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Missed Opportunities for Early HIV diagnosis: Critical Insights from Stories of Kenyan Women Living with HIV

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Abstract

Early HIV testing is critical to prevention and timely treatment. Missed opportunities for HIV diagnosis can result in unnecessary deaths at a time when access to antiretroviral treatment proves life saving. While HIV prevention and treatment research has increased, less research exists on women's experiences with HIV diagnosis, despite the fact that women are most affected. Insights from local women are critical in designing culturally meaningful interventions that thwart missed opportunities for early HIV diagnosis. The purpose of our study was to uncover steps women took to know their HIV diagnosis. Using narrative inquiry methodology informed by post-colonial feminism, we interviewed 40 HIV- positive women in Kenya. Five themes emerged related to uptake of HIV testing for women: (a) spouse's critical illness or death; (b) years of suffering from HIV-related symptoms; (c) sick children; (d) prenatal testing; and (e) personal desire to know one's HIV status. These findings centered on women experiences provide an important basis for health promotion interventions related to HIV prevention, earlier detection, and treatment.

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Conflict of interest statement

The authors report no real or perceived vested interests relating to this article (including relationships with pharmaceutical companies, biomedical device manufacturers, grantors, or other entities whose products or services relate to topics covered in this manuscript) that could be construed as conflicts of interest.

Keywords

early HIV diagnosis; HIV-positive women; qualitative study; missed opportunities; Kenya

Introduction

Lack of early HIV diagnosis results in possible illness transmission and stymied opportunities for life saving treatment (UNAIDS, 2010). Previous studies indicate that early HIV diagnosis is key to saving lives (Drew & Patel 2011). Even so, women in Kenya are often diagnosed late, some after their husbands have died of AIDS (Kenya Aids NGOs Consortium [KANCO], 2002). Without creative interventions, women will continue to die leaving children orphaned by AIDS. Orphaned children, especially girls, are less likely to attend school, which perpetuates a cycle of poverty that places women and girls at an initial risk for HIV.

Measures for early HIV diagnosis are crucial in for controlling this epidemic, because late diagnosis increases the probability of transmission since persons unaware of infection often have higher viral loads and are less likely to adopt safer sexual practices (Marks, Crepaz, & Janssen, 2006). In addition, high HIV viral load levels and low cluster of differentiation antigen 4 (CD4) cell counts might weaken client's response to antiretroviral treatment (Sobrinho-Vegas et al., 2009).

In Kenya, where HIV is largely heterosexual and women are most affected (NASCO, 2008); individual protection is not in line with the family structure in which Kenyan women find themselves (Njue, Rombo, & Ngige 2007). Under recommendations from the United Nations, the Ministry of Health in Kenya, first advocated a client-initiated, opt-in approach to testing in which clients needed to request testing after undergoing a detailed consent process (CDC, 1993). Though successful, this approach emphasized requests for individual testing; hence those who did not perceive their HIV risk were not tested (World Health Organization [WHO] & UNAIDS, 2007). Recently, the Kenyan healthcare system, in attempt to scale-up universal access to HIV testing (UNAIDS, 2010), shifted to opt-out and provider-initiated strategies as per the latest Centers for Disease Control HIV testing guidelines (Branson, 2006; NASCO, 2008; WHO & UNAIDS, 2007). As more providers adopt opt out provider-initiated approaches, the need to shift from an individual focus to family focus emerges, (Njeru, Blystad, Shayo, Nyamongo, & Fylkesnes, 2011). There is also an urgent need to identify how women learn of their HIV diagnoses in order to pinpoint missed opportunities for earlier diagnosis. Though recent studies focus on factors leading to potential missed opportunities, it is also necessary to study women's diagnostic journeys to help eliminate missed opportunities for testing (Druce & Nolan, 2007; Njeru et al., 2011)

Method

This study aims to document how women came to know their HIV diagnosis, and to identify missed opportunities for early HIV diagnosis as an opportunity for health promotion. Narrative inquiry methodological approach informed by post-colonial feminism underpinned this study. An amalgam of interdisciplinary analytic lenses and methods, narrative inquiry revolves around interest in biographical first-person particulars (Chase, 2005; C. Reissman, 1993; C. K. Reissman, 2008). The women's roles in patriarchal societies where gender power relations permeate their everyday lives warrant our use of post-colonial feminism praxis. Our application of post-colonial feminism theory emphasizes the world of women while recognizing their existence in patriarchal society (Gortner, 1993).

Through narrative in-depth interviews, we sought to elicit women's experiences with HIV diagnosis, while recognizing each woman's HIV illness trajectory. In this study we interviewed 40 women (20 rural and 20 urban) Kenyan women who self reported as HIV-positive. Based on Morse's (2000) sample size criteria, the scope, nature of phenomena, and anticipated quality of data suggest our sample size was adequate to address this study's specific aims.

Setting and Data Collection

To recruit participants, we used purposive sampling, a deliberative approach by which we invited women to share experiences learning of their HIV diagnosis. Data were collected by the first author who is fluent in Kikamba, Kiswahili, and English. Audio-taped interviews were conducted in April and May of 2006. Prior to the interviews, clinic nurses met with the women and introduced the study. Then the first author met with each participant to further explain the study to obtain informed consent and permission for audio-taping. With informed consent, standard demographic information was then collected, followed by open-ended interviews of approximately 90 minutes. Because sharing stories builds rapport, we encouraged participants to relate experiences living with HIV including personal anecdotes on seeking health care as woman living with HIV (Hall, Stevens, & Meleis, 1994).

We chose unstructured interviews to elicit women's descriptions of medical needs and process of discovering HIV status. Questions included; "How did you find out you had HIV" and "What has happened since you found out you had HIV?" Prompts were used only to encourage storytelling or to request clarification after the participant finished speaking. No monetary compensation was provided for participating in the study, but participants received bus fare, and a token of two kilograms' wheat flour and one half liter of cooking oil. All study procedures were approved by the Institutional Review Board of the University of Wisconsin-Milwaukee, Government of Kenya Ministry of Education Science, and Technology, Kenya National Hospital (KNH) Ethics and Research Committee.

Data Analysis

Taped interviews were transcribed verbatim in Kikamba, Kiswahili, or English. Segments of the transcription used for this study were translated into English by the first author and an equally proficient translator, who then compared translations to the originals, adjusting as necessary to ensure congruency, and develop a topical codebook. Data were interpreted through narrative analyses (Kako, Stevens, & Karani, 2011). Adherence to standards of rigor established by Hall and Stevens (1991) helped ensure scientific adequacy. In summer 2007, preliminary findings were presented to Kenyan researchers, HIV clinicians, participants, and groups of interested HIV clinic patients in urban and rural locales, and we incorporated their feedback as we finalized conclusions. Herein we focus on narrations concerning missed opportunities for early HIV diagnosis, we report elsewhere findings on women's reactions to HIV diagnosis, transmission risk, and challenges faced in accessing healthcare (Kako, Karani, & Stevens, 2009; Kako et al., 2011; Kako, Stevens, Karani, Mkandawire, & Banda).

Sample Description

The mean age of all study participants was 37 years (range: 26 – 54). The majority of the participants were either married 40% ($n=16$) or widowed 38% ($n=15$), two had a long-term partner, one was separated, and another one an *ĩweto*¹ (Njambi & O'Brien, 2000). Rural participants were more likely to be widowed (60%) and urban participants more likely to be

¹*ĩweto* is a woman-to-woman marriage for the purpose of bearing children to the older woman who does not have children. *ĩweto* forms relations with men for the purpose of conceiving and bearing children to raise a family for the woman she marries. All the children born by *ĩweto* belong to the woman who brought her to the family.

married (60%). Participants had an average of 4 children (range: 0 – 10). Women in the study were poor, with incomes below the international poverty line of \$1 per day. The average length of time since diagnosis was three years (range 1-10 years). Despite the fact that most of the women were less than five years from diagnosis, the majority were already symptomatic with self-reported CD4 counts of less than 250 cells/ mm³.

Results

Because we did not find significant differences between rural and urban women narratives on discovering diagnoses, we evaluated all women narratives for emerging themes. Analyses revealed five themes on missed opportunities for early HIV-testing, namely: (a) spouse's critical illness or death; (b) years of suffering from HIV-related symptoms; (c) sick children; (d) prenatal testing; and (e) personal desire to know one's HIV status. (see figure 1).

Spouse's Critical Illness or Death

Women who discovered their HIV infection after spousal illness usually has a long delay in diagnosis—in some cases, years. Some women found out that their husbands were suffering from AIDS at the brink of the husbands' deaths, when they were offered testing, usually after long periods of recurring illness. As one woman explains:

Because of his [husband's] many health problems when he was tested he was found to be positive, but it was the last minute, he was very weak. They told me it was good that I, too, get tested. I was tested and found to be also positive.

Another woman related:

My husband was in hospital three times in 2003. In May that year, he had a mouth wound that was bothering him a lot. In October, he started getting really worse, such that he was near death, that's when I told the doctor to please test him, he was found to be positive, his was already AIDS. I was then tested found to be positive. He died after two days.

These delays in testing and subsequent HIV discovery following spousal illnesses echoed throughout the narratives. Women searched for causes of their husbands' frequent illnesses, consulting multiple healthcare facilities, and begging their husbands to get tested, but they themselves were not offered HIV testing. As one woman painstakingly narrated: "He [husband] refused to be tested. He denied. Not once did he accept that he might have the virus and I was not offered testing"

Another woman, after a long period of time seeing her husband experiencing frequent illnesses, finally took it upon herself to get tested for HIV:

He [husband] was sick all that year, he had nose bleeding, and he had TB. So I thought here the way these illnesses were occurring so frequently, I decided to go finally get tested. I was found to be positive.

As in the story above, diagnostic confirmation sometimes occurred before women themselves were ill, but generally, HIV testing occurred after their husbands became critically ill or died, mostly after years of making trips to various healthcare facilities. As one woman concluded:

This illness I can say it has put me back, because I sold the children's land. Yes, while I was helping that husband of mine get treated. I sold about one acre so that I can get money to pay the hospital admission fee.

Years of Suffering from HIV-related Symptoms

Some women spent years suffering from their own symptoms before receiving a diagnosis. They described a chronology of progressively more serious illnesses for which they sought help including: typhoid, amoebic infections, malaria, skin rashes and lesions, herpes zoster, pneumonia, and tuberculosis. In the context of the Kenyan healthcare system, the focus was on sporadic symptom management, so they were not routinely offered HIV testing. Women narrated long periods of going back and forth to the health care providers (in Kenya, most providers are community health workers, community nurses, or clinical officers) without getting better, until they were finally tested for HIV. As one woman explains:

Let us talk about 2003 issues, because that is when I had TB. Often I would have malaria, pneumonia. I didn't know what it was. I started feeling sharp pain from my chest to the back. I suffered a lot. Then I started having eye problems, when I sought care for my eye, the eye doctor told me I had an eye growth which in most cases is usually found in people with HIV, he told me I should go and get tested. I was found to be positive.

Another woman spoke of frequent encounters she had with healthcare providers without being offered testing, and finally decided to be tested after listening to a radio program:

One day, I was listening to a radio program about HIV that was on a Wednesday at 2 pm. It was like I had all the symptoms, all the problems they talked about. I just decided if it is to make me die, I am going to die, so let me go and know. I went I was tested, I was found to have HIV.

The route to HIV discovery was also marked by hesitation, uncertainty, and confusion in the midst of compelling symptoms, as the following excerpt illustrates:

For me, how I found out that I was HIV positive took a long time. I started having facial rashes. So I started going to the doctor because I wondered where these painful pimples were coming from. The doctor gave me lotions, medications; he was giving me prescriptions of soaps to go buy, but nothing helped, after a long time he finally tested me, he showed me my results, 'You see here.' I told him it is written positive. I felt my whole body go cold. I asked the doctor, 'you mean I have AIDS?'

Sick children

Some women cared for children who were sick from HIV infection before their own HIV infection was diagnosed. In some cases, women delayed their own testing because lacked funds; as one woman shares: "I had my son tested first because it's the only money I had with me, and my son is the one who had most health problems I had him tested first."

Prenatal testing

Only two women in our study discovered their HIV infection at pregnancy. One of them, was tested for HIV after losing her pregnancy to complications, "I was pregnant 8 months, and then I miscarried. That's when I knew about this -that I was HIV positive."

Even though many women had multiple contacts with the health care system while pregnant, reports of routine HIV testing at pregnancy were almost nonexistent for our participants, suggesting yet another valuable opportunity for HIV testing in the Kenyan healthcare system. The participant quoted below was diagnosed with HIV during a pregnancy, but opportunistic infections prompted testing:

So the first time I was tested for this particular disease was when I was pregnant, when I was 7 months pregnant with my second child. I didn't know [my HIV

status] with the first child; they didn't test me. What happened actually, I suffered malaria. I was admitted and treated for malaria, and not until I developed pneumonia did they offer me HIV test. I was found to be positive.

Personal desire to know own HIV status

Only one woman out of the forty women interviewed discovered her HIV status out of personal desire to know in the absence of any familial illness. However, this action was accomplished against resistance from her husband:

I told my husband many, many times, like over a period of six months. And then he told me I should not go for the test. He refused me many times. He told me, 'if you go for the test and you test positive, don't come back crying to me.' Then, me, I thought it was a joke. Me, I went, and I was positive.

To help reduce the delay of HIV diagnosis, participants recommended family-focused testing, as many women recalled going to multiple facilities without ever being offered HIV testing. Our findings show Kenyan women often delay seeking health care for their own symptoms, but do seek medical services for family members. Particularly in rural areas, women were diagnosed only after exhibiting AIDS-related illnesses. Thus, most women dealt with their husband's critical illness (or death) and their own HIV-related symptoms over many years before knowing their diagnosis. As the women's stories confirm, in Kenya women are the central characters of the HIV illness in their families. Their insights inform critical points for transformational interventions focused on all points of access to medical care for both themselves and family members.

Discussion

Women shared multiple ways through which they came to find out their HIV status. In some cases, women's routes to discovery of their HIV status were unnecessarily long; in many cases, women suffered recurrent symptoms for learning their symptoms were HIV-related. These narratives identify several critical moments for early HIV diagnosis in relation to women's family roles, including while they sought care for ill relatives or early in prenatal care. That only a few women discovered their HIV infection because of wishing to know their status in the absence of symptoms is important. Some women delayed testing because they did not think they were at risk, even though they exhibited signs of HIV.

Our findings corroborate previous research on women in Kenya, who are family caretakers and are often last to be diagnosed as they are apt to take care of their sick family members first (Chu et al., 2010; Nyandiko et al., 2009). Additionally, some women delayed testing as they did not think they were at risk for contracting HIV, despite their symptoms, or could not afford testing.

Other researchers in sub-Saharan Africa have documented similar delays in healthcare access among women living with HIV (Chimwaza & Watkins, 2004; Hayes, et al., 1997; Phipps et al., 2010). Similarly, Plummer et al., (2006) found that, believing symptoms stemmed from bewitchment, HIV-infected women first used up any available money for treatment on traditional healers. Our findings suggest emphasizing family-focused HIV care might reduce HIV testing delays. Knowing one's HIV status early and receiving necessary treatment and counseling might delay the development of opportunistic illnesses, which saves lives, improves quality of life, and lessens costs for the family.

Limitations

Although we wanted to learn about how women access HIV care, we studied women who already knew their HIV positive status thus, expanding research to include the general community could offer a broader understanding of how women access HIV-related healthcare in Kenya. Our study findings may be transferable to situations and groups similar to those studied (Lincoln & Guba, 1985).

Implications for Practice

This study has important implications for healthcare providers' role to reduce missed opportunities for early HIV diagnosis in women. With most doctors practicing in urban areas while the majority of the Kenyan population (70%) lives in rural areas (Kenya National Bureau of Statistics (KNBS) and ICF Macro, 2010), adopting an effective family - focused model of early HIV diagnosis would lessen the need for health care specialists, who are often in short supply, but critical to the treatment of opportunistic infections in advanced HIV illness. When HIV illness is diagnosed early, there are fewer complications, enabling healthcare providers and educators to approach HIV as a family illness, while reducing cost.

In suggesting a family-focused HIV care approach, we wish to reinforce the strengths of women in their families. The authors recognize that the diagnostic period can be filled with intense emotions ranging from anger to depression and suicidality, so there is a need for all family members to receive pretest counseling (Kako, Stevens, & Karani, 2011). Early, family-focused psychological counseling might help curtail repercussions for women (Angotti et al., 2009), and might mean joint clinic days, or staggered clinic days tailored to the needs of each family (Felder & Kwatampora, 2009). The impact of HIV diagnosis—and in our case on multiple members—demands a streamlined support system for families, including referral to support groups.

Researchers, health care workers, and policy makers can utilize women's evaluation of HIV as a family illness to design family-focused programs that center on early diagnosis and treatment, and help alleviate unnecessary suffering for women and their families. Such programs would be grounded in the strengths and the capacities of Kenyan families. Healthcare providers and policy makers could benefit from hearing the voices of women who are caretakers to family members living with HIV, then base health promotion practices on these realities. Incorporating family-focused approaches to HIV testing and treatment is critical for management of this devastating illness.

Conclusions

Engaging women in HIV related programming and interventions, such as efforts to ensure early HIV diagnosis, is necessary to eliminate unnecessary early deaths from late diagnosis. Women's knowledge can be best applied through family-focused approaches that consider women's roles within the context of the Kenyan family as they seek treatment for themselves and family members (Tonwe-Gold et al., 2009). To further discover culturally appropriate interventions for early diagnosis in Kenya, more studies that consider the intricate roles of women are needed.

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Figure 1.
HIV diagnosis opportunities for Kenyan women