Living with HIV post-diagnosis: a qualitative study of the experiences of Nairobi slum residents

Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2012-002399
Article Type:	Research
Date Submitted by the Author:	23-Nov-2012
Complete List of Authors:	Wekesa, Eliud; Population Council, Coast, Ernestina; London School of Economics, Social Policy
Primary Subject Heading:	HIV/AIDS
Secondary Subject Heading:	Qualitative research
Keywords:	HIV & AIDS < INFECTIOUS DISEASES, QUALITATIVE RESEARCH, Anthropology < TROPICAL MEDICINE

Living with HIV post-diagnosis: a qualitative study of the experiences of Nairobi slum residents

Structured abstract

Objectives: To characterise the experiences of heterosexual men and women living with HIV post-diagnosis and explain these experiences in relation to their identity and sexuality.

Design: Qualitative study using in-depth interviews and theoretically informed biographic disruption theory.

Setting: Interviews were conducted in two Nairobi slums (Kenya).

Participants: 41 HIV-infected heterosexual men and women aged 18 years or older

Results: People living with HIV have divergent experiences surrounding HIV diagnosis. Post-diagnosis there are multiple phases of identity transition, including status (non-)disclosure, and attempts at identity repair and normalcy. For some people this process involves a transition to a new self-identity, incorporating both HIV and antiretroviral treatment (ART) into their lives. For others it involves a partial transition, with some aspects of their pre-diagnosis identity persisting, and for others it involves a rejection of HIV identity. Those people who were able to incorporate HIV/AIDS in their identity without it being disruptive to their biography, were pursuing safer sexual and reproductive lives. By contrast, those people with a more continuous biography continued to reflect their pre-diagnosis identity and sexual behaviour.

Conclusions: People living with HIV/AIDS (PLWHA) had to rework their sense of identity following diagnosis in the context of living in a slum setting. Men and women living with HIV in slums are poorly supported by health systems and services as they attempt to cope with a diagnosis of HIV. Given the availability of antiretroviral therapy, health services and professionals need to support the rights of PLWHA to be sexually active if they want to and achieve their fertility goals, while minimizing HIV transmission risk.

Article summary

Article focus

- Slum populations are under-researched, and very little empirical research examines the experiences of people living with HIV post-diagnosis
- Impact of HIV post-diagnosis identity on sexuality and reproductive intentions

Key messages

- Men and women living with HIV in slums are poorly served by health services post-diagnosis.
- Health service provision and support does not incorporate the increasing needs of people living with HIV and AIDS to navigate their sexual and reproductive lives.
- The sexual and reproductive experiences of PLWHA are influenced by their HIV post-diagnosis identity transformation.

Strengths and limitations of this study

- The first in-depth study of the experiences of people living in slums following a HIV diagnosis in relation to their identity and sexuality.
- We did not include the perspectives of relevant stake holders such as health service providers or policymakers

Introduction

Sub-Saharan Africa is the most affected region by the HIV/AIDS pandemic, accounting for over 68% of the total global burden [1]. Approximately 1.5 million adult Kenyans are currently living with HIV [2, 3]. The Kenyan HIV prevalence rate (7.4%) is higher than the SSA regional rate (5%) [4].

The introduction of anti-retroviral therapy (ART) has improved the prognosis of HIV, with the potential to transform it to a chronic condition. Access to ART in low and middle income countries has expanded rapidly, with 6.6 million people now receiving treatment, nearly half of those eligible for treatment [1]. Sixty percent of Kenyan adults and children eligible for ART are now receiving it [3]. With ART, the future life opportunities of PLWHA can change, including those related to sexuality and reproduction [5-7]. However, research has focused on issues of access and adherence to ART for treatment effectiveness [8-10]. The sexual and reproductive health rights and needs of PLWHA are under-researched and poorly understood [6, 11, 12]. There are policy concerns about treatment optimism, with an increase in riskier sexual behaviour as more people become aware that HIV/AIDS is a manageable condition with ART [13-16]. Sexuality is a crucial element of being human and sexual health (pleasurable and safe sex) is an important component of overall health [17]

> Nearly three quarters (72%) of urban residents in SSA live in slums [18] where single-room homes are densely packed [19]. The poor health status of slum residents reflects poor environmental conditions and infrastructure, limited access to treatment and preventive health services; and reliance on poor quality and informal and regulated health services [20]. Urban slums and their residents are an important, but under-researched, aspect of life in SSA. We undertook a qualitative study of the sexual and reproductive experiences and intentions of heterosexual men and women living with HIV in Nairobi slums.

Methods

Theoretical framework

We organised and analysed our data using the theoretical concept of biographical disruption [21], to understand how HIV acts as a disruptive experience to an individual's life, social relations and identity [22-24]. There are three components to biographic disruption: disruption of an individual's former behaviour or assumptions; changes in an individual's perceptions of self; and, an attempt to repair or change one's biography. Biographical disruption of HIV has been studied in the global North, and the extent to which it applies to PLWHA in other settings is unknown [23, 25].

Sampling and recruitment

Qualitative data were collected from PLWHA living in two Nairobi slums in 2010 using in-depth interviews. Respondents (n=41) were identified and recruited from a larger quantitative study (n=513) conducted by the authors which used quota sampling based on sero-prevalence ratios in slums covered by the Nairobi Urban Demographic and Health Surveillance System (NUDSS). Interviews were conducted in KiSwahili, recorded, transcribed verbatim, translated into English and analysed using NVivo [26].

Ethical considerations

We obtained written consent from all respondents and all interviews were conducted in a setting of the respondent’s choice. Privacy in home settings in slums is difficult to achieve, and respondents were given the option of being interviewed in the offices of a local health organisation. A small grocery package was provided as compensation for each respondent. Approval for the study was granted by the Kenyan Medical Research Institute (KEMRI) and the London School of Economics (LSE).

Results

The socio-demographic characteristics of the qualitative study participants are summarised in Table 1.

Table 1: Socio-demographic characteristics of respondents (n=41), 2010.

CHARACTERISTIC	PERCENT (N=41)
Slum of residence	
Korogocho	59
Viwandani	41
Sex	
Female	56
Male	44
Ethnicity	
Kikuyu	34
Luo	24
Luyia	20
Kamba	15
Other	7
Education	
No Schooling	7
Primary	66
Secondary and higher	27
Marital Status	
Married/Cohabiting	41
Divorced/separated	17
Widowed	29
Never Married	12
Age	
18-29	22
30-39	32
40-49	32
50+	15
Treatment Status	

Receiving ART	56
Not Receiving ART	44

We present detailed analyses of three case studies, purposively selected from the qualitative sample in order to draw out the complexities of biographical disruption following diagnosis with HIV. We selected these case studies to represent the range of sexual behaviour and fertility intentions (Table 2) [27].

Table 2: Summary characteristics of three case study respondents

Characteristics	Case study
Sexually abstinent, no intentions of future fertility	Malaika, female, 29 years old, widowed, known HIV status for 3 years. .
Sexually active, monogamous relationship, consistent use of condoms and/or contraception	Safari, female, 34 years old, currently cohabiting, known HIV status for 15 years.
Sexually active, multiple partners, inconsistent use of condoms and/or contraception	Jambo, male, 55 years old, widower, known HIV status for nine years.

Reactions to a diagnosis of HIV

HIV diagnosis is the first step in incorporating HIV/AIDS into an individual's identity, challenging their identity as a healthy person. Most research on HIV testing in SSA focuses on its benefits, costs and barriers [28, 29], with little understanding of people's experiences of having a test [30]. Safari's narrative is typical of health provider response and management early in the epidemic:

> INT: So how did you know your status?
>
> Safari: I kept going to *Hospital*. That is when I heard doctors saying things like HIV/AIDS and they started pointing fingers at me. Those days things were so bad; not like these days. So I just decided by myself to go and approach the doctor. I told the doctor to tell me the truth because I did not want to miss work. I was working as a maid and all this time he was refusing to tell me the truth. So he took my blood again and told me to come for the results the following day and was told…He told me; you know, there is a disease that has come out. It does not have a cure. It is not known what kind of disease it is, and Safari you have that disease.

Diagnosis often occurred during a health crisis:

> Jambo: I had a chest problem and when I went to hospital they told me that I had to be tested for HIV. I knew I had TB, but when I was tested for HIV...Oh no! aaayaai! I was surprised to be told that I was HIV+.

Being diagnosed with HIV/AIDS elicits multiple reactions, both negative (e.g.: shock) and positive (e.g.: relief) [22, 31]. People struggled to grapple with the meaning of a positive test and its implication for their life. Their biographies were initially disrupted and needed reworking to accommodate HIV/AIDS. These initial emotions evolved and changed with time. Malaika's reaction was of distress and denial; she was surprised to test positive because she perceived herself to be at low risk of infection, despite having been inherited by her brother-in-law, because she felt she had not engaged in risky behaviour. For her, it meant refusing the results of an HIV positive test:

> Malaika: I was very angry. I wished I was not alive because I saw myself as a dead person. I thought about killing myself. I wanted to kill my children but it was just that they were still very young. I did not suspect I was HIV positive because I did not go out with other men. Even when my husband died, I did not suspect that I was having it, because he did not inform me about his status.

Safari feared being associated with prostitutes, a marginalised and stigmatised group:

> Safari: I will be put with the people who are cursed in life. A person called a prostitute is a cursed person. People would think that I came to Nairobi to be a prostitute. I hated myself. I took it as a curse.

Jambo's narrative involved putting on a brave face, a reaction that is rarely reported in studies of diagnosis reactions [eg 22, 32]. Jambo displayed a "masculinity script" [33] by reporting himself to be brave, fearless, and emotionless upon testing HIV positive:

> Jambo: I wasn't angry because I am a man. You are only scared if you are not a man. Again it's not bad to inform a man something like this. It has to be diagnosed, and on you [man] for that matter. Were you not moving out [having sex] with women? You are a man, so you cannot say, No, I don't have this disease and yet you have been having sex with women…Yes, as a man you can't just stay *ndeee*! [abstinent].

Diagnosis represented a first step in HIV identity formation, followed by decisions about whether to disclose their status.

HIV status disclosure: To tell or not to tell.

Managing the flow of information about HIV status, including (non-)disclosure of HIV status is central to how people manage their identity post-diagnosis. Safari's decision to disclose was difficult and took time, encompassing a process beginning with non-disclosure and moving towards forced disclosure:

> Safari: My mother was told but not by me. When you live with people in the house they will know something and they will start talking and word goes round. After all, my body betrayed me. They [neighbours] told

> her "From what we can see your child is suffering from AIDS". So one day I decided to tell her.

Safari's disclosure was articulated as subsequently driven by a desire to educate and inform others about HIV/AIDS, a disclosure motive that has also been documented in the US [34].

> Int: Why did you tell them, let us start with your mother?
>
> Safari: I wanted her to decide whether to change her life because the way she was living her life was risky. I told her so she could know her status and also tell the others, because her behaviour was not good. She had involved herself in drugs and I saw her getting the virus easily.
>
> Int: Why did you tell other relatives then?
>
> Safari: …So I wanted to educate them more about HIV/AIDS. How you can get it and how to take care of it and how you can live with it.

Neither Malaika nor Jambo had disclosed their status to anyone beyond healthcare providers. A major barrier to their disclosure is fear of stigma and discrimination:

> Malaika: It is very difficult for me to disclose my status because people will start talking ill about me, they will not feel good when their children play together with my children and they will look down upon me. That is why I don't want to disclose it to any one and just want it to be my secret.

Jambo's explanation of his non-disclosure refers instead to issues of confidentiality:

> Jambo: How can I reveal matters affecting my body to anyone; that I have HIV? Why? Are they my doctor? Why should they know?

Fear of stigmatising attributes and behaviour such as rejection, discrimination and other negative social responses are illustrated by Safari's narrative:

> Safari: I disclosed to many people and they began calling me "*mama ukimwi*" (mother AIDS). They called me *malaya* [prostitute]. The community despises people living with the virus a lot. That is why they [PLWHA] don't want to disclose; they don't want to be deserted by their friends.

Incorporation of HIV into people's identity is shaped by both individual reaction and the reaction of others and is a process of transition involving decisions about (non-) disclosure.

Assimilation and resources for identity normalisation

The third phase involves reorganisation and / or reconstruction of biographies towards some kind of normality, possibly different to that preceding HIV diagnosis. Of our three case studies, only Safari had fully disclosed her status; she had assimilated her HIV status into her life and it had become central to her identity. For this group of people, social support groups played an integral role in creating and maintaining an HIV positive identity, forming a bio-sociality to decipher biomedical information (e.g.: CD4 cell counts, viral loads, treatment side-effects), over and above individual clinic consultations. Safari developed her identity as a new "career" [35], and formed a support group to provide social support for PLWHA and income generation activities (e.g.: selling beads, poultry farming):

> Safari: I used to hate myself before, but now I am a very informed person living positively with HIV. I have educated myself from newspapers and the television. I have a very big dream of changing the community. I chair a support group and have a dream of educating the community about HIV/AIDS. I overcame stigma and want to help other PLWHA. My efforts meant that people overcame stigma and joined support groups. I used my HIV status to remove people [PLWHA] from their beds.

Faith-based social networks also play a role in helping people to shape their new identities, including the management of anxiety and depression [36].

ART can strengthen social relationships and self-identity because it improves people's capacity to work, important for social and economic viability and validation, allowing people to play their societal role as breadwinner, parent or adult:

> Int: How has the availability of treatment changed your prospects about the future?
>
> Jambo: I feel good...I don't see a negative side...they make you feel you are in good health and not unwell... when you're using something you find beneficial, the results are obvious even your body tells it all... I can walk to the toilet, I feel strong...I feel okay and I can work just like a normal person. Am I not healthy? But it is my secret; I don't go saying: I have taken an AIDS drug and I feel I am cured. [laughs]

For many PLWHA, hope and uncertainty co-exist, leading to contrasting and ambivalent views about ART, even among those individuals who have developed a positive identity:

> Safari: I should have started using the [ART] drugs, but I said no. The doctor was pushing me to start the drugs, but I refused.
>
> Int: Why did you refuse?
>
> Safari: Let me tell you, I fear those drugs. The thing that makes me fear them is the reactions they cause. I have seen the problems they cause to people. The swelling of the feet, then there is one that removes all the fat from the body and it brings to one side. You find one's breast has grown fat; you have a bad shape. That is why I fear them.

For many PLWHA being HIV positive is simply a medical label, and not a defining feature of their identity:

Int: So life goes on as usual?
Jambo: Yes ... people might say that I have HIV, but for me that is not important…My main problem is that I have no means to earn a living, I have many challenges. I am usually rained on in this house whenever it rains, but I cannot [afford to] migrate from here.

For those PLWHA who experienced a dissonance between their HIV status and their perceived health status, this tended to lead to the rejection of an HIV identity:

Malaika: That thing [HIV diagnosis] is very painful that I even don't want to think about it I don't even want be going to the NGOs to read those things about HIV/AIDS because I know I have it. I just want to stay "*bubu* (dumb) style".

Malaika had decided not to use ART because she had concerns about the requirement for good nutrition in order to be able to take the drugs:

Int: Are you on ART?
Malaika: I am not on any treatment, I just stay like that…I don't see the need to use these drugs when I don't feel any pain in my body. In fact, I hear you need to eat well when you take those drugs and sometimes you don't have the means to buy food.

Our case studies illustrate the range of experiences around people's identities post-HIV diagnosis. Safari, with full disclosure, had started to make a career out of her HIV status, although she preferred to place her faith in religion, rather than ART, to maintain her health. Safari had completely assimilated a new HIV identity. Jambo, on the other hand, was motivated to adhere to ART in order that he would be able to work, but he had not disclosed his status to anyone outside of the healthcare system. Jambo sought to maintain his biographic continuity, not allowing for his identity to be affected by HIV diagnosis. For Malaika, a HIV diagnosis meant a biographical disruption, with neither incorporation of a new identity post-diagnosis, nor adaptation of her identity. We explore how these different responses are associated with sexual and reproductive behaviours and intentions.

Malaika's biographical disruption has implications for her sexual and reproductive life:

Malaika: No, I have not had sex since I knew about my status. I lost sexual desire completely. I don't even long for a man…
Int: Could you explain why you don't want another child?
Malaika: I always hear that there are drugs that people are given to prevent the baby from getting infected with the virus. But then don't you think that I will infect the person that I am going to sleep with, with the HIV virus? I cannot give somebody the virus knowingly like that just for him to impregnate me and then go and take drugs that will prevent

the child from getting the virus. What about that man?

Those PLWHA who were able to incorporate HIV/AIDS in their identity without it being disruptive to their biography, were pursuing sexual and reproductive lives. At the time of her interview, Safari was sexually active with a steady partner and reported consistent condom use:

> Safari: The man I am with, the first thing is, I am the person who will put the condom on for him. I do not want him to do it himself. Even if it is at night the lights have to be on, because a man is just a man, he might cut the condom and add me more viruses.

Safari also planned to have another child, in part to seek social approval and affirmation as part of her identity as a women [11, 37]. Intentions to have children might be interpreted as an attempt to regain some normalcy [38], especially in slums with high infant mortality:

> Int: Why would you want to give birth to another child?
>
> Safari: The one child that I have may die and I remain without any...I start from zero, you see! Having a child is a matter of great importance, if you do not have a child you are seen to be a cursed person. Even if you are a girl and you are not married, it is very important to have a child. The child will keep the name of the parent. Even if you die people will be happy to say this is so and so's child. The child preserves the name of the parent, the name will not disappear.

For women, the burdens of (non-)reproduction are high, and Malaika and Safari represent two different responses to childbearing after a HIV diagnosis. By contrast, Jambo's more continuous biography reflected his pre-diagnosis identity:

> INT: Did you use a condom during your last sex?
>
> Jambo: Aaahi! How can I have sex with a woman while using a condom? Am I to fuck the condom or her vagina…so my blood gets into her?! Then I go and throw away my semen in the toilet, why? I don't want it, if it's a question of condoms, I would rather do away with a vagina because it will not benefit me in any way.

From Jambo's perspective the need for sexual gratification involving sexual fluid exchange outweigh condom use [39].

Discussion

There are multiple and complex responses to diagnosis with HIV, in an era of ART availability, set against a backdrop of life in a Nairobi slum. For some people this process involves a transition to a new self-identity, incorporating both HIV and ART into their lives [40], for others it involves a partial transition, with some aspects of identity persisting, and others redefined [23, 25, 41]. Multiple phases of identity transition, including diagnosis, (non-)disclosure, positive living, attempts at repair and normalcy, play out in people's narratives and their sexual and future reproductive intentions. PLWHA try to mobilise resources to help them deal with the diagnosis [23, 24] , including social groups, faith-based organisations, and enrolling for ART. Such groups appear to provide some much needed social support to mitigate psychological distress associated with a HIV diagnosis [42]. Studies from elsewhere in SSA have documented a positive relationship between prayer/spirituality and quality of life among PLWHA [43]. The use of ART was a significant resource enabling PLWHA to regain positions as economically and socially productive members of society [44, 45]. In the context of the high premium placed on parenthood [46], HIV posed a potential threat to peoples' identities as mothers and fathers.

Sampling participants from the slum community is a major strength of our study. Most studies on PLWHA sample from HIV health services where participants are likely to have better access to services and to have been better informed about SRH services and HIV prevention than the general population of PLWHA. However, our interviews had a heterosexual and consensual sex focus and it is highly unlikely that respondents would volunteer same-sex or forced sex activities. Since these sexual identities and activities are stigmatised in Kenya, a different approach might have helped the research process, although their under-reporting might still persist. Information on sexual behaviour and fertility preferences were entirely based on self-reports using face to face interviews. Given the sensitive nature of these topics, there is likely to have been social desirability bias. Both men and women misreport their sexual behaviour [47] and respondents might be inclined to underreport their unsafe sexual behaviour. Although we took precautions to limit social desirability bias – such as training interviewers to create a climate of trust that allows free talk about such matters and using non-clinical community interviewers – its effect cannot be completely eliminated.

In spite of these limitations, this study contributes to the empirical literature on sexual and reproductive health of PLWHA in a poor setting, an under-researched topic. PLWHA experience life with HIV and face challenges around stigma, managing ART, negotiating sexual intimacy and reproduction. Our data show the need to address living with HIV/AIDS holistically, asking broad questions about lived experience of PLWHA, paying attention to structural elements of poverty, gender and socio-cultural norms, recognising PLWHA as sexual and reproductive human beings. Research in developing countries that has addressed sexual behaviour of PLWHA has focused on risky behaviour mostly using quantitative data from surveys [48]. Studies have considered the reproductive goals of PLWHA [37, 49], suggesting that sexual and reproductive behaviour of PLWHA should be understood by connecting sexuality to gender, reproductive goals and larger socio-economic contexts [50, 51].

The effect of ART on sexual and reproductive behaviour is attracting research and policy attention following ART rollout in resource-poor settings. The findings of the few studies that have examined how treatment affects sexual and reproductive behaviour in such settings have produced mixed results, highlighting the need for a better evidence base [13, 52, 53]. There is a growing recognition of the need to support the rights of PLWHA to be sexually active and achieve their fertility goals, while minimizing HIV transmission risk [54] and this study is an effort in that direction. Health care workers in Kenya rarely give HIV infected people the opportunity to articulate their fertility desires [55]. Meeting the sexual and reproductive health needs of PLWHA means more than just counselling those who want to avoid pregnancy. Psycho-social factor play a prominent role in sexual functioning, and diminished sexual interest and sexual abstinence are strongly associated with psychological distress, depression, anxiety and low quality of life, over and above disease factors such as CD4 cell counts and duration or severity of illness [56]. PLWHA could benefit from counselling around sexuality as a whole, not just risk reduction as is usually the case. Our findings speak to the need for interventions to help PLWHA to safely become sexually active if they want to. Because the process of incorporating HIV into an individual's identity is neither linear nor predictable, diagnosis presents an opportunity for healthcare providers to discuss these issues. Subsequent referrals for mental health services might, for example, become necessary depending on how individuals cope with their diagnosis.

Funding statement: This work was supported by the Wellcome Trust grant number [078471/Z/05/A]. The sponsor had no role in the design and conduct of the study; in the collection, analysis and interpretation of the data or in the preparation, review or approval of the manuscript. The opinions, results and conclusions reported in this paper are those of the authors and are independent from the funding sources.

Competing interests: None declared

Acknowledgements: We are grateful to the participants of the study for their time and contributions. We are grateful to the African Population and Health Research Centre for permission to sample from the Nairobi Urban Demographic Surveillance System.

Contributors: Study concept and design: EW, EC. Acquisition of data: EW. Analysis and interpretation of data: EW, EC. Drafting of the manuscript: EW. Critical revision of manuscript: EC, EW. Administrative, technical or material support: EW, EC

Data Sharing

Additional unpublished data from the study are available upon request from the coresponding author.

References

1. UNAIDS, *Global HIV/AIDS Response: Epidemic update and health sector progress towards Universal Access Progress Report 2011.*, 2011, World Health Organization/United Nations United Nations Joint Programme on AIDS: Geneva, Switzerland.
2. NACC, *Kenya National AIDS Strategic Plan 2009/10 – 2012/13Delivering on Universal Access to Services*, 2009, National AIDS Control Council
Nairobi.
3. UNAIDS, *Global report: UNAIDS report on the global AIDS epidemic*. 2010, Geneva: Joint United Nations Programme on HIV/AIDS (UNAIDS).
4. WHO/UNAIDS, *Towards Universal access Scaling up priority HIV/AIDS interventionsin the health sector: Progress report 2008*, 2008, World Health Organization/United Nations United Nations Joint Programme on AIDS: Geneva, Switzerland.
5. Birungi, H., C.-C. Undie, and P. Aggleton, *Recent research on sexuality in East Africa.* Culture, Health & Sexuality, 2009. **11**(8): p. 747-750.
6. Segurado, A.C. and V. Paiva, *Rights of HIV Positive People to Sexual and Reproductive Health: Parenthood.* Reproductive Health Matters, 2007. **15**(29, Supplement 1): p. 27-45.
7. WHO, *Sexual and reproductive health of women living with HIV/AIDS: Guidelines on care, treatment and*
support for women living with HIV/AIDS and their children in resource-constrained settings, 2006, World Health Organization: Geneva.
8. Bartlett, J.A., *Addressing the challenges of adherence.* Journal of Acquired Immune Deficiency Syndromes, 2002. **29**: p. S2-S10.
9. Hardon, A., Hodgkin, C. & Laing, R., *From access to adherence: The challenges of antiretroviral treatment. Studies from Botwana, Tanzania and Uganda*, 2006, World Health Organization: Geneva.
10. Orrell, C., et al., *Adherence is not a barrier to successful antiretroviral therapy in South Africa.* AIDS, 2003. **17**(9): p. 1369-1375.
11. Cooper, D., et al., *Fertility Intentions and Reproductive Health Care Needs of People Living with HIV in Cape Town, South Africa: Implications for Integrating Reproductive Health and HIV Care Services.* AIDS and Behavior, 2009. **13**(0): p. 38-46.
12. GNP+, *Advancing the Sexual and Reproductive Health and Human Rights of People Living With HIV*. 2009, Amsterdam: The Global Network of People Living with HIV/AIDS (GNP+).
13. Luchters, S., et al., *Safer sexual behaviors after 12 months of antiretroviral treatment in Mombasa, Kenya: a prospective cohort.* AIDS Patient Care & STDs, 2008. **22**(7): p. 587-594.
14. Remien, R., et al., *Medication Adherence and Sexual Risk Behavior among HIV-Infected Adults: Implications for Transmission of Resistant Virus.* AIDS and Behavior, 2007. **11**(5): p. 663-675.

15. Crepaz, N., T.A. Hart, and G. Marks, *Highly active antiretroviral therapy and sexual risk behavior - A meta-analytic review.* Jama-Journal of the American Medical Association, 2004. **292**(2): p. 224-236.
16. Kennedy, C., et al., *The impact of HIV treatment on risk behaviour in developing countries: A systematic review.* AIDS Care, 2007. **19**(6): p. 707 - 720.
17. De Ryck, I., et al., *Sexual Satisfaction Among Men Living with HIV in Europe.* AIDS and Behavior, 2011: p. 1-6.
18. UN-HABITAT, *Slums of the World: The Face of Urban Poverty in the New Millenium? Global Urban Observatory*, 2003b, Nairobi:UN-Habitat:.
19. Amuyunzu-Nyamongo, M., et al., *Putting on a brave face: The experiences of women living with HIV and AIDS in informal settlements of Nairobi, Kenya.* AIDS Care, 2007. **19**(1 supp 1): p. 25-34.
20. Zulu, E., et al., *Overview of migration, poverty and health dynamics in Nairobi City's slum settlements.* Journal of Urban Health, 2011. **88**(0): p. 185-199.
21. Bury, M., *Chronic illness as biographical disruption.* Sociology of Health & Illness, 1982. **4**(2): p. 167-182.
22. Baumgartner, L.M., *The Incorporation of the HIV/AIDS Identity Into the Self Over Time.* Qualitative Health Research, 2007. **17**(7): p. 919-931.
23. Carricaburu, D. and J. Pierret, *From biographical disruption to biographical reinforcement: the case of HIV-positive men.* Sociology of Health & Illness, 1995. **17**(1): p. 65-88.
24. Williams, S., *Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept.* Sociology of Health & Illness, 2000. **22**(1): p. 40-67.
25. Ciambrone, D.e., *Illness and other assaults on self: the relative impact of HIV/AIDS on women's lives.* Sociology of Health & Illness, 2001. **23**(4): p. 517-540.
26. Braun, V. and V. Clarke, *Using thematic analysis in psychology.* Qualitative Research in Psychology, 2006. **3**: p. 77-101.
27. Ivankova, N.V., J.W. Creswell, and S.L. Stick, *Using Mixed-Methods Sequential Explanatory Design: From Theory to Practice.* Field Methods, 2006. **18**(1): p. 3-20.
28. Kaler, A. and S. Watkins, *Asking God about the date you will die: HIV testing as a zone of uncertainty in rural Malawi.* Demographic Research, 2010. **23**(32): p. 905-932.
29. Gersovitz, M., *HIV Testing: Principles and Practice.* The World Bank Research Observer, 2011. **26**(1): p. 1-41.
30. Obermeyer, C.M. and M. Osborn, *The Utilization of Testing and Counseling for HIV: A Review of the Social and Behavioral Evidence.* Am J Public Health, 2007. **97**(10): p. 1762-1774.
31. Baumgartner, L.M. and K.N. David, *Accepting Being Poz: The Incorporation of the HIV Identity Into the Self.* Qualitative Health Research, 2009. **19**(12): p. 1730-1743.
32. Ciambrone, D.e., *Women's experiences with HIV/AIDS: mending fractured selves* 2003, Binghamton, NY: The Haworth Press.

33. Mahalik, J.R., G.E. Good, and M. Englar-Carlson, *Masculinity scripts, presenting concerns, and help seeking: Implications for practice and training.* Professional Psychology: Research and Practice, 2003. **34**(2): p. 123-131.

34. Derlega, V.J., et al., *Reasons for HIV Disclosure/Nondisclosure in Close Relationships: Testing a Model of HIV–Disclosure Decision Making.* Journal of Social and Clinical Psychology, 2004. **23**(6): p. 747-767.

35. Bartos, M. and K. McDonald, *HIV as identity, experience or career.* AIDS Care, 2000. **12**(3): p. 299-306.

36. Anderson, M., et al., *Coping With HIV: Caribbean People in the United Kingdom.* Qualitative Health Research, 2009. **19**(8): p. 1060-1075.

37. Cooper, D., et al., *"Life is still going on": Reproductive intentions among HIV-positive women and men in South Africa.* Social Science & Medicine, 2007. **65**(2): p. 274-283.

38. Smith, D.J. and B.C. Mbakwem, *Life projects and therapeutic itineraries: marriage, fertility, and antiretroviral therapy in Nigeria.* AIDS, 2007. **21**: p. S37-S41.

39. Coast, E., *Wasting sperm:The Maasai context of condom use in Northern Tanzania.* Culture, health and sexuality, 2007. **9** (4): p. 387-401

40. Russell, S. and J. Seeley, *The transition to living with HIV as a chronic condition in rural Uganda: Working to create order and control when on antiretroviral therapy.* Social Science & Medicine, 2010. **70**(3): p. 375-382.

41. Wilson, S., *'When you have children, you're obliged to live'1: motherhood, chronic illness and biographical disruption.* Sociology of Health & Illness, 2007. **29**(4): p. 610-626.

42. Kalichman, S.C., et al., *Stress, Social Support, and HIV-Status Disclosure to Family and Friends Among HIV-Positive Men and Women.* Journal of Behavioral Medicine, 2003. **26**(4): p. 315-332.

43. Friend-du Preez, N. and K. Peltzer, *HIV Symptoms and Health-Related Quality of Life Prior to Initiation of HAART in a Sample of HIV-Positive South Africans.* AIDS and Behavior, 2010. **14**(6): p. 1437-1447.

44. Campbell, C., et al., *"We, the AIDS people. . .": How Antiretroviral Therapy Enables Zimbabweans Living With HIV/AIDS to Cope With Stigma.* American Journal of Public Health, 2011. **101**(6): p. 1004-1010.

45. Castro, A. and P. Farmer, *Understanding and Addressing AIDS-Related Stigma: From Anthropological Theory to Clinical Practice in Haiti.* American Journal of Public Health, 2005. **95**(1): p. 53-59.

46. Awiti Ujiji, O., et al., *"I will not let my HIV status stand in the way." Decisions on motherhood among women on ART in a slum in Kenya- a qualitative study.* BMC Women's Health, 2010. **10**(1): p. 1-10.

47. Buvé, A., et al., *Multicentre study on factors determining differences in rate of spread of HIV in sub-Saharan Africa: methods and prevalence of HIV infection.* AIDS, 2001. **15**: p. S5-S14.

48. Bateganya, M., et al., *Antiretroviral Therapy and Sexual Behavior: A Comparative Study between Antiretroviral- Naive and -Experienced Patients at an Urban HIV/AIDS Care and Research Center in Kampala, Uganda.* AIDS Patient Care & STDs, 2005. **19**(11): p. 760-768.

49. Myer, L., C. Morroni, and K. Rebe, *Prevalence and Determinants of Fertility Intentions of HIV-Infected Women and Men Receiving Antiretroviral Therapy in South Africa.* AIDS Patient Care & STDs, 2007. **21**(4): p. 278-285.

50. Laher, F., et al., *A Qualitative Assessment of Decisions Affecting Contraceptive Utilization and Fertility Intentions among HIV-Positive Women in Soweto, South Africa.* AIDS and Behavior, 2009. **13**(0): p. 47-54.

51. Persson, A. and W. Richards, *Vulnerability, gender and "proxy negativity": Women in relationships with HIV-positive men in Australia.* Social Science & Medicine, 2008. **67**(5): p. 799-807.

52. Kaida, A., et al., *Childbearing Intentions of HIV-Positive Women of Reproductive Age in Soweto, South Africa: The Influence of Expanding Access to HAART in an HIV Hyperendemic Setting.* Am J Public Health, 2011. **101**(2): p. 350-358.

53. Sarna, A., et al., *Changes in sexual risk taking with antiretroviral treatment: influence of context and gender norms in Mombasa, Kenya.* Culture, Health & Sexuality, 2009. **11**(8): p. 783-797.

54. Kaida, A., et al., *Editorial: Introduction to the Supplement on HIV, HAART, and Fertility in sub-Saharan Africa.* AIDS and Behavior, 2009. **13**(0): p. 1-4.

55. CRR and Fida-Kenya. *At risk: Right violations of HIV- positive women in Kenya health facilities*
2008; Available from: http://reproductiverights.org/sitesdafualt/files.documents/AtRisk.pdf.

56. Florence, E., et al., *Prevalence and factors associated with sexual dysfunction among HIV-positive women in Europe.* AIDS Care, 2004. **16**(5): p. 550-557.

NOTE: PLEASE SAVE THIS TO YOUR HARD DRIVE UNDER A DIFFERENT FILE NAME AFTER YOU FILL IT OUT

STROBE Statement—checklist of items that should be included in reports of observational studies

Please fill out the page numbers on this form and upload the file as a supplemental file when you submit your revision

Manuscript Number____

	Item No	**Recommendation**	**Indicate page number ↓ (Or n/a if not applicable)**
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3
Objectives	3	State specific objectives, including any prespecified hypotheses	3
Methods			
Study design	4	Present key elements of study design early in the paper	3
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	3
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	4
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	n/a
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	n/a
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	4
Bias	9	Describe any efforts to address potential sources of bias	13
Study size	10	Explain how the study size was arrived at	n/a
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	n/a
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	n/a
		(*b*) Describe any methods used to examine subgroups and interactions	n/a
		(*c*) Explain how missing data were addressed	n/a
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy	n/a
		(*e*) Describe any sensitivity analyses	n/a
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	6
		(b) Give reasons for non-participation at each stage	n/a
		(c) Consider use of a flow diagram	n/a
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	6
		(b) Indicate number of participants with missing data for each variable of interest	6
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	n/a
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	n/a
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	n/a
		Cross-sectional study—Report numbers of outcome events or summary measures	n/a
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95%	n/a

		confidence interval). Make clear which confounders were adjusted for and why they were included	
		(*b*) Report category boundaries when continuous variables were categorized	n/a
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	7
Discussion			
Key results	18	Summarise key results with reference to study objectives	12
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	13
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	13
Generalisability	21	Discuss the generalisability (external validity) of the study results	13
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	14

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

Living with HIV post-diagnosis: a qualitative study of the experiences of Nairobi slum residents

Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2012-002399.R1
Article Type:	Research
Date Submitted by the Author:	18-Feb-2013
Complete List of Authors:	Wekesa, Eliud; Population Council, Coast, Ernestina; London School of Economics, Social Policy
Primary Subject Heading:	HIV/AIDS
Secondary Subject Heading:	Qualitative research
Keywords:	HIV & AIDS < INFECTIOUS DISEASES, QUALITATIVE RESEARCH, Anthropology < TROPICAL MEDICINE

Living with HIV post-diagnosis: a qualitative study of the experiences of Nairobi slum residents

Authors:

Coast, Ernestina[1]; Wekesa, Eliud[2]

Affiliations:

1. Population Council
   Nairobi Kenya
2. London School of Economics - Social Policy
   Houghton Street , London WC2A 2AE United Kingdom

Keywords: HIV & AIDS < INFECTIOUS DISEASES, QUALITATIVE RESEARCH, Anthropology < TROPICAL MEDICINE

Word count: 4423

Structured abstract

Objectives: To characterise the experiences of heterosexual men and women living with HIV post-diagnosis and explain these experiences in relation to their identity and sexuality.

Design: Qualitative study using in-depth interviews and theoretically informed biographic disruption theory.

Setting: Interviews were conducted in two Nairobi slums (Kenya).

Participants: 41 HIV-infected heterosexual men and women aged 18 years or older

Results: People living with HIV have divergent experiences surrounding HIV diagnosis. Post-diagnosis there are multiple phases of identity transition, including status (non-)disclosure, and attempts at identity repair and normalcy. For some people this process involves a transition to a new self-identity, incorporating both HIV and antiretroviral treatment (ART) into their lives. For others it involves a partial transition, with some aspects of their pre-diagnosis identity persisting, and for others it involves a rejection of HIV identity. Those people who were able to incorporate HIV/AIDS in their identity without it being disruptive to their biography, were pursuing safer sexual and reproductive lives. By contrast, those people with a more continuous biography continued to reflect their pre-diagnosis identity and sexual behaviour.

Conclusions: People living with HIV/AIDS (PLWHA) had to rework their sense of identity following diagnosis in the context of living in a slum setting. Men and women living with HIV in slums are poorly supported by health systems and services as they attempt to cope with a diagnosis of HIV. Given the availability of antiretroviral therapy, health services and professionals need to support the rights of PLWHA to be sexually active if they want to and achieve their fertility goals, while minimizing HIV transmission risk.

Article summary

Article focus

- Slum populations are under-researched, and very little empirical research examines the experiences of people living with HIV post-diagnosis

- Impact of HIV post-diagnosis identity on sexual behaviour.

Key messages

- Men and women living with HIV in slums are poorly served by health services post-diagnosis.

- Health service provision and support does not incorporate the increasing needs of people living with HIV and AIDS to navigate their sexual and reproductive lives.

- The sexual behaviour of PLWHA are influenced by their HIV post-diagnosis identity transformation.

Strengths and limitations of this study

- The first in-depth study of the experiences of people living in slums following a HIV diagnosis in relation to their identity and sexuality.

- We did not include the perspectives of relevant stake holders such as partners or policymakers

Introduction

Sub-Saharan Africa (SSA) is the most affected region by the HIV/AIDS pandemic, accounting for over 68% of the total global burden [1]. 1.6 million Kenyans are currently living with HIV and Kenyan adult HIV prevalence is estimated at 6.2%, higher than the SSA regional prevalence (4.9%) [2].

The introduction of anti-retroviral therapy (ART) has improved the prognosis of HIV, with the potential to transform it to a chronic condition. Access to ART in low and middle income countries has expanded rapidly, with 6.6 million people now receiving treatment, nearly half of those eligible for treatment [1]. Seventy two percent of Kenyan adults and children with advanced HIV infection receive ARVs [3] With ART, the future life opportunities of PLWHA can change, including those related to sexuality and reproduction [4-6]. However, research has focused on issues of access and adherence to ART for treatment effectiveness [7-9]. More recently, evidence about the relationships between stigma and ARV availability and uptake has emerged from low income settings[10]. At the individual level, ARV adherence is negatively affected by stigma from partners [11-13], although self-stigma has been shown to decline in contexts of increasing access to treatment[14], and stigma changes over the lifecourse.[15] Whilst the provision of ARV has the potential to reduce stigma about HIV/AIDS[16] in a wide range of low income contexts,[17-19] this relationship is not universal [20]. The relationship between ART and status disclosure to partner(s), family and community is also poorly understood, with the majority of evidence coming from high income settings [21]. Research from SSA suggests a distinctive pattern of disclosure that relies on third parties and intermediaries, especially religious leaders, as instruments of disclosure [22]. The sexual health rights and needs of PLWHA remain under-researched and poorly understood [5, 23, 24], even though issues of stigma and disclosure are likely to be closely related to sexual behaviour post-diagnosis. There are policy concerns about treatment optimism, with an increase in riskier sexual behaviour as more people become aware that HIV/AIDS is a manageable condition with ART [25-28]. Sexuality is a crucial element of being human and sexual health (pleasurable and safe sex) is an important component of overall health [29]

Nearly three quarters (72%) of urban residents in SSA live in slums [30] where single-room homes are densely packed [31]. The poor health status of slum residents reflects poor environmental conditions and infrastructure, limited access to treatment and preventive health services; and reliance on poor quality and informal and regulated health services [32]. Urban slums and their residents are an important, but under-researched, aspect of life in SSA. We undertook a qualitative study of the sexual and reproductive experiences and intentions of heterosexual men and women living with HIV in Nairobi slums.

Methods

Theoretical framework

We organised and analysed our data using the theoretical concept of biographical disruption [33], to understand how HIV acts as a disruptive experience to an individual's life, social relations and identity [34-36]. There are three components to biographic disruption: disruption of an individual's former behaviour or assumptions; changes in an individual's perceptions of self; and, an attempt to repair or change one's biography. Biographical disruption of HIV has been studied in the global North, and the extent to which it applies to PLWHA in other settings is much less well understood [35, 37, 38]. Prior to the widespread availability of ART, evidence of the ways in which identity formation was affected by a HIV diagnosis focused on the mortality implications [35], stigma [39] and any subsequent disclosure [34]. Earlier analyses tended to be based on quantitative questions in surveys [34] with limited analytic insights. More recent analyses have incorporated evidence from qualitative and mixed methods studies and highlight the ways in which identity post-diagnosis has been used as a social and political force to improve treatment access [40]. Research in Zambia, conducted pre- and post-ART roll-out suggest that whilst ART makes disclosure easier, it also changes the context into which an individual discloses [41]. Research into sexual behaviour post-HIV diagnosis in SSA has tended to focus on quantitative measures of sexual behaviour (number of partners, frequency of sex, concurrency, condom (non-)use [42] with much of the research coming from South Africa with some exceptions [43, 44]

Study Context

Data for this study were collected from two slum communities (Korogocho and Viwandani) in Nairobi, Kenya. Housing conditions in these slums are temporary, typically single rooms constructed from mud, iron sheets, cardboard boxes and polythene [31]. The settings are characterised by overcrowding, insecurity, poor sanitary conditions, poverty, high unemployment levels, poor amenities and infrastructure, limited access to preventative and curative services and reliance on poor quality, usually informal and unregulated health services [32, 45]. These conditions contribute to poor health outcomes for slum residents relative to other sub-populations in Kenya, including, higher levels of mortality and morbidity, HIV prevalence, risky sexual behaviours, unmet need for contraception and unintended pregnancies[46-49]

Sampling and recruitment

We analyse qualitative data collected as part of a larger mixed methods study of PLWHA (18 years and above) conducted in 2010. The study adopted a sequential design, with quantitative survey interviews (n=513) followed by in-depth interviews with a subsample (n=41) drawn from the survey. The quantitative sample size was determined on the basis of sample size calculations [50]. Respondents were recruited from the Nairobi Urban Demographic and Health Surveillance System through quota sampling on the basis of sero-prevalence ratios and socio-demographic characteristics in the study sites [49]. Purposive selection of respondents for the qualitative interview was based on analyses of the survey data, and identification of a range of experiences. Key informant interviews (n=14) were conducted with health providers. Eight research assistants RAs (four per site) were recruited for the quantitative survey, of which two per site were retained for the qualitative in-depth interviews. The RAs all had several years' experience of data collection in the study sites, were trained HIV/AIDs counsellors, and one RA was a PLWHA. Interviews were conducted in KiSwahili and the qualitative interviews were recorded, transcribed verbatim, translated into English and analysed using NVivo [51].

Ethical considerations

We obtained written consent from all respondents and all interviews were conducted in a setting of the respondent's choice. Privacy in home settings in slums is difficult to achieve, and respondents were given the option of being interviewed in the offices of a local health organisation. A small grocery package was provided as compensation for each respondent. Approval for the study was granted by the Kenyan Medical Research Institute (KEMRI) and the London School of Economics (LSE). Our analyses use pseudonyms for the presentation of data.

Results

The socio-demographic characteristics of the qualitative study participants are summarised in Table 1.

Table 1: Socio-demographic characteristics of respondents (n=41), 2010.

CHARACTERISTIC	PERCENT (N=41)
Slum of residence	
Korogocho	59
Viwandani	41
Sex	
Female	56
Male	44
Ethnicity	
Kikuyu	34
Luo	24
Luyia	20
Kamba	15
Other	7
Education	
No Schooling	7
Primary	66
Secondary and higher	27
Marital Status	
Married/Cohabiting	41
Divorced/separated	17
Widowed	29
Never Married	12
Age	

18-29	22
30-39	32
40-49	32
50+	15
Treatment Status	
Receiving ART	56
Not Receiving ART	44

We present detailed analyses of three typical case studies, purposively selected from the qualitative sample in order to draw out the complexities of biographical disruption following diagnosis with HIV.

Table 2: Summary characteristics of three case study respondents

Characteristics	Case study
Sexually abstinent	Malaika, female, 29 years old, widowed, known HIV status for 3 years. . After her husband's death in 2003, she was briefly "inherited" by her brother-in-law. This is a traditional practice involving a widow becoming the de facto sexual partner of her dead husband's brother.
Sexually active, monogamous relationship, consistent use of condoms and/or contraception	Safari, female, 34 years old, currently cohabiting, known HIV status for 15 years.
Sexually active, multiple partners, inconsistent use of condoms and/or contraception	Jambo, male, 55 years old, widower, known HIV status for nine years.

By selecting three case studies we contribute to deeper understanding of the ways in which individual trajectories unfold post-diagnosis, acknowledging the complexity of biographical disruption. We selected these case studies to represent a range of sexual behaviour reported by the wider qualitative sub-sample (Table 2) [52].

Reactions to a diagnosis of HIV

HIV diagnosis is the first step in incorporating HIV/AIDS into an individual's identity, challenging their identity as a healthy person. Most research on HIV testing in SSA focuses on its benefits, costs and barriers [53, 54], with little understanding of people's experiences of having a test [55]. Safari's narrative is typical of health provider response and management early in the epidemic:

> INT: So how did you know your status?
> Safari: I kept going to *Hospital*. That is when I heard doctors saying things like HIV/AIDS and they started pointing fingers at me. Those days things were so bad; not like these days…He told me; you know, there is a disease that has come out. It does not have a cure. It is not known what kind of disease it is, and Safari you have that disease.

Diagnosis often occurred during a health crisis:

> Jambo: I had a chest problem and when I went to hospital they told me that I had to be tested for HIV. I knew I had TB, but when I was tested for HIV...Oh no! aaayaai! I was surprised to be told that I was HIV+.

Being diagnosed with HIV/AIDS elicits multiple reactions, both negative (e.g.: shock) and positive (e.g.: relief) [34, 56]. People struggled to grapple with the meaning of a positive test and its implication for their life. Their biographies were initially disrupted and needed reworking to accommodate HIV/AIDS. These initial emotions evolved and changed with time. Malaika's reaction was of distress and denial:

> Malaika: I was very angry. I wished I was not alive because I saw myself as a dead person. I thought about killing myself. I wanted to kill my children but it was just that they were still very young. I did not suspect I was HIV positive because I did not go out with other men.

Safari feared being associated with prostitutes, a marginalised and stigmatised group:

> Safari: I will be put with the people who are cursed in life. A person called a prostitute is a cursed person. People would think that I came to Nairobi to be a prostitute. I hated myself. I took it as a curse.

Jambo's narrative involved putting on a brave face, a reaction that is rarely reported in studies of diagnosis reactions [eg 34, 57]. Jambo displayed a "masculinity script" [58] by reporting himself to be brave, fearless, and emotionless upon testing HIV positive:

> Jambo: I wasn't angry because I am a man. You are only scared if you are not a man.

Diagnosis represented a first step in HIV identity formation, followed by decisions about whether to disclose their status.

HIV status disclosure: To tell or not to tell.

Managing the flow of information about HIV status, including (non-)disclosure of HIV status is central to how people manage their identity post-diagnosis. Decisions to disclose evolve over time, encompassing a process beginning with non-disclosure and sometimes ended in forced disclosure:

> Safari: My mother was told but not by me. When you live with people in the house they will know something and they will start talking and word goes round. After all, my body betrayed me.

Safari's disclosure was articulated as subsequently driven by a desire to educate and inform others about HIV/AIDS, a disclosure motive that has also been documented in the US [59].

> Int: Why did you tell other relatives then?
>
> Safari: …So I wanted to educate them more about HIV/AIDS. How you can get it and how to take care of it and how you can live with it.

Neither Malaika nor Jambo had disclosed their status to anyone beyond healthcare providers. A major barrier to their disclosure is fear of stigma and discrimination:

> Malaika: It is very difficult for me to disclose my status because people will start talking ill about me, they will not feel good when their children play together with my children and they will look down upon me. That is why I don't want to disclose it to any one and just want it to be my secret.

Jambo's explanation of his non-disclosure refers instead to issues of confidentiality:

> Jambo: How can I reveal matters affecting my body to anyone; that I have HIV? Why? Are they my doctor? Why should they know?

Key informant interviews reported similar negative social responses experienced by PLWHA:

> Nurse: I can remember a client...a man who came to me... he had been tested and we were just sharing with him. He told me when he went home and shared his HIV status with the wife, the wife packed and left.

Incorporation of HIV into people's identity is shaped by both individual reaction and the reaction of others and is a process of transition involving decisions about (non-) disclosure.

Assimilation and resources for identity normalisation

The third phase involves reorganisation and / or reconstruction of biographies towards some kind of normality, possibly different to that preceding HIV diagnosis, and requires resources for support and encouragement [60]. The two main resources identified in our data include: social capital and ART. Three major sources of social capital were identified: HIV support groups; government healthcare services; and, faith-based organisations (FBOs). HIV support groups can provide confidential spaces where experiences and issues about HIV such as disclosure, sexuality and adherence are shared:

> Safari: We visit support groups where we learn a lot together. From there you just feel you belong to the society. You just feel you are [like HIV] "negative" and not "positive". We are taught so many things about living positively with the disease.

Of our three in-depth case studies, only Safari had fully disclosed her status; she had assimilated her HIV status into her life and it had become central to her identity. For this group of people, social support groups played an integral role in creating and maintaining an HIV positive identity, forming a bio-sociality to decipher biomedical information (e.g.: CD4 cell counts, viral loads, treatment side-effects), over and above individual clinic consultations. Safari developed her identity as a new "career" [61], and formed a support group to provide social support for PLWHA and income generation activities (e.g.: selling beads, poultry farming):

> Safari: I used to hate myself before, but now I am a very informed person living positively with HIV.I disclosed to many people and they began calling me *mama ukimwi* (mother AIDS), but I didn't mind. I have educated myself from newspapers and the television. I have a very big dream of changing the community. I chair a support group and have a dream of educating the community about HIV/AIDS. I overcame stigma and want to help other PLWHA.

Secondly, social capital from health workers is accessed post-diagnosis by PLWHA, regardless of their disclosure status. Community health workers are often the only sources of social capital for PLWHA who have not disclosed their status. PLWHA should be assigned a community health care workers (CHWs) who operated in the PLWHA's residential area, and were meant to meet at least once per week.

> Clinical Officer: They [CHWs] are the ones who deal mostly with these clients. They support them in the community so they can cope with the HIV situation. They are the ones helping us to do community outreaches, door to door training, door to door campaign on TB and HIV.

However, evidence from respondents suggested that this regular contact was rarely maintained, in part because community health workers often had multiple jobs in order to maximise their own incomes.

Thirdly, faith-based social networks also play a role in helping people to shape their new identities, including the management of anxiety and depression [62]:

> Safari: Because I am not taking ART I know one day, God will heal me by faith. It has been 15 years since I knew my status but I have not taken any of these drugs.

Prayer and religiosity played a pivotal role in some PLWHA's lives, providing an essential source of spiritual support. Evidence from the UK suggests that religion can help to manage anxiety and depression post-diagnosis [62].

ART can strengthen social relationships and self-identity because it improves people's capacity to work, important for social and economic viability and validation, allowing people to play their societal role as breadwinner, parent or adult. For many PLWHA, hope and uncertainty co-exist, leading to contrasting and ambivalent views about ART, even among those individuals who have developed a positive identity:

Safari: I should have started using the [ART] drugs, but I said no. The doctor was pushing me to start the drugs, but I refused.
Int: Why did you refuse?
Safari: Let me tell you, I fear those drugs. The thing that makes me fear them is the reactions they cause. I have seen the problems they cause to people. The swelling of the feet, then there is one that removes all the fat from the body and it brings to one side. You find one's breast has grown fat; you have a bad shape. That is why I fear them.

For many PLWHA being HIV positive is simply a medical label, and not a defining feature of their identity:

Int: So life goes on as usual?
Jambo: Yes ... people might say that I have HIV, but for me that is not important…My main problem is that I have no means to earn a living, I have many challenges. I am usually rained on in this house whenever it rains, but I cannot [afford to] migrate from here.

For those PLWHA who experienced a dissonance between their HIV status and their perceived health status, this tended to lead to the rejection of an HIV identity:

Malaika: That thing [HIV diagnosis] is very painful that I even don't want to think about it. I don't even want be going to the NGOs to read those things about HIV/AIDS because I know I have it. I just want to stay "*bubu* [dumb] style".

Malaika had decided not to use ART because she had concerns about the requirement for good nutrition in order to be able to take the drugs:

Int: Are you on ART?
Malaika: I am not on any treatment, I just stay like that…I don't see the need to use these drugs when I don't feel any pain in my body. In fact, I hear you need to eat well when you take those drugs and sometimes you don't have the means to buy food.

Lack of food as in issue in non-adherence to ART was highlighted by healthcare providers:
Clinical Officer: We have experienced some clients who complain that they cannot take the drugs as instructed due to lack of food since the drugs are quite strong.

Our case studies illustrate the range of experiences around people's identities post-HIV diagnosis. Safari, with full disclosure, had started to make a career out of her HIV status, although she preferred to place her faith in religion, rather than ART, to maintain her health. Safari had completely assimilated a new HIV identity. Jambo, on the other hand, was motivated to adhere to ART in order that he would be able to work, but he had not disclosed his status to anyone outside of the healthcare system. Jambo sought to maintain his biographic continuity, not allowing for his identity to be affected by HIV diagnosis. For Malaika, a HIV diagnosis meant a biographical disruption, with neither incorporation of a new identity post-diagnosis, nor adaptation of her identity. We explore how these different responses are associated with sexual behaviours.

Malaika's biographical disruption has implications for her sexual life:

> Malaika: No, I have not had sex since I knew about my status. I lost sexual desire completely. I don't even long for a man… I actually hate them [men]. You know when a woman loses feeling? I don't have [sexual] feeling at all.

Those PLWHA who were able to incorporate HIV/AIDS in their identity without it being disruptive to their biography, were pursuing sexual lives. At the time of her interview, Safari was sexually active with a steady partner and reported consistent condom use:

> Safari: The man I am with, the first thing is, I am the person who will put the condom on for him. I do not want him to do it himself. Even if it is at night the lights have to be on, because a man is just a man, he might cut the condom and add me more viruses.

By contrast, Jambo's more continuous biography reflected his pre-diagnosis identity:

> INT: Did you use a condom during your last sex?
> Jambo: Aaahi! How can I have sex with a woman while using a condom? Am I to fuck the condom or her vagina…so my blood gets into her?! Then I go and throw away my semen in the toilet, why? I don't want it, if it's a question of condoms, I would rather do away with a vagina because it will not benefit me in any way.

From Jambo's perspective the need for sexual gratification involving sexual fluid exchange outweigh condom use [63].

Discussion

There are multiple and complex responses to diagnosis with HIV, in an era of ART availability, set against a backdrop of life in a Nairobi slum. For some people this process involves a transition to a new self-identity, incorporating both HIV and ART into their lives [60], for others it involves a partial transition, with some aspects of identity persisting, and others redefined [35, 37, 64]. Multiple phases of identity transition, including diagnosis, (non-)disclosure, positive living, attempts at repair and normalcy, play out in people's narratives and their sexual lives and futures.

PLWHA try to mobilise resources to help them deal with the diagnosis [35, 36], including sources of social capital (e.g.: community healthworkers social groups, faith-based organisations), and ART. Such social networks provide support to mitigate psychological distress associated with a HIV diagnosis [65]. Studies from elsewhere in SSA have documented a positive relationship between social capital and health [66] and prayer/spirituality and quality of life among PLWHA [67]. Emerging evidence also shows that the availability of social networks such as treatment partners, health care workers, and social support groups, improves treatment outcomes, including adherence for PLWHA with access to ART [38, 66, 68].

The use of ART was a significant resource enabling PLWHA to regain positions as economically and socially productive and reproductive members of society, thereby fending off stigma [69, 70]. PLWHA face stigma in part because infection with HIV is associated with moral failures and a breach of social norms and taboos [39] In the context of the high premium placed on parenthood [71], HIV posed a potential threat to peoples' identities as mothers and fathers. Resuming sex provides an opportunity for PLWHA to lead normal lives, as well as to mitigate stigma and social disproval [72]. However, the inherent social rewards of childbearing, in the context of poverty and limited access to social security, and its inherent risk of transmitting the virus are complex issues in reproductive decisions among PLWHA.

Sampling participants from the slum community is a major strength of our study. Most studies on PLWHA sample from HIV health services where participants are likely to have better access to services and to have been better informed about SRH services and HIV prevention than the general population of PLWHA. However, our interviews had a heterosexual and consensual sex focus and it is highly unlikely that respondents would volunteer same-sex or forced sex activities. Since these sexual identities and activities are stigmatised in Kenya, a different approach might have helped the research process, although their under-reporting might still persist. Information on sexual behaviour and fertility preferences were entirely based on self-reports using face to face interviews. Given the sensitive nature of these topics, there is likely to have been social desirability bias. Both men and women misreport their sexual behaviour [73] and respondents might be inclined to underreport their unsafe sexual behaviour. Although we took precautions to limit social desirability bias – such as training interviewers to create a climate of trust that allows free talk about such matters and using non-clinical community interviewers – its effect cannot be completely eliminated.

In spite of these limitations, this study contributes to the empirical literature on sexual and reproductive health of PLWHA in a poor setting, an under-researched topic. PLWHA experience life with HIV and face challenges around stigma, managing ART, negotiating sexual intimacy and reproduction. Our data show the need to address living with HIV/AIDS holistically, asking broad questions about lived experience of PLWHA, paying attention to structural elements of poverty, gender and socio-cultural norms, recognising PLWHA as sexual and reproductive human beings. Research in developing countries that has addressed sexual behaviour of PLWHA has focused on risky behaviour mostly using quantitative data from surveys [74]. Studies have considered the reproductive goals of PLWHA [75, 76], suggesting that sexual and reproductive behaviour of PLWHA should be understood by connecting sexuality to gender, reproductive goals and larger socio-economic contexts [77, 78].

The effect of ART on sexual and reproductive behaviour is attracting research and policy attention following ART rollout in resource-poor settings. The findings of the few studies that have examined how treatment affects sexual and reproductive behaviour in such settings have produced mixed results, highlighting the need for a better evidence base [25, 79, 80]. There is a growing recognition of the need to support the rights of PLWHA to be sexually active, should they wish to be, while minimizing HIV transmission risk [81] and this study is an effort in that direction. Meeting the sexual and reproductive health needs of PLWHA means more than just counselling on risk reduction. Psycho-social factor play a prominent role in sexual functioning, and diminished sexual interest and sexual abstinence are strongly associated with psychological distress, depression, anxiety and low quality of life, in addition to underlying ill-health represented by CD4 cell counts and duration or severity of illness [82]. PLWHA could benefit from counselling around sexuality as a whole, not just risk reduction as is usually the case. Our findings speak to the need for interventions to help PLWHA to safely become sexually active if they want to. Because the process of incorporating HIV into an individual's identity is neither linear nor predictable, diagnosis presents an opportunity for healthcare providers to discuss these issues. Subsequent referrals for mental health services might, for example, become necessary depending on how individuals cope with their diagnosis.

Funding statement: This work was supported by the Wellcome Trust grant number [078471/Z/05/A]. The sponsor had no role in the design and conduct of the study; in the collection, analysis and interpretation of the data or in the preparation, review or approval of the manuscript. The opinions, results and conclusions reported in this paper are those of the authors and are independent from the funding sources.

Competing interests: None declared

Acknowledgements: We are grateful to the participants of the study for their time and contributions. We are grateful to the African Population and Health Research Centre for permission to sample from the Nairobi Urban Demographic Surveillance System.

Contributors: Study concept and design: EW, EC. Acquisition of data: EW. Analysis and interpretation of data: EW, EC. Drafting of the manuscript: EW. Critical revision of manuscript: EC, EW. Administrative, technical or material support: EW, EC. Both authors have read and approved the final manuscript.

References

1. UNAIDS, *Global HIV/AIDS Response: Epidemic update and health sector progress towards Universal Access Progress Report 2011.*, 2011, World Health Organization/United Nations United Nations Joint Programme on AIDS: Geneva, Switzerland.
2. UNAIDS, *UNAIDS report on the global AIDS epidemic*, 2012, UNAIDS: Geneva. p. 212.
3. NACC/NASCOP, *Kenya AIDS Epidemic Update*, 2011, National AIDS and STI control programme: Nairobi. p. 144.
4. Birungi, H., C.-C. Undie, and P. Aggleton, *Recent research on sexuality in East Africa.* Culture, Health & Sexuality, 2009. **11**(8): p. 747-750.
5. Segurado, A.C. and V. Paiva, *Rights of HIV Positive People to Sexual and Reproductive Health: Parenthood.* Reproductive Health Matters, 2007. **15**(29, Supplement 1): p. 27-45.
6. WHO, *Sexual and reproductive health of women living with HIV/AIDS: Guidelines on care, treatment and support for women living with HIV/AIDS and their children in resource-constrained settings*, 2006, World Health Organization: Geneva.
7. Bartlett, J.A., *Addressing the challenges of adherence.* Journal of Acquired Immune Deficiency Syndromes, 2002. **29**: p. S2-S10.
8. Hardon, A., Hodgkin, C. & Laing, R., *From access to adherence: The challenges of antiretroviral treatment. Studies from Botwana, Tanzania and Uganda*, 2006, World Health Organization: Geneva.
9. Orrell, C., et al., *Adherence is not a barrier to successful antiretroviral therapy in South Africa.* AIDS, 2003. **17**(9): p. 1369-1375.
10. Mahajan, A.P., et al., *Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward.* AIDS, 2008. **22**(Suppl.2): p. S67-S79.
11. Nachega J. B , S.D.M., . Lehman D. A, Hilatshwayo D., Mothopeng R., et al . *Adherence to Antiretroviral Therapy in HIV-Infected Adults in Soweto, South Africa.* AIDS Research and Human Retroviruses 2004. **20**(10): p. 1053–1056.
12. Dlamini, P.S., et al., *HIV Stigma and Missed Medications in HIV-Positive People in Five African Countries.* AIDS Patient Care & STDs, 2009. **23**(5): p. 377-387.
13. Weiser, S., et al., *Barriers to antiretroviral adherence for patients living with HIV infection and AIDS in Botswana.* Jaids-Journal of Acquired Immune Deficiency Syndromes, 2003. **34**(3): p. 281-288.
14. Roura, M., et al., *Scaling up stigma? The effects of antiretroviral roll-out on stigma and HIV testing. Early evidence from rural Tanzania.* Sexually Transmitted Infections, 2009. **85**(4): p. 308-312.
15. Abrahams, N. and R. Jewkes, *Managing and resisting stigma: a qualitative study among people living with HIV in South Africa* Journal of the International AIDS Society, 2012. **15**(2).

16. Preston-Whyte, E.M., *Contexts of vulnerability: Sex, secrecy and HIV/AIDS* African Journal of AIDS Research, 2003. **2**(2): p. 89–94.

17. Abadía-Barrero, C.E. and A. Castro, *Experiences of stigma and access to HAART in children and adolescents living with HIV/AIDS in Brazil.* Social Science & Medicine, 2006. **62**(5): p. 1219-1228.

18. Cao, X., et al., *Understanding HIV–Related Stigma And Discrimination in a "Blameless" Population.* AIDS Education and Prevention, 2006. **18**(6): p. 518-528.

19. Farmer, P., et al., *Community-based approaches to HIV treatment in resource-poor settings.* The Lancet, 2001. **358**(9279): p. 404-409.

20. Maughan-Brown, B., *Stigma rises despite antiretroviral roll-out: A longitudinal analysis in South Africa.* Social Science & Medicine, 2010. **70**(3): p. 368-374.

21. Smith, R., K. Rossetto, and B.L. Peterson, *A meta-analysis of disclosure of one's HIV-positive status, stigma and social support.* AIDS Care, 2008. **20**(10): p. 1266-1275.

22. Neville Miller, A. and D.L. Rubin, *Factors Leading to Self-Disclosure of a Positive HIV Diagnosis in Nairobi, Kenya: People Living With HIV/AIDS in the Sub-Sahara.* Qualitative Health Research, 2007. **17**(5): p. 586-598.

23. Cooper, D., et al., *Fertility Intentions and Reproductive Health Care Needs of People Living with HIV in Cape Town, South Africa: Implications for Integrating Reproductive Health and HIV Care Services.* AIDS and Behavior, 2009. **13**(0): p. 38-46.

24. GNP+, *Advancing the Sexual and Reproductive Health and Human Rights of People Living With HIV*. 2009, Amsterdam: The Global Network of People Living with HIV/AIDS (GNP+).

25. Luchters, S., et al., *Safer sexual behaviors after 12 months of antiretroviral treatment in Mombasa, Kenya: a prospective cohort.* AIDS Patient Care & STDs, 2008. **22**(7): p. 587-594.

26. Remien, R., et al., *Medication Adherence and Sexual Risk Behavior among HIV-Infected Adults: Implications for Transmission of Resistant Virus.* AIDS and Behavior, 2007. **11**(5): p. 663-675.

27. Crepaz, N., T.A. Hart, and G. Marks, *Highly active antiretroviral therapy and sexual risk behavior - A meta-analytic review.* Jama-Journal of the American Medical Association, 2004. **292**(2): p. 224-236.

28. Kennedy, C., et al., *The impact of HIV treatment on risk behaviour in developing countries: A systematic review.* AIDS Care, 2007. **19**(6): p. 707 - 720.

29. De Ryck, I., et al., *Sexual Satisfaction Among Men Living with HIV in Europe.* AIDS and Behavior, 2011: p. 1-6.

30. UN-HABITAT, *Slums of the World: The Face of Urban Poverty in the New Millenium? Global Urban Observatory*, 2003b, Nairobi:UN-Habitat:.

31. Amuyunzu-Nyamongo, M., et al., *Putting on a brave face: The experiences of women living with HIV and AIDS in informal settlements of Nairobi, Kenya.* AIDS Care, 2007. **19**(1 supp 1): p. 25-34.

32. Zulu, E., et al., *Overview of migration, poverty and health dynamics in Nairobi City's slum settlements.* Journal of Urban Health, 2011. **88**(0): p. 185-199.

33. Bury, M., *Chronic illness as biographical disruption.* Sociology of Health & Illness, 1982. **4**(2): p. 167-182.

34. Baumgartner, L.M., *The Incorporation of the HIV/AIDS Identity Into the Self Over Time.* Qualitative Health Research, 2007. **17**(7): p. 919-931.

35. Carricaburu, D. and J. Pierret, *From biographical disruption to biographical reinforcement: the case of HIV-positive men.* Sociology of Health & Illness, 1995. **17**(1): p. 65-88.

36. Williams, S., *Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept.* Sociology of Health & Illness, 2000. **22**(1): p. 40-67.

37. Ciambrone, D.e., *Illness and other assaults on self: the relative impact of HIV/AIDS on women's lives.* Sociology of Health & Illness, 2001. **23**(4): p. 517-540.

38. Wouters, E., et al., *Public-sector ART in the Free State Province, South Africa: Community support as an important determinant of outcome.* Social Science & Medicine, 2009. **69**(8): p. 1177-1185.

39. Parker, R. and P. Aggleton, *HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action.* Social Science & Medicine, 2003. **57**(1): p. 13-24.

40. Levy, J.M. and K.T. Storeng, *Living Positively: Narrative Strategies of Women Living with HIV in Cape Town, South Africa.* Anthropology & Medicine, 2007. **14**(1): p. 55-68.

41. Frank, E., *The relation of HIV testing and treatment to identity formation in Zambia.* African Journal of AIDS Research, 2009. **8**(4): p. 515-524.

42. Kiene, S.M., et al., *Sexual risk behaviour among HIV-positive individuals in clinical care in urban KwaZulu-Natal, South Africa.*

. AIDS, 2006. **20**(13): p. 1781-4.

43. Moatti, J.-P., et al., *Access to antiretroviral treatment and sexual behaviours of HIV-infected patients aware of their serostatus in Côte d'Ivoire*

AIDS, 2003. **17**(supplement 3): p. S69–S77.

44. Pettifor, A., et al., *Continued High Risk Sexual Behavior Following Diagnosis with Acute HIV Infection in South Africa and Malawi: Implications for Prevention.* AIDS and Behavior, 2011. **15**(6): p. 1243-1250.

45. APHRC, *Population and health dynamics in Nairobi's informal settlements*, 2002, African Population and Health Research Center: Nairobi.

46. Madise, N.J., et al., *Are slum dwellers at heightened risk of HIV infection than other urban residents? Evidence from population-based HIV prevalence surveys in Kenya.* Health & Place, (0).

47. Montgomery, M., *Urban poverty and health in developing countries.* Population Bulletin, 2009. **64**(2).

48. Zulu, E., F. Dodoo, and A. Ezeh, *Sexual risk-taking in the slums of Nairobi, Kenya, 1993-98.* Popul Stud (Camb), 2002. **56**(3): p. 311 - 323.

49. Madise, N.J., et al., *Are slum dwellers at heightened risk of HIV infection than other urban residents? Evidence from population-based HIV prevalence surveys in Kenya.* Health & Place, 2012. **18**(5): p. 1144-1152.

50. Magnani, R., *Sampling guide.* 1997, MPACT Food Security and Nutrition Monitoring Project

Arlington, Va.

.

51. Braun, V. and V. Clarke, *Using thematic analysis in psychology.* Qualitative Research in Psychology, 2006. **3**: p. 77-101.

52. Ivankova, N.V., J.W. Creswell, and S.L. Stick, *Using Mixed-Methods Sequential Explanatory Design: From Theory to Practice.* Field Methods, 2006. **18**(1): p. 3-20.

53. Kaler, A. and S. Watkins, *Asking God about the date you will die: HIV testing as a zone of uncertainty in rural Malawi.* Demographic Research, 2010. **23**(32): p. 905-932.

54. Gersovitz, M., *HIV Testing: Principles and Practice.* The World Bank Research Observer, 2011. **26**(1): p. 1-41.

55. Obermeyer, C.M. and M. Osborn, *The Utilization of Testing and Counseling for HIV: A Review of the Social and Behavioral Evidence.* Am J Public Health, 2007. **97**(10): p. 1762-1774.

56. Baumgartner, L.M. and K.N. David, *Accepting Being Poz: The Incorporation of the HIV Identity Into the Self.* Qualitative Health Research, 2009. **19**(12): p. 1730-1743.

57. Ciambrone, D.e., *Women's experiences with HIV/AIDS: mending fractured selves* 2003, Binghamton, NY: The Haworth Press.

58. Mahalik, J.R., G.E. Good, and M. Englar-Carlson, *Masculinity scripts, presenting concerns, and help seeking: Implications for practice and training.* Professional Psychology: Research and Practice, 2003. **34**(2): p. 123-131.

59. Derlega, V.J., et al., *Reasons for HIV Disclosure/Nondisclosure in Close Relationships: Testing a Model of HIV–Disclosure Decision Making.* Journal of Social and Clinical Psychology, 2004. **23**(6): p. 747-767.

60. Russell, S. and J. Seeley, *The transition to living with HIV as a chronic condition in rural Uganda: Working to create order and control when on antiretroviral therapy.* Social Science & Medicine, 2010. **70**(3): p. 375-382.

61. Bartos, M. and K. McDonald, *HIV as identity, experience or career.* AIDS Care, 2000. **12**(3): p. 299-306.

62. Anderson, M., et al., *Coping With HIV: Caribbean People in the United Kingdom.* Qualitative Health Research, 2009. **19**(8): p. 1060-1075.

63. Coast, E., *Wasting sperm:The Maasai context of condom use in Northern Tanzania.* Culture, health and sexuality, 2007. **9** (4): p. 387-401

64. Wilson, S., *'When you have children, you're obliged to live'1: motherhood, chronic illness and biographical disruption.* Sociology of Health & Illness, 2007. **29**(4): p. 610-626.

65. Kalichman, S.C., et al., *Stress, Social Support, and HIV-Status Disclosure to Family and Friends Among HIV-Positive Men and Women.* Journal of Behavioral Medicine, 2003. **26**(4): p. 315-332.

66. Pronyk, P.M., et al., *Is social capital associated with HIV risk in rural South Africa?* Social Science & Medicine, 2008. **66**(9): p. 1999-2010.

67. Friend-du Preez, N. and K. Peltzer, *HIV Symptoms and Health-Related Quality of Life Prior to Initiation of HAART in a Sample of HIV-Positive South Africans.* AIDS and Behavior, 2010. **14**(6): p. 1437-1447.

68. Binagwaho, A. and N. Ratnayake, *The Role of Social Capital in Successful Adherence to Antiretroviral Therapy in Africa.* PLoS Med, 2009. **6**(1): p. e18.

69. Campbell, C., et al., *"We, the AIDS people. . .": How Antiretroviral Therapy Enables Zimbabweans Living With HIV/AIDS to Cope With Stigma.* American Journal of Public Health, 2011. **101**(6): p. 1004-1010.

70. Castro, A. and P. Farmer, *Understanding and Addressing AIDS-Related Stigma: From Anthropological Theory to Clinical Practice in Haiti.* American Journal of Public Health, 2005. **95**(1): p. 53-59.

71. Awiti Ujiji, O., et al., *"I will not let my HIV status stand in the way." Decisions on motherhood among women on ART in a slum in Kenya- a qualitative study.* BMC Women's Health, 2010. **10**(1): p. 1-10.

72. Smith, D.J. and B.C. Mbakwem, *Antiretroviral therapy and reproductive life projects: Mitigating the stigma of AIDS in Nigeria.* Social Science & Medicine, 2010. **71**(2): p. 345-352.

73. Buvé, A., et al., *Multicentre study on factors determining differences in rate of spread of HIV in sub-Saharan Africa: methods and prevalence of HIV infection.* AIDS, 2001. **15**: p. S5-S14.

74. Bateganya, M., et al., *Antiretroviral Therapy and Sexual Behavior: A Comparative Study between Antiretroviral- Naive and -Experienced Patients at an Urban HIV/AIDS Care and Research Center in Kampala, Uganda.* AIDS Patient Care & STDs, 2005. **19**(11): p. 760-768.

75. Cooper, D., et al., *"Life is still going on": Reproductive intentions among HIV-positive women and men in South Africa.* Social Science & Medicine, 2007. **65**(2): p. 274-283.

76. Myer, L., C. Morroni, and K. Rebe, *Prevalence and Determinants of Fertility Intentions of HIV-Infected Women and Men Receiving Antiretroviral Therapy in South Africa.* AIDS Patient Care & STDs, 2007. **21**(4): p. 278-285.

77. Laher, F., et al., *A Qualitative Assessment of Decisions Affecting Contraceptive Utilization and Fertility Intentions among HIV-Positive Women in Soweto, South Africa.* AIDS and Behavior, 2009. **13**(0): p. 47-54.

78. Persson, A. and W. Richards, *Vulnerability, gender and "proxy negativity": Women in relationships with HIV-positive men in Australia.* Social Science & Medicine, 2008. **67**(5): p. 799-807.

79. Kaida, A., et al., *Childbearing Intentions of HIV-Positive Women of Reproductive Age in Soweto, South Africa: The Influence of Expanding Access to HAART in an HIV Hyperendemic Setting.* Am J Public Health, 2011. **101**(2): p. 350-358.

80. Sarna, A., et al., *Changes in sexual risk taking with antiretroviral treatment: influence of context and gender norms in Mombasa, Kenya.* Culture, Health & Sexuality, 2009. **11**(8): p. 783-797.

81. Kaida, A., et al., *Editorial: Introduction to the Supplement on HIV, HAART, and Fertility in sub-Saharan Africa.* AIDS and Behavior, 2009. **13**(0): p. 1-4.

82. Florence, E., et al., *Prevalence and factors associated with sexual dysfunction among HIV-positive women in Europe.* AIDS Care, 2004. **16**(5): p. 550-557.

Living with HIV post-diagnosis: a qualitative study of the experiences of Nairobi slum residents

Structured abstract

Objectives: To characterise the experiences of heterosexual men and women living with HIV post-diagnosis and explain these experiences in relation to their identity and sexuality.

Design: Qualitative study using in-depth interviews and theoretically informed biographic disruption theory.

Setting: Interviews were conducted in two Nairobi slums (Kenya).

Participants: 41 HIV-infected heterosexual men and women aged 18 years or older

Results: People living with HIV have divergent experiences surrounding HIV diagnosis. Post-diagnosis there are multiple phases of identity transition, including status (non-)disclosure, and attempts at identity repair and normalcy. For some people this process involves a transition to a new self-identity, incorporating both HIV and antiretroviral treatment (ART) into their lives. For others it involves a partial transition, with some aspects of their pre-diagnosis identity persisting, and for others it involves a rejection of HIV identity. Those people who were able to incorporate HIV/AIDS in their identity without it being disruptive to their biography, were pursuing safer sexual and reproductive lives. By contrast, those people with a more continuous biography continued to reflect their pre-diagnosis identity and sexual behaviour.

Conclusions: People living with HIV/AIDS (PLWHA) had to rework their sense of identity following diagnosis in the context of living in a slum setting. Men and women living with HIV in slums are poorly supported by health systems and services as they attempt to cope with a diagnosis of HIV. Given the availability of antiretroviral therapy, health services and professionals need to support the rights of PLWHA to be sexually active if they want to and achieve their fertility goals, while minimizing HIV transmission risk.

Article summary

Article focus

- Slum populations are under-researched, and very little empirical research examines the experiences of people living with HIV post-diagnosis
- Impact of HIV post-diagnosis identity on ~~sexuality and reproductive intentions~~sexual behaviour.

Key messages

- Men and women living with HIV in slums are poorly served by health services post-diagnosis.
- Health service provision and support does not incorporate the increasing needs of people living with HIV and AIDS to navigate their sexual and reproductive lives.
- The sexual ~~and reproductive experiences~~behaviour of PLWHA are influenced by their HIV post-diagnosis identity transformation.

Strengths and limitations of this study

- The first in-depth study of the experiences of people living in slums following a HIV diagnosis in relation to their identity and sexuality.
- We did not include the perspectives of relevant stake holders such as ~~health service providers~~partners or policymakers

Introduction

~~Sub-Saharan Africa is the most affected region by the HIV/AIDS pandemic, accounting for over 68% of the total global burden [1]. Approximately 1.5 million adult Kenyans are currently living with HIV [2, 3]. The Kenyan HIV prevalence rate (7.4%) is higher than the SSA regional rate (5%) [4].~~

~~The introduction of anti-retroviral therapy (ART) has improved the prognosis of HIV, with the potential to transform it to a chronic condition. Access to ART in low and middle income countries has expanded rapidly, with 6.6 million people now receiving treatment, nearly half of those eligible for treatment [1]. Sixty percent of Kenyan adults and children eligible for ART are now receiving it [3]. With ART, the future life opportunities of PLWHA can change, including those related to sexuality and reproduction~~ Sub-Saharan Africa (SSA) is the most affected region by the HIV/AIDS pandemic, accounting for over 68% of the total global burden [1]. 1.6 million Kenyans are currently living with HIV and Kenyan adult HIV prevalence is estimated at 6.2%, higher than the SSA regional prevalence (4.9%) [2].

The introduction of anti-retroviral therapy (ART) has improved the prognosis of HIV, with the potential to transform it to a chronic condition. Access to ART in low and middle income countries has expanded rapidly, with 6.6 million people now receiving treatment, nearly half of those eligible for treatment [1]. Seventy two percent of Kenyan adults and children with advanced HIV infection receive ARVs [3] With ART, the future life opportunities of PLWHA can change, including those related to sexuality and reproduction [4-6]. However, research has focused on issues of access and adherence to ART for treatment effectiveness ~~[5-7]~~[7-9]~~. However, research has focused on issues of access and adherence to ART for treatment effectiveness [8-10]. The sexual and reproductive health rights and needs of PLWHA are under-researched and poorly understood~~ . More recently, evidence about the relationships between stigma and ARV availability and uptake has emerged from low income settings[10]. At the individual level, ARV adherence is negatively affected by stigma from partners ~~[6, 11, 12]~~[11-13]~~. There are policy concerns about treatment optimism, with an increase in riskier sexual behaviour as more people become aware that HIV/AIDS is a manageable condition with ART [13-16]. Sexuality is a crucial element of being human and sexual health (pleasurable and safe sex) is an important component of overall health [17]~~

, although self-stigma has been shown to decline in contexts of increasing access to treatment[14], and stigma changes over the lifecourse.[15] Whilst the provision of ARV has the potential to reduce stigma about HIV/AIDS[16] in a wide range of low income contexts,[17-19] this relationship is not universal [20]. The relationship between ART and status disclosure to partner(s), family and community is also poorly understood, with the majority of evidence coming from high income settings [21]. Research from SSA suggests a distinctive pattern of disclosure that relies on third parties and intermediaries, especially religious leaders, as instruments of disclosure [22]. The sexual health rights and needs of PLWHA remain under-researched and poorly understood [5, 23, 24], even though issues of stigma and disclosure are likely to be closely related to sexual behaviour post-diagnosis. There are policy concerns about treatment optimism, with an increase in riskier sexual behaviour as more people become aware that HIV/AIDS is a manageable condition with ART [25-28]. Sexuality is a crucial element of being human and sexual health (pleasurable and safe sex) is an important component of overall health [29]

Nearly three quarters (72%) of urban residents in SSA live in slums ~~[18]~~[30] where single-room homes are densely packed ~~[19].~~[31]. The poor health status of slum residents reflects poor environmental conditions and infrastructure, limited access to treatment and preventive health services; and reliance on poor quality and informal and regulated health services ~~[20].~~[32]. Urban slums and their residents are an important, but under-researched, aspect of life in SSA. We undertook a qualitative study of the sexual and reproductive experiences and intentions of heterosexual men and women living with HIV in Nairobi slums.

Formatted: Indent: Left: 0"

Methods

Theoretical framework

We organised and analysed our data using the theoretical concept of biographical disruption ~~[21]~~[33], to understand how HIV acts as a disruptive experience to an individual's life, social relations and identity ~~[22-24]~~[34-36]~~. There are three components to biographic disruption: disruption of an individual's former behaviour or assumptions; changes in an individual's perceptions of self; and, an attempt to repair or change one's biography. Biographical disruption of HIV has been studied in the global North, and the extent to which it applies to PLWHA in other settings is unknown [23, 25].~~

. There are three components to biographic disruption: disruption of an individual's former behaviour or assumptions; changes in an individual's perceptions of self; and, an attempt to repair or change one's biography. Biographical disruption of HIV has been studied in the global North, and the extent to which it applies to PLWHA in other settings is much less well understood [35, 37, 38]. Prior to the widespread availability of ART, evidence of the ways in which identity formation was affected by a HIV diagnosis focused on the mortality implications [35], stigma [39] and any subsequent disclosure [34]. Earlier analyses tended to be based on quantitative questions in surveys [34] with limited analytic insights. More recent analyses have incorporated evidence from qualitative and mixed methods studies and highlight the ways in which identity post-diagnosis has been used as a social and political force to improve treatment access [40]. Research in Zambia, conducted pre- and post-ART roll-out suggest that whilst ART makes disclosure easier, it also changes the context into which an individual discloses [41]. Research into sexual behaviour post-HIV diagnosis in SSA has tended to focus on quantitative measures of sexual behaviour (number of partners, frequency of sex, concurrency, condom (non-)use [42] with much of the research coming from South Africa with some exceptions [43, 44]

Study Context

Data for this study were collected from two slum communities (Korogocho and Viwandani) in Nairobi, Kenya. Housing conditions in these slums are temporary, typically single rooms constructed from mud, iron sheets, cardboard boxes and polythene [31]. The settings are characterised by overcrowding, insecurity, poor sanitary conditions, poverty, high unemployment levels, poor amenities and infrastructure, limited access to preventative and curative services and reliance on poor quality, usually informal and unregulated health services [32, 45]. These conditions contribute to poor health outcomes for slum residents relative to other sub-populations in Kenya, including, higher levels of mortality and morbidity, HIV prevalence, risky sexual behaviours, unmet need for contraception and unintended pregnancies[46-49]

Formatted: Left, Don't adjust space between Latin and Asian text, Don't adjust space between Asian text and numbers

Sampling and recruitment

~~Qualitative data were collected from PLWHA living in two Nairobi slums in 2010 using in-depth interviews. Respondents (n=41) were identified and recruited from a larger quantitative study (n=513) conducted by the authors which used quota sampling based on sero-prevalence ratios in slums covered by the Nairobi Urban Demographic and Health Surveillance System (NUDSS). Interviews were conducted in KiSwahili, recorded, transcribed verbatim, translated into English and analysed using NVivo [26].~~

We analyse qualitative data collected as part of a larger mixed methods study of PLWHA (18 years and above) conducted in 2010. The study adopted a sequential design, with quantitative survey interviews (n=513) followed by in-depth interviews with a subsample (n=41) drawn from the survey. The quantitative sample size was determined on the basis of sample size calculations [50]. Respondents were recruited from the Nairobi Urban Demographic and Health Surveillance System through quota sampling on the basis of sero-prevalence ratios and socio-demographic characteristics in the study sites [49]. Purposive selection of respondents for the qualitative interview was based on analyses of the survey data, and identification of a range of experiences. Key informant interviews (n=14) were conducted with health providers. Eight research assistants RAs (four per site) were recruited for the quantitative survey, of which two per site were retained for the qualitative in-depth interviews. The RAs all had several years' experience of data collection in the study sites, were trained HIV/AIDs counsellors, and one RA was a PLWHA. Interviews were conducted in KiSwahili and the qualitative interviews were recorded, transcribed verbatim, translated into English and analysed using NVivo [51].

Ethical considerations

We obtained written consent from all respondents and all interviews were conducted in a setting of the respondent's choice. Privacy in home settings in slums is difficult to achieve, and respondents were given the option of being interviewed in the offices of a local health organisation. A small grocery package was provided as compensation for each respondent. Approval for the study was granted by the

Kenyan Medical Research Institute (KEMRI) and the London School of Economics (LSE). Our analyses use pseudonyms for the presentation of data.

Formatted: Font: Bold

Results

The socio-demographic characteristics of the qualitative study participants are summarised in Table 1.

Table 1: Socio-demographic characteristics of respondents (n=41), 2010.

CHARACTERISTIC	PERCENT (N=41)
Slum of residence	
Korogocho	59
Viwandani	41
Sex	
Female	56
Male	44
Ethnicity	
Kikuyu	34
Luo	24
Luyia	20
Kamba	15
Other	7
Education	
No Schooling	7
Primary	66
Secondary and higher	27
Marital Status	
Married/Cohabiting	41
Divorced/separated	17
Widowed	29
Never Married	12
Age	
18-29	22
30-39	32
40-49	32
50+	15
Treatment Status	
Receiving ART	56
Not Receiving ART	44

We present detailed analyses of three typical case studies, purposively selected from the qualitative sample in order to draw out the complexities of biographical disruption following diagnosis with HIV. ~~We selected these case studies to represent the range of sexual behaviour and fertility intentions (Table 2) [27].~~

Table 2: Summary characteristics of three case study respondents

Characteristics	Case study
Sexually abstinent~~, no intentions of future fertility~~	Malaika, female, 29 years old, widowed, known HIV status for 3 years. . After her husband's death in 2003, she was briefly "inherited" by her brother-in-law. This is a traditional practice involving a widow becoming the de facto sexual

Formatted: Left

Formatted: Font: 11 pt

Formatted: Font: 11 pt, All caps

Formatted: Font: 11 pt

Formatted: Font: 11 pt, All caps

Formatted Table

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

Formatted: Font: 11 pt

	partner of her dead husband's brother.
Sexually active, monogamous relationship, consistent use of condoms and/or contraception	Safari, female, 34 years old, currently cohabiting, known HIV status for 15 years.
Sexually active, multiple partners, inconsistent use of condoms and/or contraception	Jambo, male, 55 years old, widower, known HIV status for nine years.

By selecting three case studies we contribute to deeper understanding of the ways in which individual trajectories unfold post-diagnosis, acknowledging the complexity of biographical disruption. We selected these case studies to represent a range of sexual behaviour reported by the wider qualitative sub-sample (Table 2) [52].

Reactions to a diagnosis of HIV

HIV diagnosis is the first step in incorporating HIV/AIDS into an individual's identity, challenging their identity as a healthy person. Most research on HIV testing in SSA focuses on its benefits, costs and barriers ~~[28, 29]~~[53, 54], with little understanding of people's experiences of having a test ~~[30].~~[55]. Safari's narrative is typical of health provider response and management early in the epidemic:

> INT: So how did you know your status?
>
> Safari: I kept going to *Hospital*. That is when I heard doctors saying things like HIV/AIDS and they started pointing fingers at me. Those days things were so bad; not like these days~~. So I just decided by myself to go and approach the doctor. I told the doctor to tell me the truth because I did not want to miss work. I was working as a maid and all this time he was refusing to tell me the truth. So he took my blood again and told me to come for the results the following day and was told~~…He told me; you know, there is a disease that has come out. It does not have a cure. It is not known what kind of disease it is, and Safari you have that disease.

Diagnosis often occurred during a health crisis:

> Jambo: I had a chest problem and when I went to hospital they told me that I had to be tested for HIV. I knew I had TB, but when I was tested for HIV...Oh no! aaayaai! I was surprised to be told that I was HIV+.

Formatted: Indent: Left: 0.5", Hanging: 1"

Being diagnosed with HIV/AIDS elicits multiple reactions, both negative (e.g.: shock) and positive (e.g.: relief) ~~[22, 31].~~[34, 56]. People struggled to grapple with the meaning of a positive test and its implication for their life. Their biographies were initially disrupted and needed reworking to accommodate HIV/AIDS. These initial emotions evolved and changed with time. Malaika's reaction was of distress and denial~~; she was surprised to test positive because she perceived herself to be at low risk of infection, despite having been inherited by her brother-in-law, because she felt she had not engaged in risky behaviour. For her, it meant refusing the results of an HIV positive test:~~:

Malaika: I was very angry. I wished I was not alive because I saw myself as a dead person. I thought about killing myself. I wanted to kill my children but it was just that they were still very young. I did not suspect I was HIV positive because I did not go out with other men. ~~Even when my husband died, I did not suspect that I was having it, because he did not inform me about his status.~~

Safari feared being associated with prostitutes, a marginalised and stigmatised group:

Safari: I will be put with the people who are cursed in life. A person called a prostitute is a cursed person. People would think that I came to Nairobi to be a prostitute. I hated myself. I took it as a curse.

~~Jambo's narrative involved putting on a brave face, a reaction that is rarely reported in studies of diagnosis reactions [eg 22, 32]. Jambo displayed a "masculinity script" [33] by reporting himself to be brave, fearless, and emotionless upon testing HIV positive:~~

Jambo's narrative involved putting on a brave face, a reaction that is rarely reported in studies of diagnosis reactions [eg 34, 57]. Jambo displayed a "masculinity script" [58] by reporting himself to be brave, fearless, and emotionless upon testing HIV positive:

Jambo: I wasn't angry because I am a man. You are only scared if you are not a man. ~~Again it's not bad to inform a man something like this. It has to be diagnosed, and on you [man] for that matter. Were you not moving out [having sex] with women? You are a man, so you cannot say, No, I don't have this disease and yet you have been having sex with women…Yes, as a man you can't just stay *ndeee*! [abstinent].~~

Diagnosis represented a first step in HIV identity formation, followed by decisions about whether to disclose their status.

HIV status disclosure: To tell or not to tell.

Managing the flow of information about HIV status, including (non-)disclosure of HIV status is central to how people manage their identity post-diagnosis. ~~Safari's decision~~Decisions to disclose ~~was difficult and took~~evolve over time, encompassing a process beginning with non-disclosure and ~~moving towards~~sometimes ended in forced disclosure:

Safari: My mother was told but not by me. When you live with people in the house they will know something and they will start talking and word goes round. After all, my body betrayed me.~~ They [neighbours] told~~

~~her "From what we can see your child is suffering from AIDS". So one day I decided to tell her.~~

~~Safari's disclosure was articulated as subsequently driven by a desire to educate and inform others about HIV/AIDS, a disclosure motive that has also been documented in the US [34].~~

~~Int: Why did you tell them, let us start with your mother?~~
~~Safari: I wanted her to decide whether to change her life because the way she was living her life was risky. I told her so she could know her status and also tell the others, because her behaviour was not good. She had involved herself in drugs and I saw her getting the virus easily.~~

Safari's disclosure was articulated as subsequently driven by a desire to educate and inform others about HIV/AIDS, a disclosure motive that has also been documented in the US [59].

Int: Why did you tell other relatives then?
Safari: …So I wanted to educate them more about HIV/AIDS. How you can get it and how to take care of it and how you can live with it.

Neither Malaika nor Jambo had disclosed their status to anyone beyond healthcare providers. A major barrier to their disclosure is fear of stigma and discrimination:

Malaika: It is very difficult for me to disclose my status because people will start talking ill about me, they will not feel good when their children play together with my children and they will look down upon me. That is why I don't want to disclose it to any one and just want it to be my secret.

Jambo's explanation of his non-disclosure refers instead to issues of confidentiality:

Jambo: How can I reveal matters affecting my body to anyone; that I have HIV? Why? Are they my doctor? Why should they know?

~~Fear of stigmatising attributes and behaviour such as rejection, discrimination and other~~Key informant interviews reported similar negative social responses ~~are illustrated~~experienced by ~~Safari's narrative:~~ PLWHA:

~~Safari: I disclosed to many people and they began calling me "*mama ukimwi*" (mother AIDS). They called me *malaya* [prostitute]. The community despises people living with the virus a lot. That is why they [PLWHA] don't want to disclose; they don't want to be deserted by their friends.~~
Nurse: I can remember a client…a man who came to me… he had been tested and we were just sharing with him. He told me when he went home and shared his HIV status with the wife, the wife packed and left.

Incorporation of HIV into people's identity is shaped by both individual reaction and the reaction of others and is a process of transition involving decisions about (non-) disclosure.

Formatted: Don't adjust space between Latin and Asian text, Don't adjust space between Asian text and numbers, Tab stops: Not at 0.5" + 1" + 1.5" + 2" + 2.5" + 3" + 3.5" + 4" + 4.5" + 5" + 5.5" + 6" + 6.5" + 7"

Formatted: Indent: Left: 0.5"

Assimilation and resources for identity normalisation

The third phase involves reorganisation and / or reconstruction of biographies towards some kind of normality, possibly different to that preceding HIV diagnosis~~.~~, and requires resources for support and encouragement [60]. The two main resources identified in our data include: social capital and ART. Three major sources of social capital were identified: HIV support groups; government healthcare services; and, faith-based organisations (FBOs). HIV support groups can provide confidential spaces where experiences and issues about HIV such as disclosure, sexuality and adherence are shared:

> Safari: We visit support groups where we learn a lot together. From there you just feel you belong to the society. You just feel you are [like HIV] "negative" and not "positive". We are taught so many things about living positively with the disease.

Of our three in-depth case studies, only Safari had fully disclosed her status; she had assimilated her HIV status into her life and it had become central to her identity. For this group of people, social support groups played an integral role in creating and maintaining an HIV positive identity, forming a bio-sociality to decipher biomedical information (e.g.: CD4 cell counts, viral loads, treatment side-effects), over and above individual clinic consultations. Safari developed her identity as a new "career" ~~[35]~~[61], and formed a support group to provide social support for PLWHA and income generation activities (e.g.: selling beads, poultry farming):

Formatted: Font: 10 pt

> Safari: I used to hate myself before, but now I am a very informed person living positively with HIV. I disclosed to many people and they began calling me *mama ukimwi* (mother AIDS), but I didn't mind. I have educated myself from newspapers and the television. I have a very big dream of changing the community. I chair a support group and have a dream of educating the community about HIV/AIDS. I overcame stigma and want to help other PLWHA. ~~My efforts meant that people overcame stigma and joined support groups. I used my HIV status to remove people [PLWHA] from their beds.~~

Formatted: Indent: Left: 0.5", Hanging: 1"

~~Faith-based social networks also play a role in helping people to shape their new identities, including the management of anxiety and depression [36].~~

Secondly, social capital from health workers is accessed post-diagnosis by PLWHA, regardless of their disclosure status. Community health workers are often the only sources of social capital for PLWHA who have not disclosed their status. PLWHA should be assigned a community health care workers (CHWs) who operated in the PLWHA's residential area, and were meant to meet at least once per week.

> Clinical Officer: They [CHWs] are the ones who deal mostly with these clients. They support them in the community so they can cope with

> the HIV situation. They are the ones helping us to do community outreaches, door to door training, door to door campaign on TB and HIV.

However, evidence from respondents suggested that this regular contact was rarely maintained, in part because community health workers often had multiple jobs in order to maximise their own incomes.

Thirdly, faith-based social networks also play a role in helping people to shape their new identities, including the management of anxiety and depression [62]:

> Safari: Because I am not taking ART I know one day, God will heal me by faith. It has been 15 years since I knew my status but I have not taken any of these drugs.

Prayer and religiosity played a pivotal role in some PLWHA's lives, providing an essential source of spiritual support. Evidence from the UK suggests that religion can help to manage anxiety and depression post-diagnosis [62].

ART can strengthen social relationships and self-identity because it improves people's capacity to work, important for social and economic viability and validation, allowing people to play their societal role as breadwinner, parent or adult~~:~~

> ~~Int: How has the availability of treatment changed your prospects about the future?~~
> ~~Jambo: I feel good...I don't see a negative side...they make you feel you are in good health and not unwell... when you're using something you find beneficial, the results are obvious even your body tells it all... I can walk to the toilet, I feel strong...I feel okay and I can work just like a normal person. Am I not healthy? But it is my secret; I don't go saying: I have taken an AIDS drug and I feel I am cured. [laughs]~~

. For many PLWHA, hope and uncertainty co-exist, leading to contrasting and ambivalent views about ART, even among those individuals who have developed a positive identity:

> Safari: I should have started using the [ART] drugs, but I said no. The doctor was pushing me to start the drugs, but I refused.
> Int: Why did you refuse?
> Safari: Let me tell you, I fear those drugs. The thing that makes me fear them is the reactions they cause. I have seen the problems they cause to people. The swelling of the feet, then there is one that removes all the fat from the body and it brings to one side. You find one's breast has grown fat; you have a bad shape. That is why I fear them.

For many PLWHA being HIV positive is simply a medical label, and not a defining feature of their identity:

Int: So life goes on as usual?

Jambo: Yes ... people might say that I have HIV, but for me that is not important…My main problem is that I have no means to earn a living, I have many challenges. I am usually rained on in this house whenever it rains, but I cannot [afford to] migrate from here.

For those PLWHA who experienced a dissonance between their HIV status and their perceived health status, this tended to lead to the rejection of an HIV identity:

Malaika: That thing [HIV diagnosis] is very painful that I even don't want to think about it. I don't even want be going to the NGOs to read those things about HIV/AIDS because I know I have it. I just want to stay "*bubu* ~~(~~[dumb~~)~~] style".

Malaika had decided not to use ART because she had concerns about the requirement for good nutrition in order to be able to take the drugs:

Int: Are you on ART?

Malaika: I am not on any treatment, I just stay like that…I don't see the need to use these drugs when I don't feel any pain in my body. In fact, I hear you need to eat well when you take those drugs and sometimes you don't have the means to buy food.

Formatted: Indent: Left: 0.5", Hanging: 1"

Lack of food as in issue in non-adherence to ART was highlighted by healthcare providers:

Clinical Officer: We have experienced some clients who complain that they cannot take the drugs as instructed due to lack of food since the drugs are quite strong.

Our case studies illustrate the range of experiences around people's identities post-HIV diagnosis. Safari, with full disclosure, had started to make a career out of her HIV status, although she preferred to place her faith in religion, rather than ART, to maintain her health. Safari had completely assimilated a new HIV identity. Jambo, on the other hand, was motivated to adhere to ART in order that he would be able to work, but he had not disclosed his status to anyone outside of the healthcare system. Jambo sought to maintain his biographic continuity, not allowing for his identity to be affected by HIV diagnosis. For Malaika, a HIV diagnosis meant a biographical disruption, with neither incorporation of a new identity post-diagnosis, nor adaptation of her identity. We explore how these different responses are associated with sexual ~~and reproductive~~ behaviours ~~and intentions~~.

Malaika's biographical disruption has implications for her sexual ~~and reproductive~~ life:

Malaika: No, I have not had sex since I knew about my status. I lost sexual desire completely. I don't even long for a man… I actually hate them [men]. You know when a woman loses feeling? I don't have [sexual] feeling at all.

~~Int: Could you explain why you don't want another child?~~

~~Malaika: I always hear that there are drugs that people are given to prevent the baby from getting infected with the virus. But then don't you think that I will infect the person that I am going to sleep with, with the HIV virus? I cannot give somebody the virus knowingly like that just for him to impregnate me and then go and take drugs that will prevent the child from getting the virus. What about that man?~~

Those PLWHA who were able to incorporate HIV/AIDS in their identity without it being disruptive to their biography, were pursuing sexual ~~and reproductive~~ lives. At the time of her interview, Safari was sexually active with a steady partner and reported consistent condom use:

Safari: The man I am with, the first thing is, I am the person who will put the condom on for him. I do not want him to do it himself. Even if it is at night the lights have to be on, because a man is just a man, he might cut the condom and add me more viruses.

~~Safari also planned to have another child, in part to seek social approval and affirmation as part of her identity as a women [11, 37]. Intentions to have children might be interpreted as an attempt to regain some normalcy [38], especially in slums with high infant mortality:~~

~~Int: Why would you want to give birth to another child?~~

~~Safari: The one child that I have may die and I remain without any…I start from zero, you see! Having a child is a matter of great importance, if you do not have a child you are seen to be a cursed person. Even if you are a girl and you are not married, it is very important to have a child. The child will keep the name of the parent. Even if you die people will be happy to say this is so and so's child. The child preserves the name of the parent, the name will not disappear.~~

~~For women, the burdens of (non-)reproduction are high, and Malaika and Safari represent two different responses to childbearing after a HIV diagnosis.~~ By contrast, Jambo's more continuous biography reflected his pre-diagnosis identity:

INT: Did you use a condom during your last sex?

Jambo: Aaahi! How can I have sex with a woman while using a condom? Am I to fuck the condom or her vagina…so my blood gets into her?! Then I go and throw away my semen in the toilet, why? I don't want it, if it's a question of condoms, I would rather do away with a vagina because it will not benefit me in any way.

~~From Jambo's perspective the need for sexual gratification involving sexual fluid exchange outweigh condom use [39].~~
From Jambo's perspective the need for sexual gratification involving sexual fluid exchange outweigh condom use [63].

Discussion

There are multiple and complex responses to diagnosis with HIV, in an era of ART availability, set against a backdrop of life in a Nairobi slum. For some people this process involves a transition to a new self-identity, incorporating both HIV and ART into their lives ~~[40]~~[60], for others it involves a partial transition, with some aspects of identity persisting, and others redefined ~~[23, 25, 41]~~[35, 37, 64]. Multiple phases of identity transition, including diagnosis, (non-)disclosure, positive living, attempts at repair and normalcy, play out in people's narratives and their sexual ~~and future reproductive intentions.~~ lives and futures.

PLWHA try to mobilise resources to help them deal with the diagnosis ~~[23, 24]~~[35, 36]~~,~~, including sources of social capital (e.g.: community healthworkers social groups, faith-based organisations~~,~~), and ~~enrolling for~~ ART. Such ~~groups appear to~~social networks provide ~~some much needed social~~ support to mitigate psychological distress associated with a HIV diagnosis ~~[42].~~[65]. Studies from elsewhere in SSA have documented a positive relationship between social capital and health [66] and prayer/spirituality and quality of life among PLWHA ~~[43].~~[67]. Emerging evidence also shows that the availability of social networks such as treatment partners, health care workers, and social support groups, improves treatment outcomes, including adherence for PLWHA with access to ART [38, 66, 68].

The use of ART was a significant resource enabling PLWHA to regain positions as economically and socially productive and reproductive members of society~~.~~, thereby fending off stigma ~~[44, 45]~~[69, 70]~~.~~. PLWHA face stigma in part because infection with HIV is associated with moral failures and a breach of social norms and taboos [39] In the context of the high premium placed on parenthood ~~[46]~~[71], HIV posed a potential threat to peoples' identities as mothers and fathers. Resuming sex provides an opportunity for PLWHA to lead normal lives, as well as to mitigate stigma and social disproval [72]. However, the inherent social rewards of childbearing, in the context of poverty and limited access to social security, and its inherent risk of transmitting the virus are complex issues in reproductive decisions among PLWHA.

Sampling participants from the slum community is a major strength of our study. Most studies on PLWHA sample from HIV health services where participants are likely to have better access to services and to have been better informed about SRH services and HIV prevention than the general population of PLWHA. However, our interviews had a heterosexual and consensual sex focus and it is highly unlikely that respondents would volunteer same-sex or forced sex activities. Since these sexual identities and activities are stigmatised in Kenya, a different approach might have helped the research process, although their under-reporting might still persist.

Information on sexual behaviour and fertility preferences were entirely based on self-reports using face to face interviews. Given the sensitive nature of these topics, there is likely to have been social desirability bias. ~~Both men and women misreport their sexual behaviour [47] and respondents might be inclined to underreport their unsafe sexual behaviour.~~Both men and women misreport their sexual behaviour [73] and respondents might be inclined to underreport their unsafe sexual behaviour. Although we took precautions to limit social desirability bias – such as training interviewers to create a climate of trust that allows free talk about such matters and using non-clinical community interviewers – its effect cannot be completely eliminated.

In spite of these limitations, this study contributes to the empirical literature on sexual and reproductive health of PLWHA in a poor setting, an under-researched topic. PLWHA experience life with HIV and face challenges around stigma, managing ART, negotiating sexual intimacy and reproduction. Our data show the need to address living with HIV/AIDS holistically, asking broad questions about lived experience of PLWHA, paying attention to structural elements of poverty, gender and socio-cultural norms, recognising PLWHA as sexual and reproductive human beings. Research in developing countries that has addressed sexual behaviour of PLWHA has focused on risky behaviour mostly using quantitative data from surveys ~~[48].~~[74]. Studies have considered the reproductive goals of PLWHA ~~[37, 49]~~[75, 76], suggesting that sexual and reproductive behaviour of PLWHA should be understood by connecting sexuality to gender, reproductive goals and larger socio-economic contexts ~~[50, 51]~~[77, 78].

The effect of ART on sexual and reproductive behaviour is attracting research and policy attention following ART rollout in resource-poor settings. The findings of the few studies that have examined how treatment affects sexual and reproductive behaviour in such settings have produced mixed results, highlighting the need for a better evidence base ~~[13, 52, 53]~~[25, 79, 80]. There is a growing recognition of the need to support the rights of PLWHA to be sexually active~~ and achieve their fertility goals~~, should they wish to be, while minimizing HIV transmission risk ~~[54] and this study is an effort in that direction. Health care workers in Kenya rarely give HIV infected people the opportunity to articulate their fertility desires [55]. Meeting the sexual and reproductive health needs of PLWHA means more than just counselling those who want to avoid pregnancy.~~[81] and this study is an effort in that direction. Meeting the sexual and reproductive health needs of PLWHA means more than just counselling on risk reduction. Psycho-social factor play a prominent role in sexual functioning, and diminished sexual interest and sexual abstinence are strongly associated with psychological distress, depression, anxiety and low quality of life, ~~over and above disease factors such as~~in addition to underlying ill-health represented by CD4 cell counts and duration or severity of illness ~~[56].~~[82]. PLWHA could benefit from counselling around sexuality as a whole, not just risk reduction as is usually the case. Our findings speak to the need for interventions to help PLWHA to safely become sexually active if they want to. Because the process of incorporating HIV into an individual's identity is neither linear nor predictable, diagnosis presents an opportunity for healthcare providers to discuss these issues.

Subsequent referrals for mental health services might, for example, become necessary depending on how individuals cope with their diagnosis.

Funding statement: This work was supported by the Wellcome Trust grant number [078471/Z/05/A]. The sponsor had no role in the design and conduct of the study; in the collection, analysis and interpretation of the data or in the preparation, review or approval of the manuscript. The opinions, results and conclusions reported in this paper are those of the authors and are independent from the funding sources.

Competing interests: None declared

Acknowledgements: We are grateful to the participants of the study for their time and contributions. We are grateful to the African Population and Health Research Centre for permission to sample from the Nairobi Urban Demographic Surveillance System.

Contributors: Study concept and design: EW, EC. Acquisition of data: EW. Analysis and interpretation of data: EW, EC. Drafting of the manuscript: EW. Critical revision of manuscript: EC, EW. Administrative, technical or material support: EW, EC

~~Data Sharing~~

~~Additional unpublished data from the study are available upon request from the coresponding author.~~

References

1. UNAIDS, *Global HIV/AIDS Response: Epidemic update and health sector progress towards Universal Access Progress Report 2011.*, 2011, World Health Organization/United Nations United Nations Joint Programme on AIDS: Geneva, Switzerland.

2. ~~NACC, *Kenya National AIDS Strategic Plan 2009/10 – 2012/13Delivering on Universal Access to Services*, 2009, National AIDS Control Council~~UNAIDS, *UNAIDS report on the global AIDS epidemic*, 2012, UNAIDS: Geneva. p. 212. ~~Nairobi.~~

~~3. UNAIDS, *Global report: UNAIDS report on the global AIDS epidemic*. 2010, Geneva: Joint United Nations Programme on HIV/AIDS (UNAIDS).~~

~~4. WHO/UNAIDS, *Towards Universal access Scaling up priority HIV/AIDS interventionsin the health sector: Progress report 2008*, 2008, World Health Organization/United Nations United Nations Joint Programme on AIDS: Geneva, Switzerland.~~

~~5~~3. NACC/NASCOP, *Kenya AIDS Epidemic Update*, 2011, National AIDS and STI control programme: Nairobi. p. 144.

4. Birungi, H., C.-C. Undie, and P. Aggleton, *Recent research on sexuality in East Africa.* Culture, Health & Sexuality, 2009. **11**(8): p. 747-750.

~~6~~5. Segurado, A.C. and V. Paiva, *Rights of HIV Positive People to Sexual and Reproductive Health: Parenthood.* Reproductive Health Matters, 2007. **15**(29, Supplement 1): p. 27-45.

~~7~~6. WHO, *Sexual and reproductive health of women living with HIV/AIDS: Guidelines on care, treatment and support for women living with HIV/AIDS and their children in resource-constrained settings*, 2006, World Health Organization: Geneva.

~~8~~7. Bartlett, J.A., *Addressing the challenges of adherence.* Journal of Acquired Immune Deficiency Syndromes, 2002. **29**: p. S2-S10.

~~9~~8. Hardon, A., Hodgkin, C. & Laing, R., *From access to adherence: The challenges of antiretroviral treatment. Studies from Botwana, Tanzania and Uganda*, 2006, World Health Organization: Geneva.

~~10~~9. Orrell, C., et al., *Adherence is not a barrier to successful antiretroviral therapy in South Africa.* AIDS, 2003. **17**(9): p. 1369-1375.

~~11~~10. Mahajan, A.P., et al., *Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward.* AIDS, 2008. **22**(Suppl.2): p. S67-S79.

11. Nachega J. B , S.D.M., . Lehman D. A, Hilatshwayo D., Mothopeng R., Chaisson R.E, and A.S Karstaedt . *Adherence to Antiretroviral Therapy in HIV-Infected Adults in Soweto, South Africa.* AIDS Research and Human Retroviruses 2004. **20**(10): p. 1053–1056.

12. Dlamini, P.S., et al., *HIV Stigma and Missed Medications in HIV-Positive People in Five African Countries.* AIDS Patient Care & STDs, 2009. **23**(5): p. 377-387.

Formatted: Adjust space between Latin and Asian text, Adjust space between Asian text and numbers

Formatted: Centered, Indent: Left: 0", First line: 0"

Formatted: Font: Calibri

Formatted: Font: Calibri

Formatted: Font: Calibri

Formatted: Font: Calibri

Formatted: Font: Calibri

Formatted: Font: Calibri

Formatted: Font: Calibri

Formatted: Font: Calibri

13. Weiser, S., et al., *Barriers to antiretroviral adherence for patients living with HIV infection and AIDS in Botswana.* Jaids-Journal of Acquired Immune Deficiency Syndromes, 2003. **34**(3): p. 281-288.
14. Roura, M., et al., *Scaling up stigma? The effects of antiretroviral roll-out on stigma and HIV testing. Early evidence from rural Tanzania.* Sexually Transmitted Infections, 2009. **85**(4): p. 308-312.
15. Abrahams, N. and R. Jewkes, *Managing and resisting stigma: a qualitative study among people living with HIV in South Africa*
Journal of the International AIDS Society, 2012. **15**(2).
16. Preston-Whyte, E.M., *Contexts of vulnerability: Sex, secrecy and HIV/AIDS*
African Journal of AIDS Research, 2003. **2**(2): p. 89–94.
17. Abadía-Barrero, C.E. and A. Castro, *Experiences of stigma and access to HAART in children and adolescents living with HIV/AIDS in Brazil.* Social Science & Medicine, 2006. **62**(5): p. 1219-1228.
18. Cao, X., et al., *Understanding HIV–Related Stigma And Discrimination in a "Blameless" Population.* AIDS Education and Prevention, 2006. **18**(6): p. 518-528.
19. Farmer, P., et al., *Community-based approaches to HIV treatment in resource-poor settings.* The Lancet, 2001. **358**(9279): p. 404-409.
20. Maughan-Brown, B., *Stigma rises despite antiretroviral roll-out: A longitudinal analysis in South Africa.* Social Science & Medicine, 2010. **70**(3): p. 368-374.
21. Smith, R., K. Rossetto, and B.L. Peterson, *A meta-analysis of disclosure of one's HIV-positive status, stigma and social support.* AIDS Care, 2008. **20**(10): p. 1266-1275.
22. Neville Miller, A. and D.L. Rubin, *Factors Leading to Self-Disclosure of a Positive HIV Diagnosis in Nairobi, Kenya: People Living With HIV/AIDS in the Sub-Sahara.* Qualitative Health Research, 2007. **17**(5): p. 586-598.
23. Cooper, D., et al., *Fertility Intentions and Reproductive Health Care Needs of People Living with HIV in Cape Town, South Africa: Implications for Integrating Reproductive Health and HIV Care Services.* AIDS and Behavior, 2009. **13**(0): p. 38-46.
~~12~~24. GNP+, *Advancing the Sexual and Reproductive Health and Human Rights of People Living With HIV*. 2009, Amsterdam: The Global Network of People Living with HIV/AIDS (GNP+).
~~13~~25. Luchters, S., et al., *Safer sexual behaviors after 12 months of antiretroviral treatment in Mombasa, Kenya: a prospective cohort.* AIDS Patient Care & STDs, 2008. **22**(7): p. 587-594.
~~14~~26. Remien, R., et al., *Medication Adherence and Sexual Risk Behavior among HIV-Infected Adults: Implications for Transmission of Resistant Virus.* AIDS and Behavior, 2007. **11**(5): p. 663-675.
~~15~~27. Crepaz, N., T.A. Hart, and G. Marks, *Highly active antiretroviral therapy and sexual risk behavior - A meta-analytic review.* Jama-Journal of the American Medical Association, 2004. **292**(2): p. 224-236.
~~16~~28. Kennedy, C., et al., *The impact of HIV treatment on risk behaviour in developing countries: A systematic review.* AIDS Care, 2007. **19**(6): p. 707 - 720.

Formatted: Font: Calibri

Formatted: Font: Calibri

Formatted: Font: Calibri

Formatted: Font: Calibri

Formatted: Font: Calibri

Formatted: Font: Calibri

~~17~~29. De Ryck, I., et al., *Sexual Satisfaction Among Men Living with HIV in Europe.* AIDS and Behavior, 2011: p. 1-6.

~~18~~30. UN-HABITAT, *Slums of the World: The Face of Urban Poverty in the New Millenium? Global Urban Observatory*, 2003b, Nairobi:UN-Habitat:.

~~19~~31. Amuyunzu-Nyamongo, M., et al., *Putting on a brave face: The experiences of women living with HIV and AIDS in informal settlements of Nairobi, Kenya.* AIDS Care, 2007. **19**(1 supp 1): p. 25-34.

~~20~~32. Zulu, E., et al., *Overview of migration, poverty and health dynamics in Nairobi City's slum settlements.* Journal of Urban Health, 2011. **88**(0): p. 185-199.

~~21~~33. Bury, M., *Chronic illness as biographical disruption.* Sociology of Health & Illness, 1982. **4**(2): p. 167-182.

~~22~~34. Baumgartner, L.M., *The Incorporation of the HIV/AIDS Identity Into the Self Over Time.* Qualitative Health Research, 2007. **17**(7): p. 919-931.

~~23~~35. Carricaburu, D. and J. Pierret, *From biographical disruption to biographical reinforcement: the case of HIV-positive men.* Sociology of Health & Illness, 1995. **17**(1): p. 65-88.

~~24~~36. Williams, S., *Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept.* Sociology of Health & Illness, 2000. **22**(1): p. 40-67.

~~25~~37. Ciambrone, D.e., *Illness and other assaults on self: the relative impact of HIV/AIDS on women's lives.* Sociology of Health & Illness, 2001. **23**(4): p. 517-540.

~~26~~38. Wouters, E., et al., *Public-sector ART in the Free State Province, South Africa: Community support as an important determinant of outcome.* Social Science & Medicine, 2009. **69**(8): p. 1177-1185.

39. Parker, R. and P. Aggleton, *HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action.* Social Science & Medicine, 2003. **57**(1): p. 13-24.

40. Levy, J.M. and K.T. Storeng, *Living Positively: Narrative Strategies of Women Living with HIV in Cape Town, South Africa.* Anthropology & Medicine, 2007. **14**(1): p. 55-68.

41. Frank, E., *The relation of HIV testing and treatment to identity formation in Zambia.* African Journal of AIDS Research, 2009. **8**(4): p. 515-524.

42. Kiene, S.M., et al., *Sexual risk behaviour among HIV-positive individuals in clinical care in urban KwaZulu-Natal, South Africa.*

. AIDS, 2006. **20**(13): p. 1781-4.

43. Moatti, J.-P., et al., *Access to antiretroviral treatment and sexual behaviours of HIV-infected patients aware of their serostatus in Côte d'Ivoire*

AIDS, 2003. **17**(supplement 3): p. S69–S77.

44. Pettifor, A., et al., *Continued High Risk Sexual Behavior Following Diagnosis with Acute HIV Infection in South Africa and Malawi: Implications for Prevention.* AIDS and Behavior, 2011. **15**(6): p. 1243-1250.

45. APHRC, *Population and health dynamics in Nairobi's informal settlements,* 2002, African Population and Health Research Center: Nairobi.

Formatted: Font: Calibri

Formatted: Font: Calibri

Formatted: Font: Calibri

Formatted: Font: Calibri

Formatted: Font: Calibri

Formatted: Font: Calibri

Formatted: Font: Calibri

Formatted: Font: Calibri

Formatted: Font: Calibri

46. Madise, N.J., et al., *Are slum dwellers at heightened risk of HIV infection than other urban residents? Evidence from population-based HIV prevalence surveys in Kenya.* Health & Place, (0).

47. Montgomery, M., *Urban poverty and health in developing countries.* Population Bulletin, 2009. **64**(2).

48. Zulu, E., F. Dodoo, and A. Ezeh, *Sexual risk-taking in the slums of Nairobi, Kenya, 1993-98.* Popul Stud (Camb), 2002. **56**(3): p. 311 - 323.

49. Madise, N.J., et al., *Are slum dwellers at heightened risk of HIV infection than other urban residents? Evidence from population-based HIV prevalence surveys in Kenya.* Health & Place, 2012. **18**(5): p. 1144-1152.

50. Magnani, R., *Sampling guide.* 1997, MPACT Food Security and Nutrition Monitoring Project

Arlington, Va.

.

51. Braun, V. and V. Clarke, *Using thematic analysis in psychology.* Qualitative Research in Psychology, 2006. **3**: p. 77-101.

Formatted: Font: Calibri

~~27~~52. Ivankova, N.V., J.W. Creswell, and S.L. Stick, *Using Mixed-Methods Sequential Explanatory Design: From Theory to Practice.* Field Methods, 2006. **18**(1): p. 3-20.

Formatted: Font: Calibri

~~28~~53. Kaler, A. and S. Watkins, *Asking God about the date you will die: HIV testing as a zone of uncertainty in rural Malawi.* Demographic Research, 2010. **23**(32): p. 905-932.

Formatted: Font: Calibri

~~29~~54. Gersovitz, M., *HIV Testing: Principles and Practice.* The World Bank Research Observer, 2011. **26**(1): p. 1-41.

Formatted: Font: Calibri

~~30~~55. Obermeyer, C.M. and M. Osborn, *The Utilization of Testing and Counseling for HIV: A Review of the Social and Behavioral Evidence.* Am J Public Health, 2007. **97**(10): p. 1762-1774.

Formatted: Font: Calibri

~~31~~56. Baumgartner, L.M. and K.N. David, *Accepting Being Poz: The Incorporation of the HIV Identity Into the Self.* Qualitative Health Research, 2009. **19**(12): p. 1730-1743.

Formatted: Font: Calibri

~~32~~57. Ciambrone, D.e., *Women's experiences with HIV/AIDS: mending fractured selves* 2003, Binghamton, NY: The Haworth Press.

Formatted: Font: Calibri

~~33~~58. Mahalik, J.R., G.E. Good, and M. Englar-Carlson, *Masculinity scripts, presenting concerns, and help seeking: Implications for practice and training.* Professional Psychology: Research and Practice, 2003. **34**(2): p. 123-131.

Formatted: Font: Calibri

~~34~~59. Derlega, V.J., et al., *Reasons for HIV Disclosure/Nondisclosure in Close Relationships: Testing a Model of HIV–Disclosure Decision Making.* Journal of Social and Clinical Psychology, 2004. **23**(6): p. 747-767.

Formatted: Font: Calibri

~~35~~60. Russell, S. and J. Seeley, *The transition to living with HIV as a chronic condition in rural Uganda: Working to create order and control when on antiretroviral therapy.* Social Science & Medicine, 2010. **70**(3): p. 375-382.

Formatted: Font: Calibri

61. Bartos, M. and K. McDonald, *HIV as identity, experience or career.* AIDS Care, 2000. **12**(3): p. 299-306.

Formatted: Font: Calibri

~~36~~62. Anderson, M., et al., *Coping With HIV: Caribbean People in the United Kingdom.* Qualitative Health Research, 2009. **19**(8): p. 1060-1075.

Formatted: Font: Calibri

~~37. Cooper, D., et al., *"Life is still going on": Reproductive intentions among HIV-positive women and men in South Africa.* Social Science & Medicine, 2007. **65**(2): p. 274-283.~~

~~38. Smith, D.J. and B.C. Mbakwem, *Life projects and therapeutic itineraries: marriage, fertility, and antiretroviral therapy in Nigeria.* AIDS, 2007. **21**: p. S37-S41.~~

~~39~~63. Coast, E., *Wasting sperm:The Maasai context of condom use in Northern Tanzania.* Culture, health and sexuality, 2007. **9** (4): p. 387-401

Formatted: Font: Calibri

~~40~~64. ~~Russell, S. and J. Seeley, *The transition to living with HIV as a chronic condition in rural Uganda: Working to create order and control when on antiretroviral therapy.* Social Science & Medicine, 2010. **70**(3): p. 375-382.~~

Formatted: Font: Calibri

41. Wilson, S., *'When you have children, you're obliged to live'1: motherhood, chronic illness and biographical disruption.* Sociology of Health & Illness, 2007. **29**(4): p. 610-626.

Formatted: Font: Calibri

~~42~~65. Kalichman, S.C., et al., *Stress, Social Support, and HIV-Status Disclosure to Family and Friends Among HIV-Positive Men and Women.* Journal of Behavioral Medicine, 2003. **26**(4): p. 315-332.

Formatted: Font: Calibri

~~43~~66. Pronyk, P.M., et al., *Is social capital associated with HIV risk in rural South Africa?* Social Science & Medicine, 2008. **66**(9): p. 1999-2010.

67. Friend-du Preez, N. and K. Peltzer, *HIV Symptoms and Health-Related Quality of Life Prior to Initiation of HAART in a Sample of HIV-Positive South Africans.* AIDS and Behavior, 2010. **14**(6): p. 1437-1447.

Formatted: Font: Calibri

~~44~~68. Binagwaho, A. and N. Ratnayake, *The Role of Social Capital in Successful Adherence to Antiretroviral Therapy in Africa.* PLoS Med, 2009. **6**(1): p. e18.

69. Campbell, C., et al., *"We, the AIDS people. . .": How Antiretroviral Therapy Enables Zimbabweans Living With HIV/AIDS to Cope With Stigma.* American Journal of Public Health, 2011. **101**(6): p. 1004-1010.

Formatted: Font: Calibri

~~45~~70. Castro, A. and P. Farmer, *Understanding and Addressing AIDS-Related Stigma: From Anthropological Theory to Clinical Practice in Haiti.* American Journal of Public Health, 2005. **95**(1): p. 53-59.

Formatted: Font: Calibri

~~46~~71. Awiti Ujiji, O., et al., *"I will not let my HIV status stand in the way." Decisions on motherhood among women on ART in a slum in Kenya- a qualitative study.* BMC Women's Health, 2010. **10**(1): p. 1-10.

Formatted: Font: Calibri

~~47~~72. Smith, D.J. and B.C. Mbakwem, *Antiretroviral therapy and reproductive life projects: Mitigating the stigma of AIDS in Nigeria.* Social Science & Medicine, 2010. **71**(2): p. 345-352.

73. Buvé, A., et al., *Multicentre study on factors determining differences in rate of spread of HIV in sub-Saharan Africa: methods and prevalence of HIV infection.* AIDS, 2001. **15**: p. S5-S14.

Formatted: Font: Calibri

~~48~~74. Bateganya, M., et al., *Antiretroviral Therapy and Sexual Behavior: A Comparative Study between Antiretroviral- Naive and -Experienced Patients at an Urban HIV/AIDS Care and Research Center in Kampala, Uganda.* AIDS Patient Care & STDs, 2005. **19**(11): p. 760-768.

Formatted: Font: Calibri

~~49~~75. Cooper, D., et al., *"Life is still going on": Reproductive intentions among HIV-positive women and men in South Africa.* Social Science & Medicine, 2007. **65**(2): p. 274-283.

76. Myer, L., C. Morroni, and K. Rebe, *Prevalence and Determinants of Fertility Intentions of HIV-Infected Women and Men Receiving Antiretroviral Therapy in South Africa.* AIDS Patient Care & STDs, 2007. **21**(4): p. 278-285.

~~50~~77. Laher, F., et al., *A Qualitative Assessment of Decisions Affecting Contraceptive Utilization and Fertility Intentions among HIV-Positive Women in Soweto, South Africa.* AIDS and Behavior, 2009. **13**(0): p. 47-54.

~~51~~78. Persson, A. and W. Richards, *Vulnerability, gender and "proxy negativity": Women in relationships with HIV-positive men in Australia.* Social Science & Medicine, 2008. **67**(5): p. 799-807.

~~52~~79. Kaida, A., et al., *Childbearing Intentions of HIV-Positive Women of Reproductive Age in Soweto, South Africa: The Influence of Expanding Access to HAART in an HIV Hyperendemic Setting.* Am J Public Health, 2011. **101**(2): p. 350-358.

~~53~~80. Sarna, A., et al., *Changes in sexual risk taking with antiretroviral treatment: influence of context and gender norms in Mombasa, Kenya.* Culture, Health & Sexuality, 2009. **11**(8): p. 783-797.

~~54~~81. Kaida, A., et al., *Editorial: Introduction to the Supplement on HIV, HAART, and Fertility in sub-Saharan Africa.* AIDS and Behavior, 2009. **13**(0): p. 1-4.

~~55. CRR and Fida Kenya. *At risk: Right violations of HIV- positive women in Kenya health facilities* 2008; Available from: http://reproductiverights.org/sitesdafualt/files.documents/AtRisk.pdf.~~

~~56~~82. Florence, E., et al., *Prevalence and factors associated with sexual dysfunction among HIV-positive women in Europe.* AIDS Care, 2004. **16**(5): p. 550-557.

Formatted: Font: Calibri

Formatted: Font: Calibri

Formatted: Font: Calibri

Formatted: Font: Calibri

Formatted: Font: Calibri

Formatted: Font: Calibri

Formatted: Font: Calibri

NOTE: PLEASE SAVE THIS TO YOUR HARD DRIVE UNDER A DIFFERENT FILE NAME AFTER YOU FILL IT OUT

STROBE Statement—checklist of items that should be included in reports of observational studies

Please fill out the page numbers on this form and upload the file as a supplemental file when you submit your revision

Manuscript Number____

	Item No	Recommendation	**Indicate page number ↓ (Or n/a if not applicable)**
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3
Objectives	3	State specific objectives, including any prespecified hypotheses	3
Methods			
Study design	4	Present key elements of study design early in the paper	3
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	3
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	4
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	n/a
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	n/a
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	4
Bias	9	Describe any efforts to address potential sources of bias	13
Study size	10	Explain how the study size was arrived at	n/a
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	n/a
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	n/a
		(*b*) Describe any methods used to examine subgroups and interactions	n/a
		(*c*) Explain how missing data were addressed	n/a
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy	n/a
		(*e*) Describe any sensitivity analyses	n/a
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	6
		(b) Give reasons for non-participation at each stage	n/a
		(c) Consider use of a flow diagram	n/a
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	6
		(b) Indicate number of participants with missing data for each variable of interest	6
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	n/a
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	n/a
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	n/a
		Cross-sectional study—Report numbers of outcome events or summary measures	n/a
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95%	n/a

		confidence interval). Make clear which confounders were adjusted for and why they were included	
		(*b*) Report category boundaries when continuous variables were categorized	n/a
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	7
Discussion			
Key results	18	Summarise key results with reference to study objectives	12
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	13
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	13
Generalisability	21	Discuss the generalisability (external validity) of the study results	13
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	14

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.