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Barriers and Facilitators to HIV Testing and Linkage to Primary Care: Narratives of People with Advanced HIV in the Southeast

Sandra I. McCoy^{a,*}, William C. Miller^{a,b}, Pia D. M. MacDonald^a, Christopher Hurt^b, Peter A. Leone^{a,b,c}, Joseph J. Eron^{a,b}, and Ronald P. Strauss^c

^aDepartment of Epidemiology, University of North Carolina, Chapel Hill, USA

^bDepartment of Medicine, University of North Carolina, Chapel Hill, USA

^cNorth Carolina Department of Health and Human Services, Raleigh, USA; ^cDepartment of Dental Ecology, University of North Carolina, Chapel Hill, USA

Abstract

Persons with unrecognized HIV infection forgo timely clinical intervention and may unknowingly transmit HIV to partners. However, in the United States, unrecognized infection and late diagnosis are common. To understand barriers and facilitators to HIV testing and care, we conducted a qualitative study of 24 HIV infected persons attending a Southeastern HIV clinic who presented with clinically advanced illness. The primary barrier to HIV testing prior to diagnosis was perception of risk; consequently, most participants were diagnosed after the onset of clinical symptoms. While most patients were anxious to initiate care rapidly after diagnosis, some felt frustrated by the passive process of connecting to specialty care. The first visit with an HIV care provider was identified as critical in the coping process for many patients. Implications for the implementation of recent CDC HIV routine screening guidelines are discussed.

Keywords

HIV Infection; Voluntary Counseling and Testing; Delivery of Health Care; Southeastern United States; Social Support

Introduction

Unrecognized HIV infection has important public health consequences. In addition to limiting the benefits of early medical care including antiretroviral therapy and prophylaxis for opportunistic infections, persons with unrecognized infection may unknowingly transmit HIV to partners (MacKellar et al., 2006; Marks, Crepaz, Senterfitt, & Janssen, 2005). Despite these benefits, unrecognized infection and consequently, late diagnosis, are common among HIV infected adults. In the United States, 40% of those tested in 2004 were diagnosed with AIDS less than 1 year after the initial HIV diagnosis (Centers for Disease Control and Prevention, 2003b, 2006). Further, approximately 25% of all adults living with HIV/AIDS in the U.S. do not know their status, and as many as one-third may not be receiving care (Fleming & Wasserheit, 1999). Even more concerning is that the severity of immune suppression at first presentation may be worsening among some groups (Keruly & Moore, 2007).

*smccoy@unc.edu.

Delayed presentation to care can be attributed to late diagnosis, delays between diagnosis and care, or both (Samet et al., 1998). Most of the research on delayed presentation to care has focused on descriptive characteristics of individuals who present late in the disease course, information often derived from medical records or clinical cohorts (Gay, Napravnik, & Eron, 2006; Keruly & Moore, 2007; Krawczyk et al., 2006a). While these data are informative about the population at risk, without context they limit causal inference and the subsequent design of public health interventions. Few have investigated the availability of voluntary counseling and testing services (VCT) and primary care, the barriers and facilitators to utilizing services, and the personal belief systems which influence the decision-making process. Although VCT and HIV specialty care is widely available in most U.S. settings and safe and effective therapy has extended the life expectancy of those diagnosed with HIV, many obstacles to timely presentation to care remain in the U.S. (Schackman et al., 2006).

Our objective was to understand barriers and facilitators to HIV testing and care among HIV infected persons attending a Southeastern HIV clinic who presented with clinically advanced illness. HIV positive patients in this region of the U.S. may face different challenges than the rest of the country, given the rural nature of the region and the degree to which heterosexual involvement is evident in the epidemic (Krawczyk, Funkhouser, Kilby, & Vermund, 2006b). Through detailed patient narratives, we describe the process of diagnosis and entering care among a unique group of HIV positive patients.

Methods

Study setting and population

The source population for the study was a large, university-based medical center that follows approximately 1,300 HIV infected patients per year and provides comprehensive HIV primary care services. Patients were eligible for the study if they (1) were at least 18 years old, (2) entered care between April 2006 and April 2008 and had not received HIV care elsewhere, (3) had a CD4+ T-lymphocyte cell count <350 cells/mm³ at entry, and (4) were cognitively competent to participate. By purposefully basing study inclusion on clinical criteria, patients with delayed diagnosis as well as patients who postponed entering care after a more distal diagnosis were included in the study.

Recruitment

Eligible patients were approached by a clinic-based research assistant on or after their second clinic visit, once laboratory results were available and the patient had the opportunity to discuss research participation. Interested patients met with the study interviewer before or after their clinic visit or at a separate appointment time. We employed a small purposeful study sample to collect in-depth narratives; data collection was guided by the achievement of theme saturation (Glaser & Strauss, 1967; Ulin, Robinson, & Tolley, 2005).

Data Collection

We identified in-person, qualitative interviews as the most appropriate method for our research question because we sought to understand the process, meaning, and context within which HIV positive persons make decisions about health care (Maxwell, 2004). A single female study interviewer explained the study and obtained written, informed consent at the start of the interview. In-depth, semi-structured, qualitative interviews were then conducted with study participants using an interview guide approach (Ulin et al., 2005). We developed a conceptual framework for VCT utilization based on constructs described in the Information-Motivation-Behavioral Skills (IMB) model and the Health Belief Model (HBM) to inform our interview guide (Figure 1) (Fisher & Fisher, 1992) (Janz & Becker, 1984).

Interviews were audio recorded and averaged 43 minutes. Patients were compensated with a grocery gift card. At the completion of each interview, interview summaries were created to record non-verbal attributes, first impressions, and suggested improvements for future interviews.

Analysis

Interviews were recorded and transcribed verbatim. Analysis was ongoing and first involved single-case analysis, including the generation of memos and interview summaries, followed by cross-case analyses to identify emergent themes and patterns (Maxwell, 2004). A start list of deductive, descriptive codes was used to begin coding, however, coding was continuous and evolving to include interpretive, inductive codes (Maxwell, 2004; Miles & Huberman, 1984; Ulin et al., 2005). Interviews were broadly coded for themes, examined for narrative structure, and compared to the conceptual framework. Coding sorts and sub-themes of each code were evaluated to examine differences in the variation and context of narratives within the same code. Atlas/ti software (Berlin, Germany) was used for analysis.

Human subjects protection

All participants provided written informed consent and HIPAA authorization to access to medical information. This study was approved by the UNC Institutional Review Board.

Results

The study was conducted from April 2007 through April 2008. During this time, 89 eligible patients had visits in the clinic, of which 41 of 46 (89%) approached about the study were interested in participation. Of these 41, 24 (59%) interviews were completed, one person refused, and the remaining 16 people could not be re-located or wanted to be interviewed at another time. Most (67%) patients presented to care with less than 200 CD4 cells/mm³, and most initiated primary care quickly after diagnosis (Table 1).

HIV-related information and experience

Prior to diagnosis, HIV-related knowledge varied. Most participants reported understanding fundamental HIV concepts, including modes of transmission and clinical impact. The media and family members and friends living with HIV were often cited as sources of information. Most (71%) knew someone with HIV prior to diagnosis; however, many held stereotypes about the types of people affected by HIV. There was a dichotomy of people who believed that an HIV diagnosis meant imminent death and those who believed that HIV was a manageable illness.

Perceived susceptibility

Most did not perceive themselves as having been susceptible to HIV infection. The lack of perceived vulnerability could be broadly divided into three themes: people who did not recognize their behavior as risky, people who viewed their behavior as very low risk, and people who felt like exposure to HIV was unlikely, regardless of behavior. Their narratives highlight the lack of susceptibility many participants felt prior to diagnosis and their surprise once diagnosed (Table 2). Several acknowledged engaging in risky behavior, but they felt it wasn't risky enough to expose them to HIV. Others felt that regardless of their personal risk, HIV acquisition was unlikely. Together, these narratives indicate that most felt that their behavior did not place them at enough risk to warrant seeking testing, either because of beliefs about risk behavior or denial of the risks of their behaviors.

Perceived benefits and barriers

Participants were probed about their beliefs prior to diagnosis about the value of seeking VCT services (perceived benefits) and about the material or psychological costs (perceived barriers). We separated benefits from cues to action, which are antecedent events that motivated participants to take action.

Benefits—Overall, few participants identified benefits of seeking an HIV test. Only 3 participants sought testing on their own, and all of them reported a cue to take action (the onset of symptoms or finding out a sexual partner was positive). In general, the facilitating factors to seek testing included being concerned about one's health, wanting to take action in case one was positive, and being able to rule HIV out as a cause of illness.

Barriers—The lack of perceived susceptibility to HIV infection was the predominant barrier to testing. In addition to risk perception, participants listed numerous barriers to accessing VCT services including fear, substance abuse, and the presence or absence of symptoms. One participant explained, "I felt like ... I ain't got it so what's the use of being tested? And then part of me was scared to find out." While stigma was a predominant theme in the narratives about the trauma of discovering one's HIV status, stigma was only mentioned explicitly by one person as a barrier to testing.

Cues to take action

All but one of the participants (who was diagnosed after blood donation) were eventually diagnosed because of an event that incited testing. Most participants (58%) were diagnosed because their provider initiated testing after the onset of symptoms. In some of these cases, HIV was a diagnosis of last resort, in others, HIV testing was recommended because of signs and symptoms consistent with HIV/AIDS (e.g. Kaposi's sarcoma) or factors indicative of a higher risk of HIV infection (e.g. sexually transmitted disease). Several participants described screening events where testing was offered such as prison intake, a testing event at a residential substance abuse recovery program, and screening during clinical examinations. In these cases, participants were amenable to testing when it was readily available and free. Few (n=3) sought testing on their own; two participants sought testing after the onset of symptoms and another after finding out his ex-partner had recently died with HIV.

Connecting to medical care

Most were diagnosed due to symptomatic illness and consequently initiated medical care rapidly thereafter. However, some patients delayed medical care for 12 months or longer, and almost all participants reported having some fears or anxiety about initiating HIV care. Although the psychological impact of HIV was not the focus of this study, it was clear that the shock and devastation of diagnosis with advanced HIV had implications for connection to HIV specialty care with respect to deciding when and where to seek care.

Most patients were anxious to start care after diagnosis. The primary facilitator to enter care was avoidance of illness and death as well as wanting to take control of the situation and begin the journey toward health. When asked about any worries or fears about starting HIV care, a 26-year old man described his sense of urgency to schedule an appointment, "I felt like I was kind of on autopilot ... I have to make this phone call ... you know, because I didn't want to wind up sick."

Patients listed several barriers to initiating medical care. While not a predominant barrier to VCT, stigma was often at the forefront of patient's minds after diagnosis when considering attending an HIV clinic. Patients were worried about being judged by healthcare professionals and being recognized in the clinic. Patients reported not wanting to go through

the ups and downs of care, and a handful expressed a willingness to die rather than deal with the medical system. After diagnosis, six people reported feeling suicidal and of these, four made attempts. The desire to be remembered the way they were prior to getting sick was expressed by several patients. Transportation and financial concerns were rarely mentioned. Three patients delayed care for more than one year after diagnosis; their narratives suggest that the decision and process of engaging and maintaining care can be complex.

Some patients reported challenges when being transferred from one doctor or institution to HIV specialty care. This phenomenon was described by one man as “passing the buck” and often patients felt isolated and frustrated about their healthcare provider’s lack of HIV knowledge (Table 3, quotations 1–2). However, the first clinical visit for HIV care was identified as a turning point in the coping process for some. Up until their first visit in the HIV outpatient clinic, many who were diagnosed by non-HIV specialty physicians felt abandoned, confused, and terrified about the impending medical care to come. Some attempted to research HIV, often online, and felt overwhelmed by the findings. It was not until they met with an HIV specialist that their fears were reduced (Table 3, quotations 3–5).

For some, the first visit was the first time they felt in control since diagnosis. It was a time to allay some of their fears and to learn the basics about HIV pathogenesis and immunologic monitoring, that death wasn’t imminent and that they had time to carefully consider decisions about therapy, and that although antiretroviral therapy may have side effects for some people, HIV can be a manageable disease. During the period from diagnosis until entry to care, patients without this basic information may be paralyzed, suicidal, and isolated as they come to terms with HIV.

Discussion

In the U.S. Southeast, a substantial proportion of people living with HIV are diagnosed or enter care late in the course of illness. In the hospital outpatient clinic where our study was conducted, 75% of all patients have an indication for antiretroviral therapy at their first clinic visit, and 50% have a CD4+ T-cell count less than 200 cells/mm³ (Gay et al., 2006). Likewise, in Birmingham, Alabama, 41% of patients presenting to an HIV/AIDS outpatient clinic had progressed to Centers for Disease Control and Prevention (CDC) defined AIDS (Krawczyk et al., 2006a). These findings and the knowledge of the unique HIV epidemic in the South raise special concerns about access to testing and medical services in the region (Krawczyk et al., 2006b).

Our study examined barriers and facilitators to HIV testing and medical care among a group of HIV-positive patients in the southeastern U.S. who entered care with moderate to advanced immunosuppression. Our findings suggest that lack of perceived susceptibility to HIV was the predominant barrier to early HIV testing. Predominantly, patients were tested and subsequently entered care due to the onset of clinical symptoms, consistent with other reports (Centers for Disease Control and Prevention, 2003a, 2003b; Samet, Freedberg, Savetsky, Sullivan, & Stein, 2001). Most felt an urgency to enter care after diagnosis, but encountered multiple barriers and sources of frustration before entering care. All of those in our study missed the benefits of early medical care and some may have unknowingly transmitted HIV to others.

Our study has several noteworthy limitations. First, clinic-based studies of delayed presentation to care are limited by only including patients who successfully entered care. HIV positive individuals who had not entered care are unobserved, and they may have different experiences than the patients in the study who all eventually entered care. Further, our qualitative study was comprised of a small purposeful sample that cannot be used to

make generalizations or provide insight on to what extent these findings are unique to individuals who presented to care with advanced HIV infection. Despite these limitations, the results of the study have important implications for universal screening programs and linkage to care after diagnosis.

Our findings underscore the barrier that delayed diagnosis poses to HIV prevention. Recent CDC testing guidelines for the adoption of routine testing in all healthcare settings may have an impact on reducing the numbers of individuals who first test positive late in the course of disease (Branson et al., 2006). From a public health perspective, even small changes in the proportion of persons living with HIV/AIDS who are aware of their serostatus can have large impacts in preventing new infections (Pinkerton, Holtgrave, & Galletly, 2008). In our study, most participants accepted testing when it was offered; suggesting that routine screening may increase the numbers of people tested and de-stigmatize the testing process. However, for the program to have impact, people living with unrecognized HIV infection must have contact with the healthcare system. Given that in the Southeast, HIV infection is often a disease of the rural and poor, new strategies to improve health care access will be a necessary precursor for any increased screening to reach the groups most in need.

The fact that public health messages to encourage HIV testing did not reach the individuals in the study who were diagnosed recently, primarily in 2006 and 2007, is concerning. Southeastern residents live within a complex social and structural environment that may elevate their risk of HIV acquisition independent of personal behavior (Adimora, Schoenbach, & Doherty, 2006). Health and economic disparities drive HIV transmission in the Southeast. High rates of sexually transmitted diseases increase the likelihood of HIV acquisition and transmission (Reif, Geonnotti, & Whetten, 2006). The loss of African American men from their communities, either from excess mortality or incarceration, disrupts partnerships and promotes concurrency (Adimora et al., 2006; Doherty, Leone, & Aral, 2007). Stigma, trust in providers, marriage rates, and injection and non-injection drug use are also associated with the epidemic (Reif et al., 2006; Whetten & Reif, 2006). These factors result in frequent heterosexual transmission and a non-urban epidemic (Krawczyk et al., 2006b). It is worrisome that public awareness campaigns for VCT and routine contact with the healthcare system were ineffective in our study population.

Although few participants reported significant delays between HIV diagnosis and entering care, their narratives highlight shortcomings in our system to link newly diagnosed individuals to primary care. As HIV screening becomes increasingly incorporated in non-traditional testing settings, specialized case-management programs to rapidly and effectively link patients to care could bridge the gap between HIV diagnosis and primary care, and allay patient concerns during this unsettling time (Gardner et al., 2005). At least 25% of participants in this study considered or attempted suicide after diagnosis, consistent with other reports (Cooperman & Simoni, 2005; Sherr et al., 2008; Stevens & Hildebrandt, 2006). A study of HIV positive women in New York found that of those who made a suicide attempt after their diagnosis, 86% reported that their diagnosis was very much or partly related to their suicide attempt (Cooperman & Simoni, 2005). It is unclear if the HIV diagnosis acted an “accelerator” or “inducer” of suicide ideation in our study, but this finding warrants further examination to understand risk factors for suicide and whether active referral with follow-up is the optimal standard of care (Marzuk, 1991; Simoni, Nero, & Weinberg, 1998).

Fortunately, the issue of late diagnosis and delayed presentation to care is receiving increased attention among public health and medical professionals. As evidenced by this study, a rote or passive approach to increasing HIV testing and the subsequent linkage to care may miss segments of the population, some of whom are at high risk. A reliance on

personal awareness of risk to initiate testing did not work for this group of people who entered care with moderate to advanced immunosuppression. Many felt disillusioned after diagnosis as they encountered difficulties when trying to navigate the health care system. Focusing research efforts toward these issues may help to avert late diagnosis and delayed entry to care in the future.

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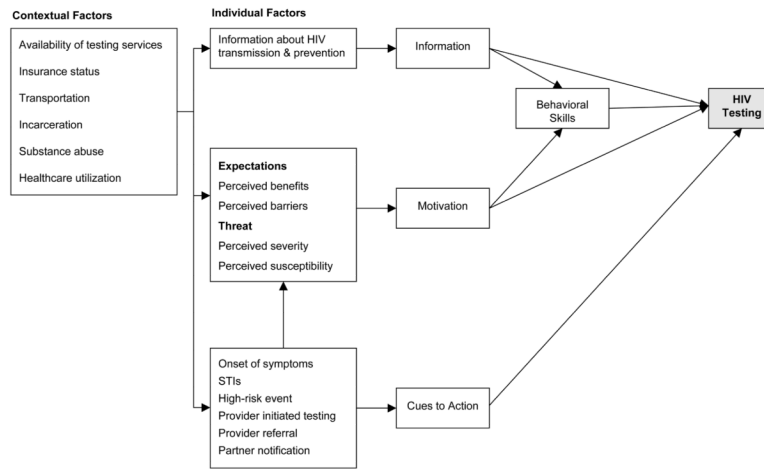


Figure 1. Conceptual framework of HIV testing utilization based on the Information-Motivation-Behavioral Skills model and the Health Belief Model (Fisher & Fisher, 1992; Janz & Becker, 1984).

Table 1

Descriptive characteristics of 24 HIV positive patients initiating HIV primary care between April 2006 and April 2008 at the University of North Carolina outpatient infectious disease clinic.

Characteristic	N (%)
Year of Diagnosis	
1985	1 (4.2)
2005	2 (8.3)
2006	15 (62.5)
2007	6 (25.0)
Gender	
Male	19 (79.2)
Female	5 (20.8)
Race	
African American	12 (50.0)
Hispanic	1 (4.2)
White	11 (45.8)
Age (median, years)	42.5 years (range: 26–62)
CD4+ T-cell count at entry to care (median, cells/ml)	92 cells/ml (range: 17–332)
Time between diagnosis and entry to care (median, days)	40.5 days (range: 0–22.7 years)
HIV testing method	
Provider-initiated	16 (66.7)
Client-initiated	3 (12.5)
Routine screening (e.g., blood donation, prison)	5 (20.8)

Table 2

Illustrative participant quotations about the lack of perceived susceptibility to HIV infection.

Participant Quotations	
1	"I didn't fit any of the, you know, I know I wasn't using drugs, I didn't sleep with men, and ... I wasn't sleeping around, you know."
2	"It wasn't something that had entered in my mind and I always knew that I could get in a car accident or things like that but I didn't think that [HIV] was one of the possibilities, you know? That you could wind up with a disease. I just never really put any thought into that."
3	"It never occurred to me. Actually at one point when I was so sick I thought maybe I have cancer. Never occurred to me the HIV, I was that in denial."
4	"I had tested once ... and I was negative but soon thereafter I was having a lot of unsafe sex practices ... Ignorance is bliss a little bit ... In retrospect it was ridiculous that I didn't go get tested. I could keep myself from a lot of, you know, illness there, the treatment. But, yeah, I think it was just easy to not think about it."
5	"I knew that maybe along my life maybe I did a few slip-ups here and there but nothing that would lead me to HIV. I never had any STDs or venereal diseases so I was like there's no way I have HIV or AIDS."
6	"I knew I was taking some chances when I went out ... I experimented with the same sex but I didn't consider myself to be in that same category if that makes any sense. And ... in my addiction I got careless you know. You really don't have any control over that drug. ... Drugs'll tell you anything and make you believe anything. Couple times it told me that I couldn't get no STD."
7	"The likelihood is just pretty slim ... it's just that I fell on the side of the bad statistic. It's like the girl that has sex once and gets pregnant."
8	"I pretty much knew to get tested and it affected African Americans a lot, especially in the male population. A lot of our women were suffering from it. Being in the homosexual community I knew that it was a big part. Get tested get tested. They promoted at clubs, they promoted at other venues ... I didn't think it would come that close to home. I didn't know anyone who had died from it within my circle."

Table 3

Participant quotations about referral from their primary care physician to HIV care after diagnosis and the importance of their first clinical visit for HIV care.

Participant Quotations	
1	“At that point he [primary provider] completely said ‘well, I have no idea what to do. I’m going to try and get you an appointment at the hospital, but you are very sick and you need help immediately.’ And that was absolutely terrifying to me.”
2	“He’s always like, ‘well, there ain’t nothing I can do for you...but give you a referral.’”
3	“I was really scared, and I said, am I dying? ...She looked at me and said, ‘Look. HIV is not a death sentence anymore if you take care of yourself.’ And that, I live by that now.”
4	“I went in thinking that it was like a death sentence and I came out thinking, oh wow, my doctor rocks, you know? ... To talk to someone who knew what they were talking about for a change. Someone that I understood and someone that knew all the treatments and knew exactly where I was and things like that. I mean I walked out ten times the person that I was, you know. I think I probably walked in looking at the floor and walked out looking at eye level.”
5	“When I first came up here, not knowing what a CD4 count or none of that is, when I come up here I find out my CD4 count, a normal person’s is supposed to be high, I found out mine is under 100, you know, and it’s like that’s a risk of AIDS right there already, and it was really scary. But then once I came in here and talked to [physician], [I] was a lot more relieved. It was a lot easier when I walked out the door.”