

A Qualitative Look at Decreasing Barriers to Receiving Uninterrupted Care for People Living with HIV in Rural Southern Georgia

Joshua M. Kies

School of Nursing, Georgia Southern University, Statesboro, USA

Email: jkies@georgiasouthern.edu

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Abstract

Early linkage to antiretroviral therapy (ART) after HIV diagnosis extends life. Low socioeconomic populations with HIV face regional concerns that inhibit early treatment. Barriers include religious-based stigma, lack of local treatment facilities, fear of discovery and purposeful secrecy fostering increased HIV transmission and decreased ART adherence. This ethnographic qualitative study employed semi-structured interviews with 10 health care providers (HCP) and 10 people living with HIV (PLWH) to discover methods to streamline care and increase medication adherence. Clients perceive enhanced care when they are active participants in treatment. HCPs reported positive health outcomes when there was active multidisciplinary communication. Obstacles included a lack of consistent medication assistance programs, homelessness, and limited access to specialized services. There is a need for further investigation on how to provide individualized, holistic treatment to a population of patients with extremely limited federal funding in a geographic region where religious stigma surrounding HIV is widespread.

Keywords

Antiretroviral Treatment (ART), Barriers, Compliance, HIV, Rural

1. Introduction

Georgia ranks as one of the leading states in the country for lifetime risk of acquiring HIV [1]. Georgia also has the poorest health outcomes directly related to HIV and AIDS and its long-term sequelae [2]. Persons from recognized low socioeconomic groups represent only 16% of the general population, however, 44% of new HIV or AIDS diagnoses in Georgia are from that category of individuals [1]. Stratification of data reveals that high concentrations of new and ex-

isting HIV cases are focused in rural, southern Georgia [1]. Clients that live within a defined low socioeconomic group are less likely to proactively seek and maintain an HIV treatment regimen than individuals from other categories [3]. A delay of more than five years between HIV diagnosis and treatment initiation may decrease healthy living by more than a decade and more than double overall lifetime healthcare spending [4]. Early and uninterrupted linkage of the client to specialized health care providers (HCPs) deliver much needed education about the disease, immediate medication initiation, and effective measures to help decrease culturally-based and disease stigma-related issues through education [5]. Long-term benefits of early treatment after HIV diagnosis have been shown to increase healthy living years and decrease lifetime health care dollars spent on medical management of comorbidity fallout [4]. While these measures have been shown to be effective in reducing health care burden from HIV in other regions of the United States, a focused study within southern Georgia has not been published.

Significance of HIV

A goal of the HCP is to successfully initiate or refer the client for specialized care and/or for disease management [5]. While attempts to proactively manage and synchronize this process have been attempted, only 49% of those with the disease are actively engaged in care [2]. Attempts by the National Institutes of Health (NIH) and CDC to introduce and maintain public health campaigns about the importance of HIV testing and treatment maintenance have shown limited results to the most vulnerable, rural, and low socioeconomic groups [6]. Improving client retention in HIV treatment protocols is essential to viral load reduction, which decreases the chances of transmission, increases healthy living years, and reduces the overall national health care burden. [5]

With a care retention rate of less than half, the country's health care system is failing at treating the HIV epidemic [2]. Studies have shown that when geographically specific measures are incorporated with medical treatment, success rates may be up to a third higher than the national average [7]. Acknowledging and recognizing the importance of psychosocial factors and social determinants of health should be foundational when creating a treatment plan [7].

The state of Georgia ranks fourth in the United States for new HIV diagnoses and reports the lowest treatment compliance rates as compared to any other state [1]. Rural persons in southern Georgia that fall within a recognized low socioeconomic group may possess challenging odds to enter and be retained in care and education programs. Research is desperately needed in rural, southern Georgia to uncover reasons for the lack of HIV-specific medical care, disease education, and long-term health successes. With data gathered from targeted questioning of both HCPs and clients, obstacles to care, both short and long-term, may be proactively discovered.

2. Purpose

The purpose of this project was to uncover environmental, societal, and personal barriers to receiving high-quality HIV treatment in rural, southern Georgia. The main objective was to recognize care obstacles and learn what enhances treatment success.

Outcomes

Discoveries from this study will assist stakeholders in determining issues, problems, and positive factors that will enable clients to engage and maintain treatment. Ultimately this should promote improved adherence to medical care for people living with HIV (PLWH) thus extending healthy living years while simultaneously reducing health care expenditures.

Short-term goals of this project included:

- Determine PLWH perspective of disease management.
- Determine HCP perspective on how to expedite uninterrupted care for PLWH.
- Determine perceived psychosocial barriers to uninterrupted HIV care.

3. Background

3.1. Overview

Several studies have explored the depth of education about the disease, personal attitudes, and societal practices of PLWH as well as their care providers, financial status, and the corresponding responsiveness to treatment options [8]. Self-efficacy and commitment to treatment are major factors that have been shown to enhance adherence to ART [9].

3.2. Barriers and Enhancers that Influence Treatment Adherence

Cultural and socially based fear and stigma have been long-standing barriers for pursuing and continuing treatment for PLWH [10]. Challenges to care plan compliance

have often been related to the accessibility and demands of the treatment regimen, lack of social support, diminished personal funds, substance abuse and mental illness [11]. Adherence to treatment is influenced by factors that may be categorized into four main themes: patient factors, medication characteristics, interpersonal characteristics/social supports, and the availability of specialized health care [10].

3.3. Mental Health and Substance Abuse

Treatment compliance for PLWH is problematic when clients have identified mental health issues as well as illicit substance abuse problems [12] [10]. Several psychosocial issues affect patients and treatment compliance. Issues include posttraumatic stress disorder, anxiety disorders, and body image dissatisfaction [10] [13]. Research findings indicate alcohol use is higher among PLWH as compared to the general population [11].

3.4. Homelessness and Social Factors

A client's level of social support will often facilitate adherence to treatment regimens [10]. Treatment adherence is also impacted by the client's living situation [14]. Clients who are homeless demonstrate greater challenges in adhering to their HIV treatment [15]. Individuals who are identified as coming from low socioeconomic groups tend to have greater challenges accessing health care and are at higher risk for poor health outcomes and reduced healthy living years [14]. Furthermore, homeless persons living with HIV have been found to be less likely to access and receive optimal regular HIV care [15].

3.5. Care Approaches and Perception of HIV Treatment Providers

Inherent communication styles and individual culture influence the relationship between client and treatment providers which can adversely affect a client's adherence to a treatment regimen [10]. Compliance rates vary based on interventions with proven successful outcomes. For example, the use of adherence counselors increased treatment adherence [16]. In order to improve treatment adherence, ongoing and long-term follow-up is needed to change an individual's belief system and reduce the complex barriers that influence negative attitudes towards HIV treatment [16]. Client education and counseling by pharmacists increase treatment adherence rates and clinical outcomes through coordination and notification of medication refills [13].

3.6. Contributors to Health Outcomes

Overarching themes were identified during the literature review that directly relate to both obstacles and successful, positive incentives to maintain medical treatment plans and social-based treatments for PLWH. Themes with the potential to affect health outcomes for patients are organized within three headings: client components, environmental components, and HCP components.

Client components identified included absence of social support, low socioeconomic status, questionable work history, lack of primary education, lack of disease education, uncertain housing status, and unmanaged/undiagnosed mental health conditions [10] [15]. The largest predictors for treatment compliance are mental health disorders, housing status, and current employment [14] [15]. When a client's primary focus is on daily survival, HIV treatment suffers [10] [15].

Environmental components influencing compliance to established treatment included cultural stigma, social rejection, reasonable and reliable accessibility to the clinic, and the perceived difficulty of the treatment program [11]. Clients may positively or negatively change their behaviors as influenced by personal factors and interactions they have with their environment [17].

When examining HCP components most studies have focused on the practices and perceptions of the PLWH in reference to treatment adherence and not on

that of the role of the HCP in the clients' adherence behaviors [14] [15]. There is a lack of research relating to the health care system and the evaluation of the providers who participate in the treatment of PLWH at it relates to their adherence [8] [16].

4. Methods

4.1. Design

A qualitative ethnographic study was implemented to discover obstacles and enhancers to receiving uninterrupted HIV treatment in rural, southern Georgia. There are no published studies that delve into how the geographic uniqueness of this area affects PLWH adherence to treatment regimens. Interviews with both HCPs and PLWH provided an intimate view of life, health, and the battle waged with HIV. Impediments to care were sought and solutions discussed with all involved in the study. It is through these interviews that new information was gained to streamline future HIV care in this region. The study was approved by the university institutional review board.

4.2. Sample and Setting

The populations examined were PLWH that reside in rural, southern Georgia and their HCPs from two rural primary health medical clinics. They provide primary and specialized HIV health care, allowing for the delivery of holistic care. Each clinic provides care to greater than 50 PLWH.

The researcher or an HCP at each clinic identified participants that met inclusion criteria, gave them a recruitment flyer, and discussed the project with the client. Clients who chose to participate either contacted the researcher or advised the HCP of their interest. Contact was made with potential participants and a one-hour, audio-recorded interview was scheduled. The interviews were conducted on-site at the clinic during the client's next scheduled visit, or when practical.

Clinic HCPs were contacted by telephone and a script was used to offer participation in the study. For HCPs that agreed, a time was set up to conduct an audio-recorded interview with them in their private office.

The sample size was twenty with ten clients and ten providers. All participants gave informed consent to being interviewed and the information they provided is protected and is only reported as aggregate or de-identified.

4.3. Demographic Questions

Demographic information gathered included clients' age, identified gender, race, and time in active treatment, defined as greater than six months of uninterrupted care, and medication adherence. This information helped identify the percentages of enrollment based on these factors as well as may help to guide the creation of future research studies based on ethnicity and geographical dispersion of the disease.

4.4. Interview Questions

The primary focus of interview questions was to determine barriers and enhancers to uninterrupted care for PLWH from both the HCP and client perspectives. The HCPs were asked about methods used to track progression of clients through the continuum of HIV care.

Specifically, they were asked how they ensure compliance with medication and appointments. Inquiries were made about how the HCP prevents a patient's disconnection to care, barriers to care, funding issues, and incentives to promote connection to care. Clients were asked about their perception of care, social stigma experienced, financial constraints that prevented access to care, and transportation concerns. Transcripts were made of all interviews and themes were identified.

4.5. Procedures

The client participants were met at the agreed upon time in the waiting room at the clinic and were escorted to a private room in the clinic. The provider participants were met at the agreed upon time in their office or private room in the clinic. Participant medical records were reviewed for adherence to appointment and treatment data. All participants gave consent to the interviews which were audio-recorded and later transcribed.

4.6. Interview

A semi-structured, one-hour, ethnographic interview was conducted with each participant. The interviews began with broad questions, followed by more focused questions based on the participant's initial responses.

As part of the interview process, a concerted effort was made to identify and quantify specific barriers and enhancers to uninterrupted HIV treatment in rural, southern Georgia. Clients and HCPs were asked specifically what would make care more convenient to relieve both actual and perceived health care burdens.

4.7. Analysis Strategies

Qualitative, ethnographic data analysis of transcribed interviews was conducted using Dedoose 8.0.1. Dedoose is an online program which correlates themes and interpretation of qualitative information. Theoretical concept categories were developed using the illustrative method. These categories are derived from empirical examples and excerpts from interviews. The excerpts are then compared and matched across all interviews. Matches within categories aid and assist in narrowing explanations for the phenomena of interest, which aligns with the theoretical framework.

Themes and categories that emerged align with the Social Cognitive Theory, which served as a basis for this study [17]. The process began by uploading transcribed interviews into the DeDoose program using common coding structure.

The data were then organized by clinic sites. This broad view of the information allowed for a generation of themes in data and to evaluate consistency. Code categories provided the structure for development of themes from interviews. These themes were compared and contrasted in order to validate and substantiate results across clinical sites.

5. Results

5.1. Participant Demographics

Participants included a convenience sample of 10 ethnically diverse providers and 10 clients ($n = 20$). The mean age of providers was 47 years with six women and four men. The mean age of clients was 34 years with six men and four women. The provider participants identified as two Asian/Pacific Islander, two African-American, and six White. The client participants identified as seven African-American, one Hispanic, and two White. All provider participants had graduate school degrees. The patient participants consisted of six with no high school diploma, two with some college experience, and two with a bachelor's degree. The time since an individual HIV diagnosis for the clients ranged from six months to 14 years.

5.2. Provider Roles

Nine of the providers interviewed were nurse practitioners and one was a physician. On average, the providers reported encountering approximately eight HIV-positive clients per day. One provider stated, "I see anywhere from about 15 to 18 HIV-positive clients per day depending on the scheduling and appointment adherence rates not counting the approximate five phone calls per day and numerous emails from HIV-positive clients I respond to on a daily basis."

5.3. Non-Adherence Rate

The rate of non-adherence to treatment was calculated by averaging the data found in the medical record review. Non-adherence for the purpose of this study was defined as missing two or more scheduled follow-up visits within the past six months. The non-adherence rate at Clinic A was 33% and 36% at Clinic B. One provider participant at Clinic A mentioned, "As our partnership with the Department of Public Health (DPH) improves along with the inclusion of a social worker on each case, client expectations from a holistic perspective will be met, so we may expect better medication and appointment compliance because the client will feel as though most, if not all, of their needs, are being addressed."

The following excerpt summarized a provider's opinion at Clinic B.

First of all, I think we need to have HIV management experts come in to help us design a program that addresses not only the best, evidence-based practices to care, but also, potentially more important, the psychosocial barriers to clients receiving HIV treatment. An expert HIV provider would provide a different perspective to the care we offer and be able to offer constructive feedback on

how to build a more resilient and effective program.

5.4. Time Limitations

Based on a provider's view from Clinic A, comorbidities may not be addressed because of a time limitation:

Large portions of our clients have HIV, but they also have other significant disease processes that will eventually affect their day-to-day living. Because of billing and time limitations, I was told to only treat their HIV and refer the patient out for care of other diseases. As a nurse practitioner, I feel as though I should be educating and treating the entire person. I make a referral for hypertension care, for example, and all I can do is hope they make an appointment and have their HTN treated.

5.5. Patient Barriers and Enhancers to Treatment Compliance

Major themes consistent with the literature were discovered through interviews. These themes were categorized into three headings: Personal, social, and environmental factors that influence treatment adherence.

Personal and social factors identified by clients that resulted in at least one period of medical non-compliance included lack of social support from family and friends (60%), participant's lack of disclosure of illness to family and friends (30%), inability to pay for medications (55%), employment interfering with scheduled medical follow-up appointments (70%), insufficient education, as perceived by the client, to understand the importance of follow-up visits (20%). Perceived social stigma of the disease was stated as a barrier for treatment by all participants. Clients who are an intravenous drug user (70%) had a sense of being stigmatized. In published studies, these factors had a significant influence on treatment adherence [10]. Surprisingly, gender and age were not found to have a large effect on participants. However, 100% of the participants mentioned religion and reported a link to a local church. All mentioned their church provided a sense of social support.

Unemployed participants were more likely to be homeless and less likely to continue medical treatment (60%). According to a provider from Clinic A, "Patients have so many personal and social issues to cope with when they are homeless. Approaching this problem from the perspective of the hierarchy of needs, if they are facing homelessness and lack the food to feed their families, adhering to their HIV treatment protocol may be lower on their list of concerns." Participants stated they were more focused on daily survival and the safety of themselves and their children during times of financial challenge.

Client participants identified illicit substance abuse as a personal factor that negatively influenced medication compliance (40%) at some point in their care. Clients stated impaired judgment and diminished disease focus while intoxicated were major negative factors to adherence. A large majority (80%) revealed they restarted their HIV medication regimen within two weeks of discontinuing illicit drug use.

Environmental reasons for HIV treatment nonadherence include a lack of reliable transportation (60%) and pill burden (60%). According to the clients interviewed, health care obstacles included lack of HCP diversity, lack of consistent insurance coverage, availability of care after work hours, and fragmented care related to incomplete referrals.

According to patients, the main enhancers to care include motivation and the will to live (70%) and reaching an undetectable HIV viral load (80%). Helpful environmental factors included positive social support (50%), support from a responsive medical care team (40%), trusted HCP (60%), welcoming clinic setting (90%), and care coordination (70%). Continuity of care was considered a positive and motivating factor to continue treatment and was an underlying theme from all clients interviewed.

6. Discussion

The study's findings identify personal, social, and environmental variables that influenced clients' adherence to ART medication regimens. These findings are consistent at both clinical settings and with previous literature [8] [10] [15]. A provider's positive attitude and perceived engagement in the well-being of the client contributed to the adherence of the prescribed HIV regimen. Providers placed greater emphasis on the effect of psychiatric disorders and patient factors such as illicit drug abuse and food insecurity on treatment adherence above obstacles faced within the health care system [15].

A finding worthy of discussion is how religion is interwoven in almost everything mentioned during the client interviews. Some in the religious community attribute a diagnosis of HIV to what many consider promiscuity [16]. Religion was a comforting factor for some participants but was a concerning factor for others. A common sentiment that was echoed throughout the study includes:

God is my savior and I rely on my relationship with him and the church for support during the good and bad times. I know that He would not give me a burden I could not handle, so that gives me the strength and courage to try and stay healthy for not only my family, but for me. When I feel the worst, I call on Him to help guide me towards a righteous path.

Religion was also identified as an obstacle with insurmountable challenges:

Providers had their own concerns about how to handle the influx of clients coming in to be screened for HIV and/or begin a treatment regimen:

My plan is to be as proactive as possible—I mean I am that way in my personal life. But, as a provider, I feel like I am always responding to crises. We are starting to screen everyone that has been determined to be at high risk for HIV, but when someone screens positive, we do not have a system in place to help them enter treatment right away. When someone screens positive, I am not given the time I need to counsel them... I have 12 minutes per patient no matter what the diagnosis is.

7. Project Limitations

One limitation of the project is the relatively small sample size. A larger sample size may have allowed another limiting or facilitating factor to become obvious. Client participants were chosen strictly by a convenience sample and were selected based on their willingness to participate and be involved in the study. Awareness of the project and its intended outcome may have influenced some responses. Therefore, there is no guarantee that the clients' responses were unbiased.

8. Recommendations

Disease management education highlighting innovative strategies for providers will maximize efficiency and efficacy of time spent with clients [3]. There is a need to develop regional networks for providers to communicate best practices for areas that share geographical and cultural similarities. It is clear most clients desire more information about their illness to not only lead more productive and healthy lives but also to educate their friends and families about the disease [16]. This education should be designed with the intent to alleviate social and cultural stigma of the illness. Approaches to care may incorporate the use of adherence counselors, motivational interviews, care coordination, and text messaging. Incorporating the assumptions of the Social Cognitive Theory such as increasing provider's caring attitudes and reinforcing positive behaviors should enhance disease treatment compliance and client satisfaction concerning perceived quality of care [17]. Treatment adherence may be improved by completing a detailed client history and physical, concentrating on psychosocial elements such as support systems and those in the client's life that remain focused on the health and well-being of the patient [13]. Allowing extra time to gather this information in the beginning of an HCP relationship, leverage can be found to identify a disease treatment regimen that is client-specific with the strength to be resilient over time [16]. The study shows that it cannot be stressed more highly that individual treatment plans are critical for long-term success and viral suppression. This will maximize healthy living years for the client.

While this topic has been researched numerous times, a geographical study that relates to barriers to ongoing care in southern Georgia has not been published. It would be interesting to investigate HIV treatment compliance and religious beliefs which may uncover a positive link between religious activities and HIV treatment compliance. Larger scale studies could investigate the extent to which HCP's education level and sexual orientation affect their perceptions and treatment of PLWH. A study focusing on education of providers at local health clinics about effective and efficient treatment plans to enhance care outcomes is warranted.

9. Conclusion

Several variables emerged as barriers and enhancers to ongoing HIV care in

southern Georgia. Barriers found can be summarized as being related to time, including time off work for appointment and time during appointment to meet all client needs; lack of social support from friends, family, and providers; limited financial resources related to inability to work, lack of insurance, and cost of medications; lack of knowledge related to importance of treatment adherence; and stigma related to disease, sexual orientation, and religion [1]. Enhancers identified include structured programs that provide holistic care; partnerships with HIV experts; and a comprehensive care team that includes physicians, nurse practitioners, registered nurses with specialized HIV training, and dedicated social workers. Increasing HIV treatment compliance will necessitate the improved education of providers, clients, and the public to destigmatize the disease. Sharing of best practices and creating holistic, individualized treatment plans for the individual client is vital [16].

Conflicts of Interest

The author declares no conflicts of interest regarding the publication of this paper.

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