the impact of competing demands.

Limitations

There were several limitations to this study. First, there was a high level of homogeneity within the sample due to the convenience sampling method and the fact that the participants had been living with HIV for at least 2 years. Thus, their experiences in dealing with HIV were likely different from a sample of newly diagnosed persons. Second, the participants were predominantly sampled from one clinic. This compromised the generalizability of most of the concerns about environmental factors (i.e., policies, procedures, and stigma). Lastly, most (84%) of the participants indicated that they went to the clinic for care “every 3–4 months”, which is the average number of months that appointments are set. Hence, the sample lacks variability in the range of attendance to medical visits, although most could discuss barriers and facilitators related to their previous experiences or others’ experiences.

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Table 1**Barriers to and Facilitators for Attending Regularly Scheduled Medical Care Visits**

| Barriers | |
|----------|---|
| 1 | Competing Demands |
| 2 | System of Care |
| 3 | Stigma |
| 4 | Negative Affect |
| 5 | Beliefs About HIV Health Care Not Being Important |

| Facilitators | |
|--------------|--|
| 1 | Support |
| 2 | Active Engagement in Care |
| 3 | Positive Aspects of Health Care Visit |
| 4 | Perceived Vulnerability to Negative Consequences |
