“If you start thinking positively, you won’t miss sex” Narratives of sexual (in)activity among People Living With HIV (PLHIV) in Nairobi’s Informal Settlements

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Introduction/Background

With sexual behavior long being an area of keen research interest in the social sciences, there is no dearth of studies centering on this issue in the field. A relatively less explored facet of sexual behavior, however, has been the sexuality of the chronically ill, such as people living with HIV (PLHIV), particularly in sub-Saharan Africa. Historically, much of the research attention given to the sexuality of PLHIV has privileged northern societies, with a primary focus on sexual minorities (e.g.: Stolte *et al*, 2004; Stephenson *et al*, 2003; Chen *et al*, 2002). The world-wide proliferation of anti-retroviral (ARV) therapy, however, has presently altered the landscape of HIV infection, extending lives and delaying opportunistic infections. As a corollary to this development, investigations of the sexual behavior of PLHIV in sub-Saharan Africa (SSA) have emerged. However, these studies have typically been fixated upon potential correlates of ARV therapy and risky behavior derived via quantitative inquiry (e.g.: Wilton *et al*, 2004; Moati *et al*, 2003). Qualitative studies centering on the sexual behavior of PLHIV in SSA are far less common. Gaps remain, therefore, regarding the actual meanings that sexual activity holds for PLHIV in African settings and the context in which these meanings are developed. Furthermore, sparse attention has been given to the sexuality-related experiences of PLHIV in urban poor in slum settlements of SSA, where the main concerns are often assumed to be far removed from sexuality.

This paper, thus, draws on qualitative methods to examine narratives of sexual activity (or the lack thereof) among PLHIV in two urban poor contexts in Nairobi, Kenya, and the ways in which these narratives intersect with a ubiquitous HIV prevention strategy – the 'ABC' (Abstinence, Be Faithful, Condom Use) approach. The unraveling

of these narratives gives insight into the ways that the notions and meanings around sexual activity are re-shaped by the experience of living with HIV among the urban poor.

The intersection between urban poverty and HIV infection is becoming an increasingly important area of investigation. In the Kenyan context (which has an estimated population of close to 33 million), about 9% of adult women and 5% of men may be infected with the HI-virus (KDHS, 2003) These high rates of HIV prevalence translate to more than 1 million infected adults. The National AIDS Control Council (NACC) has estimated a national HIV sero-prevalence rate of 10% in antenatal clinics. HIV sero-prevalence in Nairobi has been estimated at 5.1% (NACC, 2007). As with many other African countries, urban areas have higher prevalence than rural settings.

Because significant proportions of urban dwellers in many African cities reside in informal settlements – characterized by extreme poverty, unhygienic conditions, and high levels of risky sexual behavior – there is a need to consider high HIV prevalence rates in urban areas in the context of growing urban poverty. Indeed, preliminary evidence from an ongoing pilot study[1] suggests that infection rates within urban slum contexts in Kenya, for instance, may actually be higher than is the case in other parts of the country.

According to estimates by UNHABITAT (2003), about 72% of all urban residents in sub-Saharan Africa live in informal settlements, commonly known as slums. In Kenya, it is estimated that about 71% of all urban dwellers live in informal settlements (ibid.). These facts underscore the importance of drawing attention to the sexual behavior of PLHIV in informal/slum settlements.

[1] An ongoing HIV serological survey pilot study conducted in two informal settlements of Nairobi from 2006 to 2007 by the African Population and Health Research Center.

Conceptual Framework

The "ABCs" for HIV prevention (being *abstinent* or delaying sex, *being* faithful to one sexual partner or reducing the number of sexual partners, and the consistent and correct use of *condoms* during sex) have been widely promoted in recent times. Since its introduction, however, there have been lively debates on both sides of the divide for and against the ABC approach. While proponents of the approach attribute the dramatic reduction of HIV prevalence in Uganda to the promotion of, and adherence to, ABC behaviors (Halperin, 2004; Stoneburner and Low-Beer, 2004), others have pointed to the overly-simplistic nature of the ABC approach, with its emphasis on a few behaviors, to the neglect of equally salient gender and contextual issues (Barnett & Parkhurst, 2005; Osborne, 2005).

Against this backdrop, there are a number of studies centering on the sexual activities of PLHIV, borne out of the concern that the present context of ARV availability might provoke risky sexual behavior among this population. Indeed, findings (primarily from studies among Western men who have sex with men) have indicated a reduction in protective and preventive behaviors among PLHIV once their physical condition improved as a result of ARV therapy (Chen et al, 2002; Van der Ven et al, 2002). The data on this subject show mixed results, however, with some studies demonstrating continued engagement in unprotected sexual behavior among PLHIV (Crepaz & Marks, 2002) and others revealing that receiving ARV therapy (highly active ARV therapy in particular) did not result in increased sexual risk behavior among the PLHIV concerned (Crepaz, Hart, & Marks, 2004; Sarna et al, 2005). The ABC discourse and the prevalent assumptions regarding the sexual behavior of HIV-positive persons are the two main

issues foregrounding this paper. The narratives of sexual (in)activity among PLHIV in urban Kenyan slums are examined in the light of these two issues.

Methods

The data analyzed for this paper are drawn from a larger qualitative research study conducted within two urban slums in Kenya, exploring the needs and experiences of the HIV-infected/affected in resource-constrained settings. In 2006, a baseline study of the general experiences of households affected by HIV/AIDS in the two study communities was initiated using a combination of quantitative and qualitative methods. To ensure that the households in the sample represented the range of family experiences in the communities concerned, 126 study participants were drawn from three HIV-related household categories, namely: 'asymptomatic' (i.e., HIV positive, but asymptomatic at the time of interview), 'critically ill' (i.e., having had an episode of critical illness within the last 6 months), and 'bereaved' (i.e., having been bereaved as a result of HIV/AIDS within the last one year). A total of 100 interview respondents were selected specifically to participate in the qualitative component of the study based upon purposeful sampling procedures (Patton, 2002) in collaboration with community-based organizations (CBOs) involved in HIV/AIDS work. The study respondents formed somewhat of a select group in that they all had either proactively gone out in search of assistance from CBOs, or were identified as being HIV-infected/affected by CBOs and subsequently connected to services. The table below provides a summarized description of the study participants.

Characteristics	Asymptomatic	Critically ill	Bereaved	Total
	N=46	N=47	N=33	126

Age				
20-29	32.6	17.0	9.1	20.6
30-39	28.3	53.2	48.5	42.9
40-49	32.6	23.4	24.2	27.0
50 +	6.5	6.4	18.2	9.5
Gender				
Female	89.1	76.6	75.8	81.0
Male	10.9	23.4	24.2	19.0
Slum				
Community 1	54.4	55.3	54.6	54.8
Community 2	45.6	44.7	45.4	45.2

Through semi-structured in-depth interviews conducted with 100 out of the 126 study participants, the qualitative study sought to understand experiential issues, including households' discovery of HIV infection and general experiences thereafter; the greatest needs/concerns of households affected/infected by HIV/AIDS in the slums; the kind of care, services, or support received by, or available to, households; and households' motivations for continuing to live positively. The issue of sexuality for PLHIV emerged as a recurrent theme among the 'asymptomatic' and 'critically ill,' in particular, leading to the following research question undergirding the paper: *What do the narratives of PLHIV in urban poor Kenyan settings suggest about how they negotiate sexual activity and how do these narratives intersect with the components of the 'ABC' approach?*

The narratives drawn from the 'asymptomatic' and 'critically ill' categories of participants (approximately 50 in-depth interviews) form the basis of this paper. These sexuality-related narratives were identified, analyzed for content, and categorized according to the particular component of the ABC model that they appeared to represent. A discussion of the results of the analysis follows.

Results

Abstinence

A key finding of this study is that respondents' narratives and experiences centered overwhelmingly on the abstinence element of the ABC model for HIV prevention. Furthermore, there seemed to be two main ways in which respondents were engaging with abstinence. The first had to do with *abstinence as a form of 'positive living.'* In other words, the narratives of respondents suggest that abstinence is equated with well-known and standardized forms of positive living, such as eating well, being sure to take the necessary medication at the required times, and preserving one's mental health, by not being overly-anxious about anything:

Res: I have accepted that I have the HI-virus and I know how to live positively
Int: Can you tell me how you live?
Res: Not involving myself in sexual activities, eating well, no hard thinking and no worrying.
(community 1, age 27, separated mother)

Res: I eat well, take my medication and I won't allow a man to have sex with me. I don't have a lot of worries and I pray every now and then and thank God for taking my child this far. There are many types of virus and the more you involve yourself in sexual activities, the more you increase the number of viruses and reduce your life span.
(community 1, age 32, separated mother)

Interestingly, the mention of condom use as a means of stemming the spread of HIV, and indeed, of positive living, was glaringly absent in interviewees' sex-related accounts. The preferred strategy among the majority of respondents was often to completely evade sexual intimacy, as the following interview excerpts indicate:

> [I cope by] eating well, taking medicines as per instructions from the doctor, and when I am in this slum, I avoid the 'Njoroges' and 'Kamaus' [men] of this slum so that I can move on and leave the HI-virus behind me. That is why I have lived for all these years and I know I will live for ten more. It is my hope to live so *(community 2, age 42, single mother).*
>
> Int: Any other way you cope with life in your HIV status?
> Res: I don't like friends near me at all
> Int: Why? Are friends really bad?
> Res: I don't like male friends.
> Int: Why do you say that?
> Res: For I know if I continue with sexual activities, I will grow weaker as the virus becomes more active in the body *(community 1, single mother).*

A key question that arises is whether the study respondents concerned espoused abstinence out of a personal, informed decision, or whether this choice came about via the internalization of stigma, which has been known to make HIV-positive persons feel unworthy of love and sexual relationships (EXCHANGE). The narratives in the data set under study suggest that the choice of abstinence among PLWHA in the slums of Nairobi may be motivated by external rather than internal factors, as the following examples show:

> [I]f you go having sex with men, not eating well, thinking and worrying so much, the CD4 count goes down. **We are advised** to leave all those things to enable us live longer *(community 1, age 21, single mother)*.
>
> I take drugs always and eat a balanced diet, leave men alone. **I was told** if I want to have a good life, I should leave those sex-related things *(community 2, age 29, widowed mother)*
>
> I take my medication on schedule and **the doctor discouraged me** from having affairs with men *(community 2, age 30, married mother)*
>
> When **the doctor told me** that 'From now on, since you have the HI-virus, you are not allowed sexual activities. You must use condoms if you must,' it was hard. It was dark and I could not even find the way out *(community 2, age 42, single mother)*

This should not be taken to mean, however, that all service providers offering services to PLHIV in the slums of Nairobi were providing misleading information. Although they were often mentioned as being complicit in the abstinence inclination found among participants, it is important to point out that there were several instances in which service providers clearly made other options available to PLHIV, rather than steering them completely away from their own sexuality:

> Res: We get lessons on how to take care of ourselves for example we are not supposed to engage ourselves in careless sexual activities, use of a condom, and so on *(community 2, age 44, single mother)*.
>
> Res: The doctor told me that I should not have sexual intercourse without a condom that is if I want to live longer *(community 2, age 30, married)*.

Significantly, in the excerpt below, the interviewee concerned not only received sound advice from his doctor, but also clearly made a personal decision to remain abstinent:

> Int: What else did [the doctor] tell you to leave [alone]?
> Res: Casual love affairs, and if I have to have sex I must use a condom. But I don't bother with that because I told myself there is nothing I am going to benefit [from] at the end of the day. I don't bother with women at all. […] It won't help me at all since I have a child to look after. Once he is old enough, then I can decide if it is really necessary to have sex, even though I am comfortable without sex today.
> (*community 2, age 41, widower)*

The majority of respondents, however, gave accounts of hearing a particular form of advice around sexual behavior that seemed particularly incomprehensive and geared primarily toward abstinence.

The second way in which respondents' narratives constructed abstinence was in terms of *abstinence as a form of penance*. From the choice of words of participants, it was evident that many regarded abstinence from sex as not just a kind of punishment, but one which they rightly deserved for contracting the HI-virus. There were also frequent expressions of guilt (often clearly misplaced) by interviewees. This sentiment was built on the notion of sexual activity as being the responsible for their health predicament, rather than on *unprotected* sexual activity, coerced sex, or sex with a sero-positive partner that did not disclose:

> I keep encouraging [my kids] to live holy lives and to try to be very careful. It is better to work than to move around. From prostitution, I have earned this disease. *(community 2, age 36, separated mother)*
>
> Long ago in 1993, I started enjoying the pleasures of the world and I was mischievous. I think that is where things went wrong *(community 1, age 41, single mother).*
>
> We are dying, but when we repent and stop prostitution – as for me, I have vowed not to go back to [leading an] immoral life at all. I don't want any man near me at all because I will kill you for nothing. I am saying, my brother: don't let yourself into this pit I have gone into *(community 2, age 37, married mother).*

In the course of the interviews, each study participant was asked if there was any important issue which they felt was relevant to their lives as PLHIV, but which the interviewers had neglected to ask about. In response to this question, one respondent replied as follows:

> [You should have asked:] How am I able to live without a man? I have heard people say they cannot do without a man. **Had I trained myself not to be involved in many casual affairs, I would not be sick.** Ok, in my case, I got [HIV] in marriage because my husband was moving all over with all the women in sight. I don't think he would know who he got it from if he were alive today. I know one can live without a man or a woman. **If you start thinking positively, you won't miss sex, as it is put,** but if

> you put your mind there instead of looking ahead, you will be a victim of many other types of HI- virus. **Sex is the main problem that is affecting most people here** because instead of thinking about how they will recover, they concentrate on why they can't have a man or woman for sex. Any normal man/woman should realize that **because of sex I am in this predicament**, which alone should move you away from those thoughts and concentrate on enjoying life without ailing every other day. **When I was in counselling classes, we were also taught** that there are certain things that put the body on heat and one should avoid using them often, like coffee and tea leaves. There are some foods also which direct you to that [sex], so the best thing is to avoid them or look for an alternative. For example which kind of vegetables (inaudible) like French beans and they also provide energy in the body, I have forgotten the other one … I don't involve myself in those things because **the moment I eat those foods and my mind switches to sex, I will find myself in a trap** *(community 1, age 31, widowed mother).*

The obvious struggle with guilt that the above quote symbolizes is representative of the experience of many other respondents, as is the fact that the guilt was often misplaced. For instance, the respondent in this particular quote commences by blaming her HIV status on her failure to 'train herself' to limit her involvement in casual affairs. In the same breath, however, she acknowledges actually being infected by her husband. This lack of clarity over the 'culprit' in the context of chronic illness was shared by many of the interviewees.

Another salient notion that arose in the narratives was the sense that respondents were engaged in a 'battle' against their own sexuality – a battle which they seemed to feel obligated to win, perhaps because they had 'lost' the first battle, so to speak, by contracting HIV. The respondent above, for instance, narrates how she is careful to avoid certain kinds of food (and even tea, which is a Kenyan staple) in order to ensure that her thought are not drawn to sex. Although some of the narratives point to a sense of triumph over successful abstinent behavior, they also suggest that sexual abstinence may not as facile and uncomplicated as the respondents sometimes imply. On the one hand, this

particular interviewee asserts that "*If you start thinking positively, you won't miss sex*." On the other hand, however, she acknowledges her avoidance of certain allegedly aphrodisiacal kinds of food and drink because, "*the moment I eat those foods and my mind switches to sex, I will find myself in a trap*." This 'mind-over-matter' approach (as well as the contradictory sense of triumph over sexual urges/needs) is echoed by another interviewee:

> I live with hope for the future because of medication. Secondly, I have stopped living [a] leisurely [life]. As I speak now, I have lived for over a year without thinking of a woman's private parts. I don't even think about it […] [Men] should be very careful with their thoughts, especially lustful thoughts. A lot of things depend on thoughts. Your thoughts should not be centred in that area [sex] so much. *(community 2, age 35, single).*

Beyond any implied struggles to remain abstinent, however, a more prevalent theme in participants' narratives was an unequivocal intention to desist indefinitely from sexual activity. The excerpts below buttress this point:

> [B]ecause of sex, I am in this predicament. I don't want anyone in my house. I am better off alone *(community 1, age 42, single mother).*

> I avoid sex at all costs, and since I discovered I was positive, that was the end of me and sex *(community 2, age 36, single mother)*.

Orza's (2006) observations about PLHIV in general appear to resonate with the findings in this paper:

> Undoubtedly, choosing abstinence, or a period of abstinence, whether alone or in a relationship, can be empowering. However, this choice is often made for a number of disempowering reasons including fear (of becoming infected, or infecting others); the negative associations with sex that an HIV-positive diagnosis may result in; guilt; shame; or the internalization of stigma which may lead people living with HIV to feel that they are not worthy, and do not deserve love and sex any more. Many [PLHIV] experience a loss of sexual identity following a positive diagnosis. Where abstinence is born out of any of the negative feelings mentioned above, a false sense of

> empowerment may prevail, if [PLHIV] encounter circumstances in which they are clearly not in control of the situation, such as incidents of sexual violence, coercion or the simple realization that the choice of abstinence was motivated by external rather than internal factors (pp. 5-6).

In the next sub-section, the intersection between respondents' narratives and the second component of the ABC approach is examined.

Be Faithful

Out of all the ABC components, the narratives in this study engaged the least with the 'Be Faithful' facet. The latter featured briefly in the narratives of only three interviewees. One respondent in the study mentioned the 'B' concept of being faithful, discussing it in terms of her own faithfulness. When asked how she had been able to cope with having HIV, she responded in the following manner: "I have avoided casual relationships leading to sex and have been faithful. I have also used medicines as prescribed by the doctor and kept myself clean" *(community 1, age 28, separated mother)*.

The two other interviewees that broached the subject of being faithful, actually discussed it in terms of their partners' *un*faithfulness. An example of this is shared below:

> You have a husband who seems to be aware of his status and he still has casual love affairs every other day. You are at risk always. If you can have a chat and talk about it, that is ok, but when someone does not want even to hear about it and dismisses you as if you are from another planet and have just landed in his house – I am sure he knows what he is doing and what I don't understand is how he doesn't care at all *(community 2, age 30, married mother).*

Interviewees' focus on "unfaithfulness" (as opposed to "being faithful") is not surprising. Indeed, one of the important critiques of the 'B' component of the ABC model

is that while personal faithfulness is under an individual's control, the faithfulness of others can neither be guaranteed, nor taken for granted.

Condomise

The narratives around the condom use in this study reveal that the well-known socio-cultural barriers to using condoms find resonance in the lives of PLHIV, affecting them in similar ways as it does the non-infected. Women's challenges in negotiating condom use (and, indeed, non-use) were also relevant to the study population. As two respondents intimate:

> We were advised to be using a condom, but when I told my husband, he refused and I gave up. He never wants to use it and insists that I am a prostitute – that is why I want him to use a condom. There was a time I had it hidden in my panties. He took it and threw it away, accusing me: those are used by prostitutes, not him *(community 2, age 29, married mother).*

> I never make love to [my wife] without a condom, though this has been difficult for her to accept … [My HIV status] is now still my secret and that of the doctor because I am scared she will react badly, though I insist on using a condom or abstaining, since she insists she is not promiscuous *(community 1, age 41, married father).*

In addition to underscoring the perceived link between condom use and promiscuity, respondents' narratives also highlight another intriguing issue – the under-explored connections between "being faithful" and "condom use." The two excerpts above suggest that the non-use of condoms is often seen as evidence of faithfulness. Thus, being faithful and using condoms are much more complex issues than a 'simple' acronym such as 'ABC' would suggest. Being faithful is not merely a question of an individual's faithfulness; there is need to also take into account sexual partners' perceptions or interpretations of faithfulness. As the data here demonstrate, these complexities often lead to situations in which sero-discordant couples in

informal settlements continue to have unprotected sex. The complexities are perhaps partly responsible for the prevalence of abstinent behavior among PLHIV in this study. Narratives related to condom use suggest that abstinence is considered a socially cheaper alternative by many respondents. One rare respondent that was clearly open to leading a sexually active life explains her hesitancy in this regard, attributing it to the challenges of condom use negotiation:

I am 44 years old and I would love to live with someone. You will get a friend [lover] who is ready to assist you with rent and food for the children and even school fees. The problem arises when you insist on using a condom, which he does not want, and argues that you are lying [about your HIV status] *(community 2, age 44, single mother).*

Finally, respondents' narratives suggest that seropositivity does not necessarily impact negatively on parenthood/family-building aspirations. For a number of study participants, their partners' family-building aspirations created tensions related to condom use:

In our Luo tribe – my first husband died – when your husband dies, you are inherited by his brother. I started living with my brother-in-law … The doctor told me that I should not have sexual intercourse without a condom – that is, if I want to live longer. But this person wants a baby. How do I live with him in such a situation? I don't know how to handle this problem … His argument is, how come I am positive and he isn't after two years of staying together? … [H]e still argues he has tested negative twice. So he argues he can't use the condom since he is negative. Possibly, I have something else I am ailing from, but not HIV … So he can't stay with me without having more children. I have told him to get married again if he feels like it, but I will still remain his wife … That has been the cause of our quarrelling every now and then, and he said he will throw those condoms away or burn them. He doesn't even buy food. He told me we can't continue staying like before. He insists on having sex without a condom *(community 2, age 30, married)*

One of the problems we used to have is [my husband] wanted us to have another child, but I had refused because we were taught at the seminar that when you find yourself positive, you should avoid having children at all costs, so he used to quarrel that I have refused to have another baby *(community 2, age 40, married mother).*

Discussion

Speaking specifically of narratives in the experience of illness and healing, Greenhalgh and Hurwitz (1999) note that

> narrative provides meaning, context, and perspective for the patient's predicament. ... Understanding the narrative context of illness provides a framework for approaching a patient's problems holistically, as well as revealing diagnostic and therapeutic options. Furthermore, narratives of illness provide a medium for the education of both patients and health professionals and may also expand and enrich the research agenda.

The same argument can be made for narratives in the experience of sexuality among PLHIV in urban slums. The meanings, contexts, and perspectives provided by respondents provide pointers to how the agenda around HIV prevention may be expanded and enriched to ensure an optimal quality of life for the HIV-infected.

This paper shows that the narratives of PLHIV in the slums of Nairobi intersect in various ways with the discourse around the ABCs of HIV intervention. There have been several critiques of the ABC approach. One of them has been the potential of the model to fuel stigmatization against PLHIV who may choose not to practice abstinence, for instance. The narratives examined here seem to suggest that most respondents had internalized the notion that sexual activity is incompatible with a positive HIV diagnosis. It is possible that some study participants made an informed decision about remaining abstinent for the rest of their lives. As we have seen from some of the narratives, abstinence and the avoidance of intimate relationships actually appear to incur less social

costs than involvement in sexual activity/relationships. Nonetheless, there is also evidence to suggest that, for some, abstinent behavior may have been imposed by service providers. This unveils the need for further research around service-provision procedures in slum settings (e.g.: counseling, medical advice, post-testing clubs) to examine in-depth the nature of sexuality information/counseling made available to the urban poor. The inclination toward abstinence may, in part, be an indication of incomprehensive information, as could the lack of understanding evident in some of the narratives about HIV-discordance.

Furthermore, prevention messages have an obligation to engage with realities of PLHIV's lives that transcend beyond even the best-intentioned prevention prescriptions. For instance, while condom use is certainly rational in the context of HIV-discordance, respondents' narratives indicate that other forces (such as the desire to have children) are sometimes more powerful than the potential risk of contracting HIV. Understanding and engaging with realities such as this ought to form part of prevention models.

Finally, abstinent behavior has typically been investigated in the context of adolescence. A number of studies focusing on this subject have shown that young people who receive abstinence-only information are less likely to have protected sex when they do become sexually active, compared to their peers that were recipients of comprehensive sexuality education. An important area for further research would be the investigation of the long-term sexual behavior of PLHIV, which may have implications for new infections.

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