Published in final edited form as:

Glob Public Health. 2012 December ; 7(10): 1095–1108. doi:10.1080/17441692.2012.701318.

“Slipping through the cracks”: Policy implications of delays in HIV treatment seeking

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Abstract

Public health initiatives to “test and treat” HIV infected persons require understanding HIV care seeking. A study of 101 HIV infected women receiving anti-retroviral medications in Kampala, Uganda examined barriers to HIV care. Participants entered HIV/AIDS care late, despite knowing their risk and having sought care for symptoms. Over half the participants (51%) reported delays of up to 5 years from when they *suspected* they were infected to seeking an HIV test. Some women reported that they did not perceive a need to be tested since they “knew” they had HIV due to their partner’s death from AIDS. Once tested, delays in entering HIV specific care ranged from less than 6 months to over 5 years. The most common reason reported for entering HIV care was the occurrence of serious or persistent symptoms. Late presentation for HIV care in this cohort is due to the inability of the medical system to link women to appropriate care. Women “slip through the cracks” of this system, despite their care seeking behaviours. The inability to provide linkage to care is a challenge at the health system level that threatens the hoped for success of “test and treat” protocols.

Keywords

Uganda; HIV care seeking; AIDS treatment access; test and treat

Introduction

In the last five years HIV/AIDS prevention programmes have undergone a dramatic shift, towards a greater focus on secondary prevention. This shift derives primarily from data demonstrating the value of HIV/AIDS treatment as a means to decrease HIV incidence by decreasing infectivity of infected persons (Montaner *et al.* 2006, Granich *et al.* 2009, Dodd *et al.* 2010). The “treatment as prevention” approach is hailed as a means to bridge the gap between prevention and treatment (Fauci 2011). To succeed, however, “treatment as prevention” relies on identifying HIV infected persons and providing lifelong therapy. This approach, dubbed “seek, test, treat, and retain” (more commonly “test and treat”) is the centrepiece of “treatment as prevention” protocols. Mathematical models have highlighted the potential impact of “test and treat” on the course of the epidemic (Granich *et al.* 2009, Dodd *et al.* 2010). As research has established the feasibility of providing HIV testing in different settings (Denison *et al.* 2008), there is increased global attention to the “test and treat” approach.

This emphasis on “test and treat” calls for renewed attention to the implications of health care seeking patterns to the likely success of “test and treat” programmes. Gardner *et al.* (2011) discussed the range of issues impacting the success of “test and treat”, including the imperative that people remain “engaged” in HIV care, even if they are not medically ready for antiretroviral medications (ARVs). In considering the discouragingly low rates of engagement in care reported for US populations (Gardner *et al.* 2011, Marks *et al.* 2010), Lange (2011) asks ““Test and Treat’: Is it enough?” Research shows that current strategies to expand HIV testing fail to fully recognise the difficulties in engaging and retaining HIV infected or at risk persons in care.

As more data become available regarding difficulties in achieving the public health goals of “test and treat” and “treatment as prevention” there is need to identify factors that influence the likely success of these programmes. As such, the “test and treat” and “treatment as prevention” protocols highlight the importance of understanding when, where, and under what circumstances people seek and are able to receive HIV testing *and* treatment (Lange 2011).

In this paper we report on a study of HIV treatment seeking in women in Kampala, Uganda. The study sought to identify factors influencing the ability of HIV infected women to initiate and maintain HIV care and treatment. As such, our study contributes to the discussion of the likely success of “test and treat” programmes in this setting.

Similar to the findings reported by Lessell *et al.* (2011), women in our study of HIV treatment seeking experiences entered HIV/AIDS care late. This occurred, however, not because they were unaware of their risk or because they failed to seek biomedical care. In fact, women sought and received care for symptoms they experienced. They did not receive HIV specific care until late in the disease spectrum. For this reason, we argue, late presentation for HIV care in this cohort results not from the individuals’ failure to present for care but rather from the inability of the medical system to consistently link women to the care they need in a timely manner. In this way, women “slip through the cracks” of this system, despite their own care seeking behaviours. This inability to maintain continuity of care represents a challenge at the health system level. We conclude the paper by considering these results in terms of recommendations to enhance current efforts to “seek, test, treat and retain” HIV infected persons.

BACKGROUND

A health care seeking framework

Health care seeking is a process that unfolds over time, influenced by a range of personal, contextual, and social factors (e.g., Janzen 1978, Hatchett *et al.* 2004, Uphold and Mkanta 2005). Numerous models in the literature describe factors that influence health care seeking and how these variables relate to one another (for a review see Scrimshaw 2006). Despite differences between models, they share core elements which focus on a set of individual perceptions: perception of risk of getting the condition, perception of the severity of the disease or symptoms, and perception of the benefit of health care seeking (Scrimshaw 2006).

Social scientists view care seeking as a social process involving families and social network members in both care giving and care seeking (e.g., Janzen 1978, Ntozi 1997, Mafigiri 2007, Mafigiri *et al.* 2011). A central component of anthropological understanding of health care seeking recognises that people consult multiple sources of advice and care throughout an illness. This approach is particularly well suited to understand HIV care seeking for two important reasons. First, the HIV treatment seeking process is an especially lengthy one because HIV treatment seeking extends from infection to testing to initiation of and

retention in medical care. This highlights the importance of understanding factors that influence care seeking at different stages. Secondly, HIV/AIDS remains a stigmatised disease and, therefore, care seeking occurs in a context in which disclosure of HIV status may not have occurred and may not be desired (Unge *et al.* 2008). These two facts highlight the need to examine HIV/AIDS care seeking in a broader context that considers both availability of care and the range of experiences encountered in accessing care.

Delays in health care seeking

Research to date has found that HIV infected persons often report delays in seeking HIV care. As reviewed by Gardner *et al.* (2011) and others, delays in entering HIV care have been reported between infection and testing (e.g., Porter *et al.* 1993), between testing and presentation for care (e.g., Samet *et al.* 1998, Turner *et al.* 2000), and between onset of symptoms and presentation for treatment (e.g., Poznansky *et al.* 1995). Samet and colleagues (2001) propose a five-stage model of HIV care seeking from infection to presentation for primary medical care that incorporates cases where people “skip” directly from infection to later stages of the disease. This occurs primarily as a result of testing undertaken to fulfil certain programmatic requirements (e.g. for military service).¹

Numerous studies have identified variables which contribute to sometimes quite lengthy delays in seeking HIV testing (e.g., Stein *et al.* 1991, Wortley *et al.* 1995, Couturier *et al.* 1998) and in seeking medical care after testing (e.g., Godfrey-Faussett *et al.* 2002). These factors include: history of drug use, poor social support, lack of perceived risk (Samet *et al.* 1998, Samet *et al.* 2001), or demographic characteristics (Girardi *et al.* 2000, Hocking *et al.* 2000, Meredith *et al.* 2001, Klein *et al.* 2003), and health sector factors such as lack of insurance (Milberg *et al.* 2001, Turner *et al.* 2000), not having a regular source of care (Turner *et al.* 2000), dislike of provider approaches (Mallinson *et al.* 2007), or physician failure to assess risk (Klein *et al.* 2003). In Gabon, delays in seeking care have been attributed to a failure to seek biomedical care in favour of non-biomedical providers for early symptoms (Okome-Nkoumou *et al.* 2005). Lessells *et al.* (2011) note the importance of symptoms in leading to initiation of HIV care. In this paper we report data from Uganda on delays in care seeking and discuss the implications for test and treat protocols.

Recent history of HIV/AIDS care and treatment in Uganda

Between 2001 and 2009 there was first a decline (Mbulaiteye, 2002) and then a plateau in new HIV infections in Uganda (World Health Organization 2010, UNAIDS 2010, Ministry of Health 2010). This stabilisation was attributed in part to changes in the HIV testing and treating environment, including increased focus on provider-initiated, opt-out HIV testing, expansion of programmes for prevention of mother to child transmission (PMTCT), and increased availability of cheaper and later, free drugs.

Even with this decline, HIV prevalence in Uganda is unacceptably high; remaining stagnant at 6–10% since 2002 (United Nations General Assembly Special Session (UNGASS) 2010). Alarming, current data suggest that risk behaviours are increasing in some segments of the population in Uganda (Shafer *et al.* 2008, UNGASS 2010). Women are slightly more likely to have received an HIV test (4% of women and 3.8% of men) but most Ugandans do not know their HIV status (UNGASS 2010). Estimated overall prevalence for ages 15–49 years is 6.4% (UNGASS 2010); 7.5 % for women and 5% for men (Uganda AIDS Control Program 2010). Rates in urban areas (10%) are higher than in rural areas (6%) (UNGASS 2010). However, given an increase in the young, most at risk population between 2002 –

¹We refer to this type of testing as “structural testing” because it is required for certain activities (e.g., travel) and, although voluntary in one sense, it is not undertaken due to suspected risk or known exposure to infection.

2010, even with a stable prevalence, the actual number of people infected will continue to increase.

In Uganda, provider-initiated routine HIV counselling and testing is increasingly viewed as a means to identify early stage HIV-related conditions. This approach differs in important respects from traditional voluntary HIV counselling and testing (VCT) because it does not require a patient to specifically seek an HIV test. Provider initiated testing, therefore, does offer the possibility of identifying early cases, especially in persons who lack recognised risks or do not perceive themselves to be at risk. Provider initiated testing, however, poses different challenges including the need to educate more providers to test and to provide necessary resources for testing at different health service facilities. Home-based VCT programmes are also promoted as a means to increase access to ART (Wolff *et al.* 2005; Were *et al.* 2003). To date, however, there is only limited evidence that scale up of home based VCT is feasible in Uganda (Bateganya *et al.* 2007, Tumwesigye *et al.* 2010, Sekandi *et al.* 2011). Ultimately, the challenge of retaining HIV-infected persons in care remain significant, especially if they do not have symptoms they attribute to HIV or have to make substantial effort to obtain services. Therefore, although provider initiated testing may ultimately change the landscape of testing and treatment, at present Uganda continues to rely heavily on client-initiated, facility-based VCT.

In Kampala, the Joint Clinical Research Centre (JCRC) began providing antiretroviral medications on a fee basis in 1992. At the time of this study in 2002, JCRC was the largest provider in the country, receiving approximately 50% of all referrals for AIDS medications in the Kampala area. JCRC is the first Centre of Excellence for AIDS care, treatment, research, and training in Uganda. Services include testing and counselling as well as ongoing medical supervision, laboratories, and a pharmacy.

Since this study ended, the number of health facilities providing medications has greatly increased, including all levels of the Ugandan health care system. As is true elsewhere in the world, expansion of programmes to PTMCT has resulted in more testing and treatment. All told, however, the current “scale up” has not met the need. Treatment coverage remains low; only 53% of those most in need receive ART (UNGASS 2010). However, this figure must be considered in conjunction with the 2010 recommendation to raise the CD4 count level at which to initiate ART from 200 to 350; a change which will result in more patients being moved onto ART, thereby increasing the number of patients on ART (UNITAID, 2010). Under these criteria, treatment coverage is estimated to be only 34%. In other words, the number of people needing ART remains remarkably high; some estimates are that nearly 65% of those in need do not have access (UNITAID, 2010).

Furthermore, shifting priorities of the largest funders of expanded treatment programmes, the Global Fund to Fight AIDS, Tuberculosis, and Malaria (Global Fund) and the US President’s Emergency Plan for AIDS Relief (PEPFAR), is leading to a reduction in funding for treatment (Glauser and Simon 2010). As a result, in Uganda some treatment sites have closed and others take no new patients (Glauser and Simon 2010).

In this context, it is urgent that we understand the challenges facing the global effort to provide adequate care. For this reason, the issues identified by this study remain relevant to the current situation. To understand factors affecting ongoing access to care, we interviewed women receiving treatment to ascertain how and under what circumstances they initiated HIV/AIDS care and treatment at JCRC and what issues they face in remaining in care.

Objectives

This study examined women's experiences in accessing HIV care in Kampala with the ultimate goal of identifying avenues to enhance access to care. The study, therefore, employed a health care seeking approach, including consideration of perceived and actual barriers to care seeking as described by a sample of women receiving HIV medications. Providers' perspectives on patients' needs are reported elsewhere (Rundall *et al.* 2004).

METHODS

We conducted a cross sectional, retrospective study of care seeking among HIV infected women (N=101) in Kampala, Uganda, focusing on barriers women encounter in accessing HIV care. Women were recruited at JCRC between 2002 and 2003. The sample size was determined based on patient flow and patient load at the time. To be eligible for inclusion women had to be attending JCRC for HIV treatment and be 18 years of age or older. The study protocol was approved by the Institutional Review Boards of Case Western Reserve University and the Joint Clinical Research Centre and the National AIDS Research SubCommittee of the Uganda National Council for Science and Technology.

JCRC patients meet with a counsellor prior to seeing either a physician or a pharmacist. Study recruitment was assisted by the JCRC counsellors, who asked every third HIV infected woman if she might be interested in the study. If so, she was introduced to the study interviewer who described the study, determined eligibility and obtained informed consent.

Participants completed one semi-structured interview conducted by trained interviewers. Interviews collected demographic data, health care seeking decisions and perceived social network support for health care seeking. Knowledge and attitudes about HIV treatment were assessed by perceived efficacy of treatment, perceived risks and benefits of treatment, and knowledge of treatment options and protocols.

Frequencies and descriptive statistics were generated using SPSS (v. 11.01) and responses to open-ended questions were entered in NVivo v. 2.0 for analysis. Each interview was read and coded for themes (SAB), which were analysed for frequency.

RESULTS

Study participants

The average age of the women was 36 years (range 20 – 62 years, SD = 7.3). One third of the participants were widowed (N = 35, 35%) and another third were married (N = 35, 35%). Most participants had 1–3 children (N = 58, 57%), with a third having four or more children (N = 32, 32%). Participants lived in multi-person households and just over a third (N = 38, 38%) care for others outside their household. The majority of participants completed secondary level (N= 47, 46%) or some tertiary education (N = 42, 42%) (Table 1). All the women were paying for medications, either directly or with assistance from others.

Delays in seeking testing and treatment

Women's illness narratives describing HIV/AIDS treatment seeking typically depict a process unfolding over months and years, often characterised by lengthy delays in seeking HIV/AIDS care. Two types of delays can be identified in the women's stories. First, delays occur between the time when she first suspects that she might have HIV and when she seeks an HIV test (delay 1). Second, delays occur between when she learns that she is HIV infected and when she seeks treatment (delay 2) (Table 2).

Delay 1: Lag between suspicion of HIV and an HIV test (Table 2)—Twenty seven women (27%) reported delaying less than 6 months from when they *suspected* that they were infected until seeking an HIV test. This includes 8 women (8%) who reported that they sought HIV tests as soon as they suspected that they might have HIV, with no delay. Seven women (7%) waited more than 5 years to get tested. The remaining women (51, 51%) reported delays up to 5 years. Sixteen women (16%) reported that they never suspected that they had HIV but were tested for various reasons including couples pre-marital testing, a doctor's recommendation, in response to symptoms, or because her husband disclosed his status.

For women who tested within six months of suspecting infection, motivations included death of a husband, learning the HIV positive status of a partner or child, or having symptoms suggestive of TB or herpes. However, other women delayed testing because, in the absence of symptoms, they did not perceive a need to be tested since they already “knew” their status due to their partner's death. Overall, 30.7% of women stated that their decision to be tested was because of illness or death of a partner, whereas 22.8% of the cases tested due to her own illness. The next most common motivation for testing was advice from a doctor or other person (18.8%).

The participant quoted below suspected that her husband had died of AIDS yet she did not get tested until she became ill herself.

“My husband died 4 years ago ... He died of AIDS which quickly developed in a period of 8 months ... still denying that he had HIV but I saw the symptoms and *knew that we were infected*... I watched my health without necessarily testing for HIV because *I knew I had it anyway*. It was not until 2002 that I decided to seek serious medication after an attack of pneumonia had almost taken my life... The test result of positive did not surprise me because I already had suspected having seen my husband through his AIDS disease. I immediately began on ARVs ...”
(Emphasis added). (Widow, 32 years old)

This kind of “knowing without testing” can impact the success of prevention and treatment strategies if access to care is linked to testing but not to other primary care services.

Delay 2: Lag between positive HIV test and treatment seeking (Table II)—

Delays between testing and entering care and treatment ranged from less than 6 months to greater than 5 years. Delays at this stage are almost evenly split between those who reported seeking treatment within 6 months of testing (46%) and those who had longer delays (Table 2). The groups are primarily distinguished by the fact that most women who sought treatment soon after testing were ill when tested and, therefore, moved directly into treatment. For example, the following two women were severely ill when they were tested:

“I fell sick last February 2002 with severe malaria and diarrhoea and was admitted to Mulago hospital for a week or two at intervals of one to two months until my mother decided that I should go to home care ... When I began feeling better around January–February 2003, my mother began talking to me about testing for HIV and the benefits of early treatment. She convinced me and we came together to JCRC. I was still on the drugs of TB by then but I was tested for HIV and on testing positive I began on HIV drugs. That was April 2003.” (Single, 20 years old)

“I began falling sick in 2000 December with on and off malaria and lost weight steadily until it was so obvious that I either had HIV or something else was eating me up. Throughout 2001 I fell sick and got admitted thrice with severe malaria and diarrhoea. I however delayed to test for HIV because I did not have other reason to suspect. My boyfriend ... had long left for London and I lived without a sex partner

since his departure in 1999. ... the symptoms that emerged forced me to take an HIV test to satisfy my curiosity and in January 2002 I tested positive for HIV.” (Single, 30 years old)

In contrast, the other group of women was not sick at the time of testing. They sought care after knowing their status for some time, but only when symptoms, often severe and recurrent, appeared.

“I knew my status in 1995 ... I came to JCRC after falling sick and getting admitted seven times in 2001.” (Single, 40 years old)

“Although my husband died of AIDS in 1993, I had never fallen sick until April 2002. ... tested positive in 1994 ... I first fell sick in April 2002.” (Widow, 36 years old)

“I treated my husband throughout his sickness and saw all the known AIDS symptoms ... That was from January – July 1996. During his last month I asked the nurse to test my blood for HIV ... and I tested positive. So when I began falling sick in 2001 July I knew the cause. I suffered from all the sickness in about two months.” (Widow, 50 years old)

For both groups of women linkage to HIV-specific care occurred only after onset of HIV-associated symptoms. Of women (N=52) who reported delaying 6 months or more between a positive HIV test and seeking treatment, 56% (N=29) state that the primary reason for seeking care was the occurrence of symptoms. The majority of the remaining women sought care upon the advice of someone in their social network, such as a health care provider, parent, or partner (N=14, 27%).

Symptom-Based Referrals

For both types of delays the appearance of symptoms was a cue to seek biomedical care. In some cases, women sought care for symptoms several times before they were referred (by self, providers, or family members) for HIV-specific care. The appearance of noticeable, sometimes quite serious, symptoms also meant that other people became aware of the woman's health problems, as was noted by the woman who stated that she “...lost weight steadily until it was so obvious that I either had HIV or something else was eating me up”. In other words, she could no longer manage the symptoms without others suspecting HIV. The severity of the illness also led others, often family members, to initiate or encourage treatment seeking. For example, for these women severe symptoms and hospitalisation led their brothers to take them to JCRC for HIV testing and treatment:

“I began falling sick in 2001 when I got an attack of TB... my life stabilised but for only about three months and in January 2002 I was taken ill ...I had severe diarrhoea, high fever, coughing and boils in every dark part of the body. I was admitted for about three weeks ... In March 2002 my brother ...talked to me about AIDS. I had all along rejected pleas by my parents to test for HIV because I knew there was no solution even if I tested positive but when my brother said he would buy the drugs if I agreed to test I accepted and he drove me to JCRC where I tested positive. ...I began the ARVs immediately...” (Single, 32 year old)

“...I started falling sick now and again and got all the HIV symptoms fever, vomiting, headache, diarrhoea and was like that until early 2003 when I really went down and was being treated by my brother who is a doctor... I got a terrible skin rash and dry cough! We discussed...HIV testing. I fell seriously sick in August and went in coma. ...my other brother who is not a doctor brought me straight here at JCRC. I was almost dead, so they tested me in August 2003...” (Single, 36 year old)

These examples show that entry into care and treatment is heavily influenced by the occurrence of visible symptoms, which they have either suffered personally or have witnessed when caring for others.

Limitations—Several limitations should be considered as regards these results. First, because we only include women who have successfully sought and received HIV care we do not know the experiences of women who are not in care. Secondly, these data are cross sectional and, therefore, we do not know the long term experiences related to remaining in care.

Additionally, the majority of women in our study have completed secondary education or above (88%), whereas only 9% of women in Uganda have completed some secondary school and 2% have some tertiary education (Uganda Bureau of Statistics 2006). Therefore, women in this study may not represent the general population of women in Uganda. The availability of medications and other health services in Kampala is greater than in other areas of Uganda, although this is changing. At the time of this study it was the norm for patients to pay for medications, whereas this is no longer the case. All the women in our study were paying for their medications; in this respect, they are not representative of women in Kampala or Uganda generally at the time, because the majority of women could not afford medications. Despite these limitations, however, our data provide insight into the expected magnitude of the problem of access in the near future, as more women are in need of ART, by highlighting the range of issues that even the “best off” participants have had to overcome.

The strength of these data lies in the picture provided of the issues that impede access to care – even in a context in which many efforts are in place to improve access. As such, these data provide important insights into when and why women seek care and thereby suggest pathways to overcome barriers to entry into and retention in care.

Discussion and recommendations

This paper highlights delays in getting into treatment that have implications for “test and treat” programmes. First, delays in seeking an HIV test and in receiving HIV/AIDS care often occurred despite awareness of risk due to a partner’s illness or death and in a context of repeated contact with biomedical providers. Indeed, women often “knew” without testing, suggesting that “knowing” HIV risk or status derives from experience, even in the absence of definitive diagnosis via testing. Therefore, in situations where HIV status is acknowledged or expected from experience, asymptomatic persons may not seek biomedical confirmation via testing. As a result, special efforts are needed to highlight the benefits of testing, *including the need for testing when asymptomatic*.

Two interwoven themes in women’s descriptions of care seeking have additional implications for “test and treat” programmes: first, the importance of symptoms to HIV testing and treatment seeking and second, the role of family members in urging women to seek HIV specific care in response to symptoms. In this regard, our findings reflect those reported elsewhere (e.g., Stein *et al.* 1991, Wortley *et al.* 1995, Couturier *et al.* 1998, Lessells *et al.* 2011) with respect to the importance of symptoms. Study participants sought medical care when they were sick: being at known risk or known HIV status was less important in care seeking than *symptoms that disrupt daily living*. In extreme cases, entry into HIV-specific care occurred when it became undeniable that symptoms were HIV related, because the severity of the symptoms ruled out other options. Some women experienced repeated illnesses or several hospitalisations to the point that either a family member encouraged them to seek HIV treatment or they felt that they could no longer ignore

the fact that they were HIV-infected. In other words, women were not too sick to get tested; they were too sick to not be tested.

In a context of “knowing without testing” recognition of the need to seek care for HIV/AIDS specifically comes with *disease progression*, not an HIV test. Together these findings have two important implications for efforts to “seek, test, treat, and retain” persons in HIV care. First, programmes may benefit from focused efforts to explicate the benefits of HIV testing and treatment to asymptomatic persons as a means to retain good health. Secondly, efforts to engage people in care may benefit from targeting family members as important influences in care seeking.

In sum, our data poignantly answer Lange’s (2011) question “Is testing enough?” by demonstrating that advocating “test and treat” alone is insufficient. As test and treat paradigms gain support globally, the need to incorporate these programmes into broader calls for health care reform take on new urgency. The importance of symptoms in triggering care seeking suggests that for “test and treat” strategies to succeed individuals must be able to move seamlessly between routine and symptom based care and access a full range of health services, including HIV treatment when needed. For this reason, we argue that programmes promoting access to HIV testing and treatment must build upon efforts to integrate HIV care and treatment into primary health care so as to more fully address the needs of HIV infected persons earlier in the disease process.

The women in our study were engaged in care. Visits to clinics and providers were prompted by specific symptoms, which were then treated. Nonetheless, these women “slipped through the cracks” of the biomedical system; in other words, they did not receive HIV care until late in the disease spectrum. Our data support current calls for integration of HIV care into primary health care services. If HIV testing and care is essential to primary health care, patients who seek care for symptoms are less likely to “slip through the cracks” of the health care system. Therefore, an important step forward to achieve the goals of “seek, test, treat, and retain” programmes is to ensure the ability of local health care systems to provide continuity of care for patients seeking care for a broad range of medical needs. Only with such continuity of care will it be possible to ensure that HIV infected persons receive the lifesaving HIV care they need before they become desperately ill.

Acknowledgments

This study was funded as a supplement to the Center for AIDS Research (CFAR) at Case Western Reserve University, Michael Lederman, M.D., PI (NIH grant number AI316219). The content of this report is solely the responsibility of the authors and does not necessarily represent the official view of the National Institute of Allergy and Infectious Disease or the National Institutes of Health. We thank the women and the health care providers who participated in this study and the staff at the Joint Clinical Research Centre for their assistance with the study. Jude Tibemanya was the study interviewer; Stephanie McClure and Margaret Winchester assisted with data entry and analysis.

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Table 1

Socio-demographic characteristics of participants (N = 101) N (%)

Average age	
36 years (range 20 – 62 years, SD = 7.3)	NA
Marital Status	
Married	35 (35)
Separated or Divorced	8 (8)
Single	22 (21)
Widowed	35 (35)
Missing	1 (1)
Number of Children	
No children	11 (11)
1 to 3 children	58 (57)
4 or more children	32 (32)
Number Living in Household (not including participant)	
0	1 (1)
1 to 3	36 (35)
4 to 6	47 (47)
> 6	17 (17)
Number/Percent who care for others outside of household	38 (38)
Level of Education	
Primary	12 (12)
Secondary	47 (46)
Tertiary	42 (42)

Table 2

Delays in seeking HIV testing and treatment

Length of delay	Delay 1: Delay from suspicion to testing (N=101) N(%)	Delay 2: Delay from testing to treatment (N=101) N(%)
< 6 months	27 (26.7)	46 (45.5)
6 months – 1 year	19 (18.8)	17 (16.8)
1–2 years	14 (13.9)	13 (12.9)
2–5 years	18 (17.8)	12 (11.9)
More than 5 years	7 (6.9)	10 (9.9)
No suspicion, tested for other reasons	16 (15.8)	3 (3.0)